# APPRECIATING THE ETHICAL IMPLICATIONS OF QUALITY IMPROVEMENT IMPLEMENTATION AND RELATIONAL SAFETY: A QUALITATIVE STUDY OF PATIENT/FAMILY EXPERIENCE

by

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#### Abstract

Improving the quality of care and reducing preventable harm to patients/families are important obligations for health care professionals and institutions. Despite quality improvement's (QI) significant contributions to health care, interventions that involve patients at the point of care raise ethical questions about heretofore unexamined wider impacts *on* patients. This qualitative empirical study challenged the assumption that QI is necessarily a benign and beneficial extension of routine medical care. The research questions focused on ethical and practical implications of patient/family experiences of a pilot QI intervention that gave patients a new opportunity to improve the quality and safety of their own care.

Relational inquiry and ecological systems theory framed this ethical (values-based) analysis of moral agents in context. Using interpretive description methodology, I explored two hand hygiene QI interventions on two hospital units. Over 12 months, I observed patient care and staff meetings (~140 hours), interviewed/shadowed patients (n=25), families (n=8), providers/ volunteers (n=21), other staff (n=17), and analyzed documents.

Findings about patient/family experiences of the QI interventions (what I term *Work-as-Experienced*) showed that a multifaceted set of perceptions and behaviours occurred at once. My thematic analyses centred on the value patients/families place on *positive connections* with their providers and health care settings. Contextual features of implementation showed disconnects between how quality leaders imagined the QI intervention's success, how it was operationalized, and how patients/families experienced it. In interpreting these findings, I developed a *Relational*  *Safety Framework* to explain how relational connections result from interactions with others and are potentially grounded in relational safety (feeling safe and valued). When people in vulnerable, uncertain circumstances have a sense of relational safety, they move towards connections with others, fostering trust.

In this study I emphasize the importance of relational connections and shared meanings of quality/safety initiatives. Furthermore, evaluation is critical to assess the impact of QI on patients'/families' lives. I recommend a stronger appreciation of the ethical implications of QI implementation, and strengthening relational safety through adopting a relational, multi-level perspective to foster ethical conduct of QI in health care. Relational safety is a new, ethically-based, values-added strategy to advance health care system improvement.

### Lay Summary

My research explored what it is like for patients/families when their hospital tests a care process that gives them a new opportunity to improve the quality and safety of their *own care*. For example, to promote handwashing, some hospitals encourage patients/families to use hand sanitizer and to remind care providers to clean their hands. Quality improvement (QI) processes can create uncertainty for patients/families and providers. I learned that when patients/families have a sense of relational safety (feeling safe and valued), they move towards connections with their providers and places of care, fostering trust. Patients/families feel safer and valued when nurses and doctors take the time to communicate to them, "just so you know, we're asking you to do this now, and this is why." To build on existing strengths of QI and improve health care quality, I recommend enhancing ethical approaches to QI implementation across all health care system levels.

## Preface

This dissertation is an original, unpublished, intellectual product of the author, Brenda Sawatzky-Girling. The fieldwork reported in Chapters 6 through 8 was authorized by University of British Columbia Ethics Certificate number H15-01422.

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## List of Abbreviations

ABHR	Alcohol-Based Hand Rub
ARECCI	A pRoject Ethics Community Consensus Initiative (formerly Alberta Research Ethics Community Consensus Initiative)
CPSI	Canadian Patient Safety Institute
ICST	Interaction, Connection, Safety, Trust
ID	Interpretive Description
IHI	Institute for Healthcare Improvement
OECD	The Organisation for Economic Co-operation and Development
PDSA	Plan, Do, Study, Act test cycles
PVN	Patient Voices Network
QI	Quality Improvement
REB	Research Ethics Board
SQUIRE	Standards for QUality Improvement Reporting Excellence
TCPS 2	Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
UBC	University of British Columbia
WAD	Work-as-Done
WAE	Work-as-Experienced
WAI	Work-as-Imagined
WHO	World Health Organization

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### **Chapter 1: Introduction**

#### **1.1 Quality Improvement Interventions in Health Care**

Health care administrators and practitioners commonly use Quality Improvement (QI) to improve the planning and management of health care services, and thus improve the quality of health care and reduce preventable harm. As a concept, QI involves two key areas: (1) embedding a culture of quality; and (2) implementing systematic, data-guided initiatives tailored for local conditions to target specific processes and/or practices identified as needing improvement (G. R. Baker et al., 2008; J. K. Johnson & Sollecito, 2018b; Marshall et al., 2013; Parry, 2014; Perla et al., 2013; Powell et al., 2009; Rubenstein et al., 2014). QI initiatives often involve iterative development and testing, and institutions generally implement them as several nested interventions referred to as "bundles" (Resar et al., 2012). In clinical practice, certain types of QI interventions such as checklists to prevent errors in intensive care (Pronovost et al., 2006) and surgical (Haynes et al., 2009; Semel et al., 2010) settings have seen relatively widespread adoption (W. A. Sollecito & Johnson, 2018). Yet, these well-known, evidence-based checklists are often not fully implemented in routine practice, reinforcing that health care is highly variable when compared to other industries such as aviation or manufacturing (Dixon-Woods & Martin, 2016, p. 192; Fan et al., 2010, p. 2286; W. A. Sollecito & Johnson, 2018, p. 48). As such, despite increased use of QI approaches across the health care sector, the evidence base for their effective application and impact (intended and unintended effects) has mixed results.

Furthermore, QI activities are expected to occur within decreasing overall health care expenditures (Storkholm et al., 2017). This expectation is due, in part, to ideas generated over the

last decade by the United States-based Institute for Healthcare Improvement (IHI), ideas that have influenced health care reforms in Canada and worldwide. In particular, the IHI Triple Aim outlines a set of principles to guide health care system reform, centred around "the simultaneous pursuit of three goals: improving the individual experience of care; improving the health of populations; and reducing the per capita *costs* of care for populations" (Berwick, Nolan, & Whittington, 2008, pp. 760, emphases added). Yet these three goals are seen by some commentators as fundamentally incompatible: tensions and trade-offs within QI initiatives are exacerbated by contextual factors such as a managerial culture and ongoing fiscal constraints (Appleby, 2009; Ovretveit, 2009; Storkholm et al., 2017; M. J. Taylor et al., 2014). However, efforts to enhance QI, improve the quality of care and reduce preventable harm to patients and families – even within a context of fiscal restraints – remain important obligations (legal, ethical and moral) for policy-makers, decision-makers, health care institutions, and health care providers (Beauchamp & Childress, 2019; Davidoff, 2011; Dixon, 2017; Goldenberg, 2012; World Health Organization (WHO), 2019). That said, one of the main issues those of us interested in health care improvement have ignored is understanding the impacts improvement strategies have on patient and family<sup>1</sup> experiences. I see this lack of knowledge as a problematic gap, given the tension between the Triple Aim's goals to both improve the individual experience of care and reduce costs. Indeed, this tension presents a significant opportunity for inquiry into patients' and families' experience of QI interventions.

<sup>&</sup>lt;sup>1</sup> Throughout this dissertation I refer to *patient* to apply to any recipient of health care (such as client, user, consumer) (Shevell, 2009). A central concept of patient- and family-centred care is that "patients and families define their '*family*' [e.g., family members, loved ones, caregivers, and surrogates of patients] and determine how they will participate in care and decision-making" (Institute for Patient- and Family-Centered Care, n.d.).

Traditionally, QI has been seen as changing care processes and the way health care providers<sup>2</sup> do their work (Ovretveit, 2014). Moreover, those who implement QI interventions involving patients and families at the point of care assume interventions to be a beneficial extension of routine medical care, and tend not to recognize potential downsides for patients and families (Berger et al., 2014; Canadian Institutes of Health Research et al., 2018; The Health Foundation, 2013b). For example, QI interventions may involve – or be perceived by patients, families and some health care team members to involve – competing interests if the intervention's goals extend beyond patients' immediate interests (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005; Baily et al., 2006; Duncan et al., 2014; Grady, 2007; Paley, 2014; Radnor et al., 2012). Thus, involving patients and families in QI at the point of care raises ethical questions about unexamined wider impacts on this stakeholder group, some of whom may be in circumstances that may make them vulnerable in the context of their role as patients/families. Yet implementation of QI interventions does not generally require formal ethical oversight. In practice, then, QI interventions may introduce potential for benefits, burdens and/or harms without sufficient clarity about their distribution, and without sufficient clarity regarding other relevant ethical issues for patients and families (Canadian Institutes of Health Research et al., 2018; Nerenz, 2009; H. A. Taylor, Pronovost, Faden, et al., 2010; H. A. Taylor, Pronovost, & Sugarman, 2010; U.S. Department of Health and Human Services, 2018). This study therefore explores how patients and their families actually experience QI interventions from an ethical stance. As such, it is an innovative avenue of research that builds on the strengths of the QI field.

<sup>&</sup>lt;sup>2</sup> Throughout this dissertation, I use the term "care provider" or "provider" to refer to those who provide or manage care in health care settings (e.g., nurses, physicians, social workers, technicians, clinical leaders, administrators). Similar terms include health care professional, clinician.

#### **1.2** Impetus for the Study

I came to an understanding of the need to investigate the way patients and their families experience QI gradually, as a manager in health care administration and consulting, a research ethics board (REB) member, and a health care professional with early career training in dietetics. My administrative work exposed me to initiatives aiming to improve health care systems at international, federal, provincial, and local levels. As in other applied disciplines, health care administrators encounter situations where the current knowledge or ways of interpreting situations are not always able to solve the practical challenges arising from everyday care (Maxwell, 2013; Thorne, 2016). Thus, this research project originated from experienced-based observations, questions and concerns that arose during my career.

Initially, I perceived my administrative and REB work as separate from my interest in QI; one was in the practice and policy world, the other in research. Over time, I noticed that colleagues from different fields framed what seemed to be similar learning activities<sup>3</sup> in different ways. Specifically, people deemed some projects to be research and others to be non-research (e.g., QI or program evaluation), whereby the former required REB review and the latter did not. These differences raised questions about values and ethical rules that began to capture more of my interest, including ways of thinking about autonomy and patients' rights and interests. My observations and questions reflected those of ethicists in the field who were beginning to write

<sup>&</sup>lt;sup>3</sup> Learning activities (Faden et al., 2013, p. S19) are a group of actions to improve the planning and management of health care services related to the health of individuals or communities, which involve people or their health information. Examples include research (e.g., clinical trials), quality assurance, QI, program evaluation and administrative data analysis (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005, p. 5). Similar terms include *knowledge-generating learning activities* (Alberta Research Ethics Community Consensus Initiative Consensus Initiative (ARECCI), 2005, p. 5) and *evidence-generating initiatives* (Willison et al., 2014).

about the problem of distinguishing research from non-research projects and the ethics of QI (for example, see (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005; Baily et al., 2006; Hagen et al., 2007; Lynn et al., 2007). Later, the Hastings Center<sup>4</sup> published a series of papers that argued against what seemed to be a research–practice dichotomy (in particular, see Kass et al., 2013), and proposed re-conceptualizing ethics and ethical oversight across a "learning health care system" (see Faden et al., 2013).

By the time I was ready to consider embarking on my dissertation research, Michael McDonald and Susan Cox from the University of British Columbia (UBC) Maurice Young Centre for Applied Ethics and others had been writing about the importance of reconciling experiences of research participants with the ex ante conceptions of researchers and REBs, suggesting that estimates of benefits, burdens and harms such as those identified by ethics committees do not always correspond with the impacts described by participants (Cox et al., 2019; Cox & McDonald, 2013; M. McDonald et al., 2008, 2014; M. McDonald & Cox, 2009; Townsend & Cox, 2013). For example, these researchers found that clinical trial participants with chronic illnesses experienced profound emotional impacts from quality-of-life questionnaires that researchers considered to be routine 'minimal risk' research procedures (M. McDonald et al., 2014; Townsend et al., 2014). Their findings reinforced my awareness of the importance of investigating the nuances of the ways patients and families experience the various care processes that make up a QI intervention, particularly in a practical context of the intervention's

<sup>&</sup>lt;sup>4</sup> The Hastings Center is a nonpartisan, nonprofit organization located in New York. Scholars associated with The Hastings Center study the social and ethical issues in health care, science and technology. Since 2003, health care experts associated with this organization have been studying the ethics of using QI methods in health care.

implementation at the point of care. Ideas about broader ethical attention to projects involving QI appealed to me, and I wondered where the patient and family perspective appeared in this literature. As the ideas behind this study developed, I was driven by a personal and professional curiosity and by my conviction that it would be a worthwhile endeavour to explore what matters morally to patients and families as they encounter QI interventions.

#### **1.3 Problem Focus**

The main issue addressed in this study is the failure to grasp the ethically significant issues (both strengths and tensions) that arise in health care QI. That is, the common understanding of the impacts of QI interventions on patients and families in care delivery situations – situations with known burdens, asymmetries of power in a hierarchical system, and competing interests at stake – typically remain focused on the benefits that QI purports to offer. However, we do know about the burdens that illness and treatment place on patients/families and their related capacity to cope with further demands when ill and in hospital (Boehmer et al., 2016; Gallacher et al., 2018; May et al., 2014; Naik et al., 2009; Shippee et al., 2012), as well as the complex power dynamics within and between patient–provider, family–provider, patient–family, and provider-provider relationships (L. Baker et al., 2011; Cascio & Racine, 2018; Doane & Varcoe, 2013; Nisker, 2013; O'Shea et al., 2019; The Health Foundation, 2013a). Patients and families may be unable (too ill and/or too overwhelmed) or unwilling (uneasy or even afraid) to take on the additional burdens of QI interventions that create more work for them, or to assume new roles that require them to enact more agency.

However, given that QI activities generally do not require explicit informed consent, patients and families may not realize that QI interventions have been integrated into their hospital care. It is also not always clear what ethical issues QI might generate. Research has shown that while asking or requiring patients and families to participate in new quality/safety interventions at various points in their journey of care may empower some patients and families, for others it may contribute to further stress, guilt, strained patient/family–provider or patient–family relationships, and mistrust toward care providers (Alberta Innovates, 2010; Berger et al., 2014; Hrisos & Thomson, 2013; Shippee et al., 2012; The Health Foundation, 2013a; World Health Organization (WHO), 2013a). In this context, my study questioned whether patients and families necessarily experience QI as a beneficial extension of routine medical care. My research therefore addressed an urgent need to explore and understand the wider impacts of QI interventions using a values-based ethics lens from the patients' and families' perspectives.

#### **1.3.1** Optimistic framing.

Ideas about health care quality are framed optimistically in the literature; policy-makers, administrators and practitioners tend to see quality and QI as good things that ought to happen (Goldenberg, 2012). Furthermore, calls to increase patient and family engagement in initiatives to improve the quality of care are strongly advocated (Armstrong et al., 2013; G. R. Baker, 2014; Balik et al., 2011; Berger et al., 2014; Bergerum et al., 2019; Entwistle & Watt, 2013; O'Shea et al., 2019; Sari et al., 2011; The Health Foundation, 2013b; Wiig et al., 2013). For example, the World Health Organization advocates (n.d.b):

... partnership between patients, their families, and health-care workers to promote hand hygiene in health-care settings. **Patient engagement participation/engagement/ empowerment in hand hygiene promotion** refers to the involvement of patients in the

fostering of hand hygiene best practices by both patients and health-care workers in health-care settings. (para. 1, emphasis in original)

In other words, given QI's significance in health care, QI is typically described in positive terms. However, at the same time QI is assumed to be ethically unproblematic.

There are, to be sure, many benefits to improving quality and engaging patients and families in the health care system and in their own health care. As I have indicated above, however, to date the assumption of benefit has meant there has been little clinical or ethical focus in evaluations of the wider impacts that QI interventions have on patients/families at the point of care. Research examining benefits and harms of patient and family involvement in QI provides limited evidence of their benefit (Cené et al., 2016; Liang et al., 2018; Pomey et al., 2018; Wachter, 2010). Furthermore, Berger et al.'s (2014) systematic review of patient engagement in safety and quality initiatives (including initiatives such as hand hygiene and rapid response systems) reported, "None of the included studies evaluated harms of interventions or surveys [on patients and families]" (p. 552). It is my premise that these gaps are the result of an optimistic, positivist framing of QI as 'routine clinical care' and the assumed benefits of engaging patients and families in QI. This has led to an ambiguous ethical status for QI activities, with little incentive to study patient and family experiences of QI at the point of care or to pursue ethical oversight of QI.

#### **1.3.2** QI's ambiguous ethical status.

QI initiatives are a heterogeneous group of typically non-research activities that share many characteristics with health research (Kass et al., 2013) yet, as I have indicated above, have an

ambiguous ethical status. As Klingler et al. (2020) state, "Describing an activity as research or practice has considerable normative, procedural, and regulatory implications" (pp. 1–2). Governmental agencies in Canada and elsewhere only require formal ethical oversight for research projects for reasons that include protecting patient interests and institutional liability (Canadian Institutes of Health Research et al., 2018; Stark, 2011; H. A. Taylor, Pronovost, Faden, et al., 2010; U.S. Department of Health and Human Services, 2018). Given this requirement, the focus of ethical attention remains on sorting QI from research activities. Because those conducting QI projects tend to consider QI to be part of routine practice activities (not research), they rely on professional codes of ethics<sup>5</sup> and privacy and consent laws<sup>6</sup> in an effort to uphold patients' and families' best interests.

In some cases, Canadian organizations suggest, but rarely require, some form of ethical oversight of QI activities.<sup>7</sup> Existing mechanisms include a separate ethics process for QI initiatives (for example, see (Alberta Innovates, 2010; Hagen et al., 2007; Interior Health, 2014), or a single ethics process across research and practice activities (for example, see articles about Public Health Ontario, including (Klingler et al., 2020; Ondrusek et al., 2015; Willison et al., 2014). In addition, authors from Canada and other jurisdictions report that some QI initiatives may

<sup>6</sup> Privacy legislation, for example BC's Personal Information Protection Act, SBC 2003, c 63, <<u>http://canlii.ca/t/52pq9></u> retrieved on 2019-02-10; Canada's Personal Information Protection and Electronic Documents Act, SC 2000, c 5, <<u>http://canlii.ca/t/529tx></u> retrieved on 2019-02-10. *Consent legislation*, for example: BC's Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c 181, <<u>http://canlii.ca/t/520ts></u> retrieved on 2019-02-10.

<sup>&</sup>lt;sup>5</sup> For example: Canadian Medical Association Code of Ethics (2018); Canadian Nurses Association Code of Ethics (2017); Code of Ethics of the Canadian Physiotherapy Association (2017); Canadian Association of Social Workers Code of Ethics (2005).

<sup>&</sup>lt;sup>7</sup> For example, in the British Columbia (BC) health authorities, most QI projects do not require ethical review or approval in order to proceed, unless they contain an element of research (BC Patient Safety & Quality Council, 2019). Notable exceptions are Interior Health (2014) and the First Nations Health Authority (FNHA) (n.d.-f).

undergo REB review on an ad hoc basis (Ezzat et al., 2010; Jeffrey et al., 2019; Patel et al., 2013; Patenaude et al., 2008). Because there are no standard mechanisms or policies regarding the ethical conduct of QI, QI activities are not evaluated comprehensively for efficacy, or impacts on patients, families, staff, and organizations.

#### **1.3.3** Patient and family experiences of QI are understudied.

As noted above, the practice of engaging patients in quality and safety initiatives has been promoted as part of patient- and family-centred care, although research to support it is limited (Armstrong et al., 2013; G. R. Baker, 2014; Balik et al., 2011; Berger et al., 2014; Bergerum et al., 2019; R. E. Davis et al., 2011; Groene et al., 2009; Office of the Auditor General of British Columbia, 2008; O'Shea et al., 2019; Sari et al., 2011; The Health Foundation, 2013b; Travaglia & Robertson, 2018; Wijg et al., 2013). Family members are said to play important roles in health, wellness and health care processes for patients of all ages (Cené et al., 2016, p. 698). The concept of patient/family engagement often refers to patients and families providing input into various levels of health care organizational and system design (Carman et al., 2013a; Council of Canadian Academies, 2015; Faden et al., 2013). Yet patient/family engagement can also mean various ways of increased involvement in their own direct health care. To this end, some QI initiatives engage patients/families in new roles that include taking new responsibilities for aspects of the quality and safety of their own health care (Carman et al., 2013; Lawton et al., 2017; Longtin et al., 2010; The Health Foundation, 2013b; World Health Organization (WHO), 2009d, 2017, p. 14).

I have argued that patient and family experiences of QI interventions at the point of care are poorly understood, and have been understudied from a values-based perspective. To date, the research investigating patient/family involvement in QI has two interesting characteristics. First, patient experience data are typically quantitatively-focused and superficial; they have been used to identify future improvement opportunities and for reporting purposes, arguably with little effect (Bate & Robert, 2007; Murray, 2012; The Health Foundation, 2013c; Wiig et al., 2013). As Bate and Robert (2007) have noted, what is typically positioned as "experience data", with answers to such questions as "did you like it?" (pp. 41–42), should be considered "satisfaction data". These authors emphasize that patient experience is a highly complex phenomenon that requires understanding elements such as reflection and awareness, sensation, perception, thought, memory, imagination, emotion and expression, desire, volition, and action and conduct (p. 41). Second, despite the fact that research over the last few decades has studied patient empowerment, patient/family experience, and QI, comparatively little attention has been focused on the richness and complexity of patient/family experiences of QI at the point of care. Yet point of care is a power-laden situational context (Doane & Varcoe, 2013, 2015; Rodney, Burgess, Pauly, et al., 2013). To my knowledge there are no studies to date that have explored patient and family experience of being involved in QI interventions at the point of care using an ethical lens. The dearth of research into patient/family experiences of QI interventions is due in part to the difficulty of isolating the phenomenon of experience within routine patient care, and the complexity of measuring related outcomes.

In conclusion, despite the volume and diversity of quality and safety initiatives ongoing in health care systems worldwide, Solomon (2010; 2013) and others argue that as result of insufficient

learning and ethical attention to QI, we may unintentionally be causing harm, wasting scare resources, and entrenching disparities. Furthermore, as the literature I have reviewed above makes clear, the wider impacts (and ethical implications) of these QI initiatives *on* patients and families remain poorly understood. Without a robust, first-hand understanding of patients' and families' lived experiences of QI interventions, we as health care system 'experts' continue to miss opportunities to maximize our efforts at improvement. To understand how patients/families experience benefits, harms and burdens of health care system QI initiatives, more information is needed about the context in which these experiences occur; i.e. at the point of care.

#### **1.4 Research Questions**

Proceeding from my analyses above, in Figure 1.1, I have illustrated the rationale for inquiry to answer my research questions.



#### Figure 1.1 Rationale for inquiry to answer my research questions.

As I will elaborate on in Chapters 4 and 5, it was my conviction that a qualitative<sup>8</sup> study would enable a comprehensive and in-depth exploration of a QI intervention's impacts on patients and

<sup>&</sup>lt;sup>8</sup> Creswell (2013) describes qualitative research as involving data collection in natural settings with sensitivity to people and other elements of the setting. Data analysis is inductive and deductive, and establishes patterns or themes (p. 44). Thus, a qualitative approach requires critical reflection of how knowledge is constructed during the research process (Chenail, 2011; Creswell, 2013; Guillemin & Gillam, 2004; H. A. Taylor, Chandros Hull, & Kass, 2010; Thorne, 2016).

families, and that an ethical (values-based)<sup>9</sup> lens could highlight value conflicts and other ethical issues of significance. Moreover, it was clear that such a nuanced portrait could have significant potential to influence professional practice and health care system improvement. These observations were the impetus for the two research questions guiding this study:

- 1. How do patients and families describe their experience of being involved in a quality improvement initiative (hand hygiene) that asks them to take on specific responsibilities to improve the quality and safety of their own health care in an acute care hospital?
- 2. What are significant ethical implications of my empirical findings and how will these be translated into practice?

I entered this study with a pragmatic intent, meaning I aimed to generate knowledge with the potential to contribute to real-world action, rather than only formal theorizing. The scope of this study has been to explore patient/family experiences when receiving health care on hospital units that are piloting QI interventions involving patients in the safety of their own care.

#### 1.5 Overview of the Dissertation

This dissertation is structured into nine chapters. In this first chapter, I have provided a brief overview of what QI in health care is, the impetus for my study, the ways in which patients and families are involved in QI, and the limitations of what we know about their experiences of such involvement. I claim that an understanding of patients' and families' experiences of pilot QI

<sup>&</sup>lt;sup>9</sup> Axiology is the theory of value (OED Online, 2017a).

interventions at the point of care is understudied from a values-based perspective, and outline two research questions for this study. In Chapter 2, I elaborate on the research problem and background to the study by offering an overview of the health care ethics and quality landscapes. In Chapter 3, I describe the QI field and provide background on the focal area of QI in this study: hand hygiene interventions that involve hospital patients and families. I also review ethical approaches for QI, and summarize why involving patients and families in QI at the point of care raises ethical questions about unexamined wider impacts on this stakeholder group.

I then turn my attention to grounding the logic and criteria for conducting this study. In Chapter 4, I outline the theoretical structure, which includes a constructionist epistemological orientation. I also explicate the role of contextual and values-based inquiry, and how I applied relational inquiry (Doane & Varcoe, 2015; Sherwin & Feminist Health Care Ethics Research Network, 1998) and ecological systems theory (Bronfenbrenner, 1993) perspectives to answer my research questions. In Chapter 5, I elucidate the process of operationalizing<sup>10</sup> (implementing) the study. I set the stage by positioning why qualitative research has a vital role to play in understanding the significance of patient and family experience of QI. I justify my use of Thorne's (2016) interpretive description research methodology and my concomitant use of case studies as means

<sup>&</sup>lt;sup>10</sup> Operationalization is a widely used term within social science research. Throughout my dissertation, I use the term *operationalize* in two distinct ways. The first meaning, when used in a philosophical sense, refers to the bridge between the theories and the methods in my research study; "the act of translating a construct into its manifestation" (Trochim, 2006, p. para 4). As an example of this first use of operationalize, Ayres (2008) states, "The concepts addressed by grand theories are highly abstract and cannot easily be operationalized into variables or used in hypotheses" (p. 373). The second use of operationalize is in the colloquial sense of putting something into practice; in my study I refer specifically to *design, implement, evaluate and report QI interventions*. As an example of the second use of operationalize in the literature, May (2013) notes that, "Participants work to operationalize the interactional practices and artifacts through which shared decision-making is accomplished" (p. 31).

by which to study and interpret the context of QI interventions. I subsequently describe in detail the methods and strategies I used to answer my research questions.

In Chapter 6 I present my findings, the focus of which is on the experiences of patients and families in the context of QI generally and in relation to the hand hygiene QI case studies specifically. I provide an interpretive description of the data organized by themes that centre on one meta-theme: patient and family experiences of *moving towards* or *moving away* from relational connections with their care providers and health care settings. In Chapter 6 I also describe important findings outlining contextual features of the *patient hand wipes* intervention based on the ways I observed the intervention to be operationalized.<sup>11</sup>

In the remaining three chapters of the dissertation, I discuss the meaning, ethical implications, and practical implications of my empirical findings. In doing so, in Chapter 7 I further interpret my data and relate it to relevant literature. I focus on how my *Relational Safety Framework* (the ethical constructs of which include relational interaction, relational connection, relational safety and trust) illuminates the findings. In Chapter 8, I discuss the implications of strengthening relational safety in QI. This discussion centers on addressing the disconnects between how quality leaders and care providers perceive health care improvement interventions rolling out, how patients and families experience these same interventions, and how understanding these gaps in a relational way provides new opportunities to advance QI.

<sup>&</sup>lt;sup>11</sup> Note, this is an instance of the second use of "operationalize", in the sense of putting something into practice.

Finally, in Chapter 9, I build on my analyses and findings centring on relational safety to make recommendations to translate these findings into practice. My central recommendation from this study is that health care leaders ought to more fully appreciate the ethical implications of QI implementation, such that ethical attention to QI, including relational safety, become integral aspects of health care improvement. My recommendations include new strategies to improve the ethics and efficacy of QI processes at micro, meso and macro levels, including my reflections on ethical approaches that health care organizations commonly employ for QI interventions. I make the case that adopting a relational perspective to QI initiatives as an ethical endeavour is a new, ethically-based values-added strategy to advance health care system improvement. I close the dissertation with final reflections on my study, and suggest areas for future inquiry.

# Chapter 2: Literature Review – Patients and Families within Health Care Ethics and Quality Landscapes

#### 2.1 Chapter Overview

To set the stage for an ethical exploration of how patients and their families experience OI, over the next two chapters I concomitantly explore and link ethics through a narrative review of health care quality, patient-centred care, and QI. In this review, I summarize and synthesize how key concepts and thinking unfolded in these bodies of literature, how the actors and studies within them fit together, and why central patterns may be continuing to evolve in certain ways (Paré & Kitsiou, 2016; Punch, 2014; Thorne, 2016). Given the breadth of literature, I selectively portray significant contributions of individuals/groups to the whole, and draw attention to the value of certain perspectives situating my research problem (Paré & Kitsiou, 2016; Punch, 2014; Thorne, 2016). To facilitate rigour in my research, I searched, identified, and selected diverse sources of literature (Paré & Kitsiou, 2016, p. 161) ranging from traditional academic outputs (e.g., highly cited articles and reviews from high-impact scientific journals) to 'grey literature' (e.g., practitioner-oriented white papers and policy reports from IHI, The Health Foundation, and the First Nations Health Authority). My intention to ground my study within an analysis of diverse sources of current knowledge and interpretations is particularly important given the practice-based genesis and goals of my qualitative study (Paré & Kitsiou, 2016; Thorne, 2016).

In this chapter I provide an overview of the complex ethics and quality landscapes in which patients and families receive health care. To begin, I locate health care ethics and relevant aspects of bioethical history to explain why a sharp distinction arose between research and

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quality improvement. I also summarize contextual approaches to ethics and key aspects of the health care quality and patient safety movements. Following my exploration of systems and structures, I turn my attention more directly to patients and families, the users of health care services. I describe patient-centred care, and how aspects of patienthood such as vulnerability and power asymmetries led to a rationale for engaging patients and families more deliberately in health care. Next, I review ways of conceptualizing and measuring how patients and families experience the health care they receive, especially when asked to take on more responsibility for their own care and safety.

#### 2.2 Ethics in Health Care

#### 2.2.1 Locating ethics.

This dissertation is an ethical analysis of patient and family experiences, meaning it falls into the bioethics sphere. Ethics addresses values-based concerns. Ethics and morals are linked philosophical concepts that are used interchangeably. The difference between the two can be explained as morals being concerned with how things "ought to be", and ethics a reflective analysis of how what "ought to be" is put into action (Storch, 2013, p. 6). Fry et al. (2011) define values as "a rational conception of the desirable; a standard or quality that is esteemed, desired, and considered important" (p. 485). Rodney et al. (2009) note that the term bioethics first appeared about 50 years ago with the publication of a text on biological knowledge and human values (p. 293). Now a discipline in its own right, bioethics has evolved as a multi-disciplinary response to moral and ethical questions in applied practice contexts. According to the John Hopkins Berman Institute of Bioethics (n.d.):

Bioethical questions often involve overlapping concerns from diverse fields of study including life sciences, biotechnology, public health, medicine, public policy, law, philosophy and theology. They arise in clinical, research, and political arenas, usually in response to advances in biology, health care, and technology, particularly biotechnology. (para. 3)

The terms bioethics, biomedical ethics, medical ethics, clinical ethics, and health care ethics are also used somewhat interchangeably (Rodney, Burgess, Phillips, et al., 2013, p. 65). In this dissertation, I use the term *health care ethics* because it reflects a number of ethical issues in health research and in QI, as well as a broad definition of health and well-being (World Health Organization (WHO), 1986) – all of which involve patients, families, health care providers, communities, health care organizations, and our larger society. Within this arena, ethically difficult situations often arise from tensions between health care providers, patients, families and health care funders located in complex organizational and sociopolitical contexts.

#### 2.2.2 Modern bioethical history.

The history of modern bioethics is relatively short, and is usually traced back to the *Nuremberg Code*, the first statement on ethical conduct of medical research that resulted from the "Doctors' Trial" in 1947. In this trial, doctors and bureaucrats were accused of "war crimes and crimes against humanity for their roles in cruel and often lethal concentration camp medical experiments" (Moreno et al., 2017, p. 795). The foundational ethical concepts codified in Nuremberg – including voluntary and informed consent, favourable benefit-risk ratio, and assurance of qualified researchers – prioritized certain ethical requirements in response to the profound ethical transgressions committed by a specific group (the Nazi regime) during World War II (Emanuel et al., 2000; Moreno et al., 2017).

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Attitudes towards the ethics of biomedical<sup>12</sup> experimentation on human beings became more broadly informed during the 1960s and 1970s. The self-regulated medical profession continued to hold a privileged position in society (Kelleher et al., 2006). In 1964 the first Declaration of Helsinki was published with the final sentence being, "The investigator or the investigating team should discontinue the research if in his or their judgement, it may, if continued, be harmful to the individual" (World Medical Association, 1964, 2013). Yet, it is now evident that medical researchers in the West had not generally acknowledged that the lessons from Nuremberg also applied to their own work. Research-related scandals such as the Tuskegee Study,<sup>13</sup> one after the next, were exposed in the United States and other countries (Beecher, 1966; Emanuel, 2008; J. Goodman et al., 2003; Rothman, 1991), often long after the research was conducted. McDonald and Meslin (2003) state that for many years in Canada, attitudes were such that "the kind of cases of research misconduct widely reported in the U.S. (such as the Jewish Chronic Disease Hospital, Willowbrook, and Tuskegee) will not happen in Canada, or that such cases are not generalizable" (p. 12). However, similar research-related scandals did occur in Canada as described in Mosby's (2013) archival research about nutritional experiments in residential schools supported by the Government of Canada between 1942 and 1952; and Cameron's LSD experiments with psychiatric patients in Montreal during the 1950s and 1960s without their consent (Lemov, 2011; The Fifth Estate, 2017).

<sup>&</sup>lt;sup>12</sup> The Canadian Institutes of Health Research (2018) defines *biomedical* research as "the goal of understanding normal and abnormal human functioning, at the molecular, cellular, organ system and whole body levels, including development of tools and techniques to be applied for this purpose; developing new therapies or devices that improve health or the quality of life of individuals, up to the point where they are tested on human subjects." (p. 5) <sup>13</sup> In this experiment conducted between 1932 and 1972, the US Public Health Service knowingly denied treatment to 400 African American sharecroppers in Alabama with syphilis, even after the discovery of penicillin as an effective treatment, in favour of continuing to study the natural history of the disease (Heller, 1972).
By the 1970s, increasing societal attention to human and civil rights and challenges to authority raised tensions and ethical awareness, especially regarding groups considered vulnerable to exploitation (Batt, 2017; Kelleher et al., 2006; Sherwin, 2011b). These trends represented "a conceptual and practical shift away from paternalism" (Baily, 2011, p. 172), and reinforced that special protections were needed for people subjected to research and to protect the very integrity of the research enterprise (Beecher, 1966; Department of Health & Human Services, 1979; Emanuel, 2008). In the 1970s, the US government commissioned The Belmont Report (Belmont) (Department of Health & Human Services, 1979), which identified basic ethical principles or "general judgments that serve as a basic justification for the many particular ethical prescriptions and evaluations of human actions" (p. 4 Part B) relevant to the ethics of research involving humans. These principles were: respect of persons, beneficence and justice. In 1994, ethicist Susan Wolf observed, "as modern bioethics came of age in the last quarter century, it took shape largely as a conversation among professionals [ethical, legal, and medical experts] about the content of aspirational standards" (p. 119). The principles proposed in Belmont formed the cornerstone of the research ethics oversight paradigm throughout the industrialized world (Brody, 1998), and contributed to health care ethics more broadly.

#### 2.2.3 Initial focus on practice/research distinction.

Along with an imperative to protect people involved in human experimentation came the need to be able to distinguish research from non-research activities. An important feature of *Belmont* is the hard boundary between practice and research (Department of Health & Human Services, 1979, p. 2 Part A). This distinction stems from an analysis of whose rights and interests are being served, reflecting classic (or early) thinking in bioethics that introducing competing interests

creates the potential for ethical tension if one set of interests is sacrificed for the other. Following on this premise, the practice/research distinction is founded on the belief that in research activities, research participants are subjected to potential risks of harm for the benefit of prospective/future patients, the larger population, and/or to further the researchers'/institutions' goals. On the other hand, in clinical practice, patients' immediate interests are addressed because health care professionals are obligated to care for individual patients in a way that is personalized to benefit each patient via "the accepted and routine practice of medicine" (Department of Health & Human Services, 1979, p. 2). In other words, *Belmont* established a justification for two distinct ethical contexts, whereby the interests of research participants (unlike for patients) are understood to be subordinated (or partially and/or potentially subordinated) for the benefit of science and others (Kass et al., 2013, p. S5). In addition, social tensions about the distribution of resources (such as technology and expertise) began to emerge across research and practice. Given what we know about past and present medical ethics transgressions, the lenses through which these problems were viewed and sources of ethical tension identified, it follows that conduct of research activities was seen to require ethical scrutiny over and above that of practice/clinical activities.

## 2.2.3.1 Core ethical principles traverse research and practice.

The same year *Belmont* was published, Tom Beauchamp and James Childress (1979) published their landmark book, *Principles of Biomedical Ethics*. In the fourth edition of this text, Beauchamp and Childress (1994) expanded their conceptualization of the four ethical principles: respect for patient autonomy (voluntary choice); non-maleficence (avoid doing harm); beneficence (removing harm, doing good); and justice (distributing benefits, burdens and health care resources equitably). Together, these principles are referred to as principlism, a normative (how one ought to act) ethical framework. Two central assumptions in this principle-based approach are: (1) it serves as a guide to make practical health care decisions; and (2) the four principles are interdependent and non-absolute (prima facie, meaning accepted as correct until proved otherwise). Through a reflective process, the principles can be equally considered or one principle can override the others, depending on the situation. This means that deciding which principle takes priority requires judicious balancing and good information.

Principlism has had an influence on health care ethics throughout the industrialized world. For example, the four principles (among other ethical standards such as informed consent, truth-telling, privacy, and confidentiality) are formalized into law, guidance, and codes of ethics, and cross disciplinary boundaries including bioethical theory and the research, practice, and public health domains (Rodney, Burgess, Phillips, et al., 2013, p. 66). I will briefly summarize critiques of principlism and outline complementary ethical approaches in Section 2.2.4, and discuss the relevance of these critiques for my study.

#### 2.2.3.2 Ethics in health research.

In his survey of international, national and professional ethics norms and codes on health research for the then Law Commission of Canada, ethicist Michael McDonald (2000) identified three key ethical objectives: "A. The **promotion** of socially beneficial research; B. **Respect** for the dignity and rights of research subjects; C. As an overarching aim, the maintenance of [warranted] **trust** between the research community and society as a whole" (adapted from pp. 30–31 and 296, emphases in original). Approaches to ethics in health research around the world

are highly formalized, with standards implemented as laws, regulations, and guidelines governing research with human participants at international and regional levels.<sup>14</sup>

In Canada, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (*TCPS 2*) (2018) sets the standard for ethical review and conduct of all research in Canada involving humans (including their personal information and biological materials).<sup>15,16</sup> *TCPS 2* (2018) defines *research* as, "An undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation" (p. 13), whereby such inquiries are "conducted with the expectation that the method, results and conclusions will be able to withstand the scrutiny of the relevant research community" (p. 14). Accomplishing the three key ethical objectives set out by McDonald (above) requires a system of research ethics oversight comprised of a lifecycle of processes (such as priority setting) and actors (such as funding agencies and research institutions) at macro, meso and micro levels (J. A. Anderson et al., 2011; Canadian Institutes of Health Research, 2018). As such, the *TCPS 2* is positioned as a living document that works in conjunction with relevant ethics guidelines, policies, legislation and regulation while being responsive to social changes (p. 9). Other requirements apply to drug, device and health product

<sup>15</sup> The *TCPS 2* is informed by leading international ethics norms, and addresses novel issues of significance, as well as issues of particular relevance in Canada such as research involving First Nations, Inuit and Métis peoples (Chapter 9). As a joint policy of Canada's three federal research agencies, *TCPS 2* applies to all research involving humans. While adhering to *TCPS 2* is required by research institutions taking funding from these agencies, other groups utilize *TPCS 2* guidance on a voluntary basis (Panel on Research Ethics, 2017). For a more in-depth summary of health research ethics in Canada, see Michael McDonald's (2009) paper on the complex history of the *Tri-Council Policy Statement*, McDonald and Meslin's (2003) paper, and Chapter 8 of David Unger's (2011) text *The Canadian Bioethics Companion*.

<sup>&</sup>lt;sup>14</sup> For a comprehensive review of current international human research standards, see (Office for Human Research Protections, 2020).

<sup>&</sup>lt;sup>16</sup> CIHR (2018) organizes health research under four themes: biomedical; clinical; health services; and social, cultural, environmental, and population health (p. 5).

research,<sup>17</sup> such as the Food and Drug Regulations of Canada (Food and Drugs Act, 1985 Part C, Division 5), and the International Committee on Harmonization Good Clinical Practice Guidelines (ICH-GCP) (2016).<sup>18</sup>

The research ethics board (REB) was the main mechanism designed for providing ethical oversight of research activities in accordance with established standards and requirements (Canadian Institutes of Health Research et al., 2018 Chapter 6).<sup>19</sup> In Canada, REBs are typically established, funded, and administratively supported by the institutions that conduct research under their auspices (e.g., post-secondary educational institutions, health care agencies), but operate with high levels of autonomy. The REB's primary responsibility is to protect the rights and welfare of study participants. Other roles of the REB are to protect the interests of researchers and institutions (Stark, 2011). REB membership is comprised of a least five independent men and women with expertise in scientific and non-scientific areas, ethics, law and at least one member representing the "community" (Canadian Institutes of Health Research et al., 2018 Article 6.4; Food and Drugs Act, 1985 C.05.001).

<sup>18</sup> Other international guidelines include those from the Council for International Organizations of Medical Sciences (CIOMS) (2016), the WHO (2013a), and the World Medical Association's *Declaration of Helsinki* (2013). Examples at a country level include New Zealand's (Health Research Council Act, Sections 24 and 25, 1990) (legislation), the US's *Revised Common Rule* (U.S. Department of Health and Human Services, 2018) (regulation), and Australia's *Ethical Conduct in research with Aboriginal and Torres Strait Islander Peoples and Communities* (National Health and Medical Research Council, 2018) (guideline).

<sup>&</sup>lt;sup>17</sup> As an example, in July 2020 5,952 open clinical trials in Canada are listed on ClinicalTrials.gov, the world's leading web-based resource of clinical studies maintained by the US National Institutes of Health.

<sup>&</sup>lt;sup>19</sup> The REB concept and composition is similar in jurisdictions around the world, aligning with international practice and guidelines including the World Health Organization and The World Medical Association. Analogous terms including institutional review board (IRB, most common in the US), research ethics committee (REC, most common in the UK and Europe), and human research ethics committees (HREC, most common in Australia) (Page & Nyeboer, 2017; Unger, 2011 Chapter 8).

Unfortunately, despite the evolution of bioethics and research ethics oversight over the past half century, it is clear that bioethics-related transgressions are not just a thing of the past. Recent examples include abuse of research participants (Dougherty & Allen, 2017) and falsification and fabrication of data (Marcus & Oransky, n.d.; Ozkan, 2019). New accounts continue to be revealed as information is uncovered and societal attitudes, norms and ethical awareness evolve, as discussed in research ethics texts (for example see (Emanuel, 2008; Pimple, 2017; Resnick, 2018).

## 2.2.3.3 Ethical structures traverse research and practice.

While many ethical concepts apply to both research and practice, these concepts are expressed differently and tensions manifest differently in practice and research contexts. For self-regulating professions, credentialing to assure competence and codes of ethics are examples of structures that traverses practice and research. Codes of ethics apply the core principles as well as other salient principles (e.g., the Canadian Nurses Association (2017) includes maintaining privacy and confidentiality). Professional codes of ethics differentiate research from care via the *duty of care* (Davidoff, 2011; Goldenberg, 2012; Ogrinc et al., 2008; Wynia, 2012), thus the responsibility for clinical care, and quality, rest with clinicians. More recently, the emergence of organizational codes, such as the BC Provincial Health Services Authority Code of Ethics (2019) and the Alberta Health Services Code of Conduct (2016), set out guidelines for acceptable behaviour that apply across an organization's people and activities. Finally, ethical principles

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come through in legislation that applies across research and practice. For example, privacy legislation<sup>20</sup> and consent legislation<sup>21</sup> states that for consent to be valid it must be informed.

## 2.2.3.4 Ethics in health care practice.

Dixon (2017) provides examples of how the core ethical principles are applied in the normal practices of care providers and health care organizations: (1) demonstrating respect for patient autonomy requires care providers to take adequate time and care in explaining the nature of treatment decisions; (2) upholding a duty of care requires providing patient care that is consistent with known good practice is beneficent; (3) non-maleficence is expressed through providing privacy for patients and maintaining confidentiality of their personal information; and (4) considering justice requires health care systems to avoid being selective about patients who receive care, or receive a significant improvement in their care (pp. 7–8).

As health care systems are socially constructed, an important consideration is that how each principle is interpreted and how the principles relate to one another are highly influenced by theoretical underpinnings and sociopolitical contexts. For example, Ells et al. (2011) describe that early interpretations of autonomy in the context of rising challenges to traditional medical paternalism focused on the negative component: an individual's right to avoid unwanted interference from others. Furthermore, many authors note that for historical reasons, the principle

<sup>&</sup>lt;sup>20</sup> Examples of federal and provincial privacy legislation include Canada's Personal Information Protection and Electronic Documents Act, SC 2000, c 5, <<u>http://canlii.ca/t/529tx</u>> retrieved on 2019-02-10, and BC's Personal Information Protection Act, SBC 2003, c 63, <<u>http://canlii.ca/t/52pq9</u>> retrieved on 2019-02-10.

<sup>&</sup>lt;sup>21</sup> An example of provincial consent legislation is BC's Health Care (Consent) and Care Facility (Admission) Act, RSBC 1996, c 181, <<u>http://canlii.ca/t/520ts</u>> retrieved on 2019-02-10.

of autonomy became central in principlism, emphasizing the doctrine of informed consent for specific, vulnerable individuals (for example, see Baylis et al., 2008, p. 4; Emanuel et al., 2000; Rodney, Burgess, Phillips, et al., 2013, p. 66). Notwithstanding such theoretical and sociopolitical influences, the core ethical principles put forth by Beauchamp and Childress are significant in my study because they are generally accepted (alongside other ethical principles and concepts) throughout the health care ethics and quality landscapes in which patients and families experience the health care system.

## 2.2.4 Contextual approaches to health care ethics.

As I described above, principlism is a well-established ethical approach to health care ethics (and bioethics more generally). However, inherent in ethics are theoretical disconnects and struggles. For example, as noted above, classic thinking in ethics generates tension when one set of interests is sacrificed for the other, which pre-supposes a zero- or negative-sum game. Alongside applications of principlism, theoretical shifts – often reflecting events in the social world – have created complementary approaches to health care ethics. One important shift over the past decades has been increasing interest in the role of contextual (meaning experiential or case) knowledge in ethics (Rodney, Burgess, Pauly, et al., 2013, pp. 84–86). For example, Winkler (1993) articulated the notion of *contextualism*, stating that "moral problems must be resolved within concrete circumstances, in all their interpretive complexity, by appeal to relevant historical and cultural traditions, with reference to critical institutional and professional norms and virtues" (p. 344). In other words, it is the viewing of facts and values in the context of how we organize our social institutions that allows people to make ethical decisions.

Gillon (2015), in his defence of principlism as "good not only for medical ethics but for ethics in general" (p. 114), summarizes the main arguments put forth against principlism. These arguments include that the four principles approach is: too individualistic, with too much focus on autonomy; prone to oversimplification; too rigid; and lacking a moral theory to justify action. Hoffmaster (2018) further argues that moral considerations are "profoundly contextual" (p. 121). Overall, a contextual approach to ethics is a more social and less individualist interpretation of ethics that works toward a 'both/and' across individual and interpersonal through to societal contexts. Two conceptual examples of contextualist ethics of interest in health care situations and in my study are feminist ethics and relational ethics. Nurse ethicist Patricia Rodney and colleagues Burgess and Pauly et al. (2013) position these contextual approaches to ethics as complementary to and not (necessarily) in conflict with principlism-focused approaches. What this means, for example, is that the core principles can be viewed through ethical lenses that situate individuals within specific sociopolitical and historical contexts. In what follows, I briefly summarize feminist ethics and relational ethics.

Feminist ethics illuminates inequities and inequalities based in power and oppression. From feminist perspectives, people generally are situated in multiple unequal relationships within various influences that reinforce power inequities throughout their lives (Sherwin, 1989, p. 62). Initially focused on gender bias, sexism, and control over women's bodies (Reimer-Kirkham & Anderson, 2010; Sherwin, 1992), feminist ethics evolved to require examining the structure of *all* relationships and power dynamics at individual, organizational and societal levels (Rodney, Buckley, Street, et al., 2013; Rodney, Burgess, Pauly, et al., 2013).

Relational ethics is the second example of contextualist ethics, an ethic grounded in relationships in which people are not equally situated. Rodney, Burgess, Pauly, et al. (2013) state that relational ethics is informed by many theoretical lenses including "culture, ethics, feminism, phenomenology, pragmatism and radical hermeneutics" (p. 96). Relational accounts reject the assumption that participants operate as independent isolated individual entities and emphasize the influence of interactions with other people and sociocultural systems (Entwistle et al., 2010). As a result, relational understandings have profound implications for interpretations of ethical principles such as autonomy and justice. In 1998, Sherwin articulated a view of relational autonomy that demanded attention to the outside influences and forces that shape and potentially compromise an individual's ability to make a voluntary choice. Sherwin, writing together with Kenny and Baylis (2010) about public health ethics, explain that a relational account of justice shifts the concern about distributing benefits, burdens and health care resources equitably amongst individuals to concern about the social structures that exist to maintain and even further inequities (p. 10). Furthermore, because relational ethics is dynamic and requires ethical action, individuals studying and/or applying relational ethics need to be reflective about their own positionality (Baylis et al., 2008; Bergum, 2013; Rodney, Burgess, Pauly, et al., 2013).

Other ethical concepts also play a significant role in health care ethics. For example, trust is an essential process and outcome in health care that involves vulnerability<sup>22</sup> and risk:<sup>23</sup> well-placed

<sup>&</sup>lt;sup>22</sup> I explore the concept of vulnerability further in Section 2.4.1.1.

<sup>&</sup>lt;sup>23</sup> I use Faden et al.'s (2013) interpretation of the term risk: "to refer exclusively to a risk of 'harm,' meaning a thwarting, defeating, or setting back of an individual's interests" (p. S20). I explore the concept of harm in Section 2.4.3.2.

(warranted) trust can work in our favour, whereas misplaced trust can be dangerous (M. McDonald et al., 2008; McLeod, 2015). In what follows, I introduce two views of interpersonal trust, Baier's (1986) will-based view and Beitat's (2015) layer model.

In her foundational work *Trust and Antitrust* (1986), feminist theorist Annette Baier depicts trust as "reliance on others' competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care" (p. 259). In Baier's (1986) view, trust requires the truster to rely on another's good will and dependable habits, necessitating a focus on character and attitudes of trust in relationships. While Baier acknowledges a network of trust relationships, I found that more recent accounts of trust more explicitly situate the context of interpersonal trust between patients and care providers within sociopolitical systems. For example, Beitat's (2015) *Layer Model of Trust* describes interpersonal trust as the elemental level of trust in organizations and systems, in the context of reporting medical errors (see Figure 2.1).



# Figure 2.1 Beitat's Layer Model of Trust: Interpersonal trust is the elemental level of other trust relationships.

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In forthcoming chapters I elaborate on the role of relational ethics in informing the conceptualization of my research processes and findings.

## 2.3 Quality in Health Care

Improving the quality of care, reducing preventable<sup>24</sup> harm to patients and families, and improving the outcomes of health care are important prima facie ethical and legal obligations for policy-makers, decision-makers, health care institutions and care providers (Beauchamp & Childress, 2019; Davidoff, 2011; Dixon, 2017; Goldenberg, 2012; World Health Organization (WHO), 2019). Dual aims – to benefit individuals and the collective, and to "do no harm" – are reflected in the ethics of health care organizations and professions (Baily et al., 2006; Jennings et al., 2007). Health care organizations may have multiple and competing motivations in regard to the improvement of quality. Maximizing benefits while minimizing harms may include attracting patients, recruiting and retaining staff, reducing costs to meet budgetary goals or increase profits, complying with legislation and accreditation standards, and meeting requirements to publicly report performance (Sullivan et al., 2011; Sutherland et al., 2012; Turnbull & Adams, 2011). In this section, I summarize the history of the health quality movement in Canada.

In Canada, residents are entitled to safe, high quality health care services (Romanow, 2002, p. 51). The Canada Health Act (1985) sets out the terms of Canada's single-payer system, and states that, "continued access to quality health care without financial or other barriers will be

<sup>&</sup>lt;sup>24</sup> In this dissertation, I use Chan and Cochrane's (2016) definition of preventable: "accepted by the community as potentially reducible using evidence-informed practices" (p. 7). A similar term is avoidable.

critical to maintaining and improving the health and well-being of Canadians" (Preamble). Most aspects of health care are a provincial/territorial responsibility. A complex accountability structure of regional health authorities, hospitals and other organizations, accrediting bodies, and self-governed health professions (Hutchison et al., 2001) has undergone little change since the 1960s (Tuohy, 2018, p. 552). During the early 1980s, attention to the quality of health care rose in response to emerging statistics about the dangers of hospitals (A. Brown et al., 2012, p. 6; R. M. Wilson et al., 1995; S. M. Wolf, 1994, p. 112). At the same time, a period of fiscal restraint and increasing public accountability were factors in a health care 'quality movement' emerging in Canada, as well as the United States and the United Kingdom (Goldenberg, 2012, p. 252; Storch, 2013, p. 8). As Sheps and Cardiff (2017) note, "health care universally is challenged to deliver 'better' and more technologically complex care in a timely way to more people at lower cost" (p. 20). Thus, ideas of creating a 'quality culture' and increasing the capacity for assessment and improvement began in earnest in the 1980s using frameworks such the one proposed by physician Avedis Donabedian (1966; 1980, 2005) with three measurable organizing concepts: (1) structure (capacity of the system in which care is provided); (2) process (what is delivered along the continuum of care); and (3) outcome (impact of the care on patients). It is of particular in interest in my study that in 1994 Wolf noted the lack of intersection between activity occurring in the quality and bioethics spheres during the 1980s (p. 111).

During the 1990s, a series of high-profile tragedies and social trends in Canada further shook the public's confidence in the quality of health care services.<sup>25</sup> In addition, the impacts of ongoing cutbacks and shifting governance and resources to community settings did not solve all of the problems with quality of care, and in fact created new challenges (Sheps & Cardiff, 2017, p. 20; Storch, 2013, p. 9). Around this time, similar cases of negligence, incompetence and restructuring were being reported in other countries (Travaglia & Robertson, 2018, p. 204), providing another interesting parallel of attention to quality and safety with the growth of bioethics, where a series of crises and social tensions led to reforms. In the midst of these events in Canada, two landmark US Institute of Medicine (IOM) reports (To Err is Human: Building a Safer Health System (2000) and Crossing the Quality Chasm: A New Health System for the 21st *Century* (2001)) had a significant influence on the health care quality landscapes in many countries. Two important themes of the *Quality Chasm* report worth noting here were: (1) the acknowledgment that patient experience and patient outcomes ought to be the most important measure of quality; and (2) the need to facilitate uptake of proven therapies and processes. Then, in 2004, Baker et al. published the first-ever Canadian Adverse Events Study, estimating that of the 185,000 preventable adverse events that occur in acute care hospitals every year, between 9,000 and 24,000 people die. These statistics reiterated that health care was not *safe*,<sup>26</sup> and Storch (2013) explains that, "many taken-for-granted notions about the essential 'goodness' of health

<sup>&</sup>lt;sup>25</sup> Rowland (2013, pp. 2–3) summarizes this period as including: the tainted blood tragedy, when many thousands of individuals who received blood transfusions became infected with HIV and hepatitis C (Krever, 1997; K. Wilson, 2007); the deaths of 12 children following heart surgery at Winnipeg's Health Sciences Centre (Sinclair, 1998); an ongoing erosion of trust in institutions, including the professions (Illich, 1974; Kelleher et al., 2006; Rose, 1993); and frequent exposés of health-related scandals and mishaps in the news media (F. McDonald, 2010; Sutherland et al., 2012).

<sup>&</sup>lt;sup>26</sup> The Oxford English Dictionary defines safety as, "the state of being protected from or guarded against hurt or injury; freedom from danger" (OED Online, 2018i). Thus, safety is an absence of danger.

care were examined and found wanting" (p. 8). Moreover, Whitfield (2018) situates safety as an accepted human right, despite it "not necessarily practiced or allowed for equitably" (p. 34). By the mid-2000s, gaps in quality and patient safety in Canadian health care were well documented, and urgent areas for improvement identified (Chan & Cochrane, 2016). Danholt (2010) explains that at this time, quality and patient safety became linked as a sociotechnical problem occurring at an organizational level (p. 31). As Arries (2014) notes, "[The two IOM reports] were followed by a staggering number of scholarly publications, improvement initiatives, and the establishment of various institutions on patient safety" (p. 3).<sup>27</sup>

## 2.3.1 Defining quality of care.

The frequently used term 'quality of care' can be defined in many ways. For example, the IOM's influential *Crossing the Quality Chasm* (2001) report describes six dimensions; high quality care is safe, effective, patient-centred, timely, efficient, and equitable (pp. 5–6). The report adopted an earlier IOM (1990) definition of quality: "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (p. 44 and p. 232). The core ethical principles of autonomy, non-

<sup>&</sup>lt;sup>27</sup> In Canada, these new organizational structures included: the formation of health quality councils in several provinces; the Health Council of Canada to publicly report a system-wide perspective on health care reform, best practices and innovation (Health Council of Canada, 2013); the Canadian Health Services Research Foundation (now Canadian Foundation for Healthcare Improvement (CFHI)) to help translate new evidence into practice; and in 2003 the Canadian Patient Safety Institute (CPSI) to provide national leadership and coordinate patient safety work. CPSI continues to coordinate QI efforts across Canada to address patient safety concerns such as hand hygiene and surgical checklists but with limited authority to prioritize patient safety goals, or to set or enforce national standards. Instead, organizations such Accreditation Canada (via the Qmentum program (Accreditation Canada, n.d.) and provincial health quality councils assess and publicly report on the quality of health care (Health Council of Canada, 2013, p. 4; Sullivan et al., 2011, p. 12; Veillard et al., 2012). In addition, the Canadian Institute for Health information (CIHI) enhanced their national database to allow better comparisons of data between jurisdictions (A. Brown et al., 2012; Sutherland et al., 2012).

maleficence, beneficence, and justice are also rooted within the various dimensions of quality (W. A. Nelson et al., 2010, p. 527). However, Wolf (1994) notes that the role of ethics in identifying quality problems and solutions (such as assessing ethics practices) continued to remain largely separate from quality and safety, a trend also described more recently by others (for example, see Cribb et al., 2019; W. A. Nelson et al., 2010). Many jurisdictions across Canada and internationally have adopted (or closely adapted) the IOM definition and dimensions of quality.<sup>28</sup> For example, the current WHO (n.d.-a) definition of quality of care is: "the extent to which health care services provided to individuals and patient populations improve desired health outcomes. In order to achieve this, health care must be safe, effective, timely, efficient, equitable and people-centred" (para. 4). In particular, failing to carry out efforts to improve the safety dimension of quality increases significant risks to people's lives and thus presents a serious moral problem of unjustified, and often preventable, health care harm (Kass et al., 2013).

Building on this context of quality in health care, I now examine the quality discourse more closely. It follows that any pursuit of quality rests on what the definition of quality of care is, who defines quality, and how quality is assessed. Harrigan (2000) describes different perspectives that comprise a full reflection of quality of care:

Quality in health care can be reflected through the perspectives of its different stakeholders: the patient (client, resident), the provider, the funder, and society. From the patients' perspective, quality is defined in terms of how well their needs and expectations for care and service are met. For the providers, quality includes clinical effectiveness in terms of the correctness of the diagnosis and the appropriateness and efficacy of the treatment and care provided. From the system's perspective, quality is concerned with the efficiency of the services provided and the cost-effectiveness,

<sup>&</sup>lt;sup>28</sup> For example, see BC Patient Safety & Quality Council, 2017; Carinci et al., 2015; Health Quality Ontario, 2017; World Health Organization (WHO), n.d.-a). In February 2020, a revised BC Health Quality Matrix (BC Patient Safety & Quality Council, 2020) was released as I was finishing the write up of my dissertation.

management and use of resources to achieve desired health outcomes. Finally, to society, quality is often measured in terms of value for money and benefits to the community at large. (p. 13)

Goldenberg (2012) offers a critical ethical analysis of the 'quality movement', questioning why the phrase 'quality of care' itself is not better conceptualized in the literature. Instead, she states, quality is described in terms of the dimensions through which the phrase is expressed (p. 247), a pattern that is evident in the IOM and WHO definitions I noted above. Two aspects of Goldenberg's argument are particularly relevant here, given my interest in impacts that qualityrelated interventions have on patients/families. The first is the *persuasive* nature of the definition of quality of care, which "operates as an accepted and assumed goal worth pursuing" (p. 243) and "holds widespread rhetorical appeal" (p. 247). Second, Goldenberg clarifies that identifying and prioritizing what aspects of quality need to be improved and then selecting QI strategies and targets is informed by *values* (pp. 257–258).

Other researchers have made similar moral arguments about practical and value-based implications that result from the multiple ways of framing quality. For example, Cribb et al. (2019) suggest that quality is typically aligned within biomedical and operational discourses: "When QI is understood as about technical interventions designed to bring about measurable improvements in healthcare, then 'quality' is seen as the product of, and the label for, these measurable improvements" (p. 3). Consequently, as a result of this optimistic, pervasive and often highly biomedical framing of health care quality, policy-makers, administrators, practitioners, and possibly even patients/families tend to see quality (and by extension QI) as good things that ought to happen. As I will elaborate on below, this optimistic framing contributes to insufficient "moral debates over resources allocation and duties of care"

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(Goldenberg, 2012, p. 243) and, I argue, also contributes to the paucity of in-depth knowledge currently available about how patients/families experience QI interventions at the point of care.

## 2.3.2 Balancing the *Triple Aim* and ongoing resource constraints.

A key player in shaping ideas about health care reform in Canada<sup>29</sup> and worldwide is the USbased Institute for Healthcare Improvement (IHI), launched by Donald Berwick.<sup>30</sup> In particular, the IHI *Triple Aim* outlines a framework to guide health system reform and optimize health system performance, centring around "the simultaneous pursuit of three goals: improving the individual *experience of care*; improving the *health* of populations; and reducing the per capita *costs* of care for populations" (Berwick, Nolan, & Whittington, 2008, p. 760, emphases added). Yet, some commentators view the *Triple Aim* as fundamentally incompatible, given that tension and trade-offs between quality, safety, and costs within QI initiatives are exacerbated as a result of contextual factors such as a managerial culture<sup>31</sup> and ongoing fiscal constraints (Appleby, 2009; Ovretveit, 2009; Storkholm et al., 2017; M. J. Taylor et al., 2014).

<sup>&</sup>lt;sup>29</sup> In Canada, the CFHI partners with the IHI to accelerate health care improvement, aiming to develop QI capacity for broader system change and fostering a culture of health care improvement (Farmanova et al., 2016, p. 837). IHI's *Triple Aim* has also been adapted for use in other sectors. For example, the *Access to Justice Triple Aim* guides a common vision of "initiatives and reforms for making family and civil justice more accessible to British Columbians" (Access to Justice BC, 2019).

<sup>&</sup>lt;sup>30</sup> According to the IHI website: "IHI was officially founded in 1991, but our work began in the late 1980s as part of the National Demonstration Project on Quality Improvement in Health Care, led by Dr. Don Berwick and a group of visionary individuals committed to redesigning health care into a system without errors, waste, delay, and unsustainable costs." (para. 1)

<sup>&</sup>lt;sup>31</sup> Duncan et al. (2014) describe managerialism as, "a culture of domination over professional accountability [focusing on delivering high standards of care] by management and governmental bureaucratic processes in the name of greater efficiencies" (p. 623). Neoliberal thinking (institutional logics that favour market-oriented over government-based regulatory solutions) has had impact on aspects of the health care system such as a shift in power from health professionals to health administrators. For recent analyses of neoliberalism in health care, see Sharon Batt's (2017) book Health Advocacy Inc., and Bernadette Pauly's (2013) work on challenging health inequities.

In my study, the phenomenon of interest is the patient/family experience. In this context, several researchers note that equity and patient-centredness are difficult to quantify (Cribb et al., 2019), and that "optimizing the patient and family experience has historically been viewed as a nice-tohave, but not a fundamental aspect of a health care organization's attention" (Balik et al., 2011, p. 5). As I will expand on below, some authors suggest that in *Triple Aim* and other quality frameworks, emphasis is often placed on achieving greater efficiencies. As Stein acknowledged in (2002), "when [efficiency] is understood correctly as the best possible use of scarce resources to achieve a valued end, [it] is undoubtedly important" (p. 6), and ethicist researchers Baily et al. (2006) agree that increasing efficiency is a legitimate QI concern (p. S7). Thus, while value for money is an important goal, resource constraints are implicitly an essential consideration in the complex political and economic contexts of quality and patient safety movements and health care restructuring more generally (Allin et al., 2017, p. 10; J. E. Anderson et al., 2017; M. S. Bauer et al., 2015; Bodolica & Spraggon, 2014; Duncan et al., 2014; Goldenberg, 2012, p. 243; Harris et al., 2019; Rodney, Buckley, Street, et al., 2013, p. 189; Sheps & Cardiff, 2017; Stein, 2002). However, Marck (2013) cautions against "a pervasive cult of efficiency that automatically favours the achievement of short-term efficiencies over more sustainable levels of production and benefit (eco-efficiency) for the longer term" (p. 218). Thus, it is not clear that the push on efficiency due to resource constraints always translates into choices that reflect other important political and social values to achieve a valued end (Stein, 2002).

As I have noted above, improving the individual patient experience of care is one of the pillars of the IHI *Triple Aim* (Berwick et al., 2008). Over the past decade, the urgent need to prioritize and expand the prominence of the patient experience dimension of service delivery emerged from

what became known as the Staffordshire Hospital scandal in the UK. Serious concerns about deaths and substandard care at hospitals within the Mid Staffordshire NHS Foundation Trust between 2005 and 2009 launched a series of official inquiries, culminating in a full public inquiry (the "Francis Report") chaired by Sir Robert Francis (2013)<sup>32</sup> and the "Berwick Review" (National Advisory Group on the Safety of Patients in England, 2013). The Staffordshire situation emphasized that a fundamental lack of attention to the relational aspect of care resulted in a range of significant harms to patients (Duncan et al., 2014; Francis, 2013). The lessons from Staffordshire connect to a recent Organisation for Economic Co-operation and Development (OECD) (2019) report comparing health system performance, which notes: "A positive care experience is a strong signal of quality care and is instrumental in outcomes achieved, especially for those [patients] who manage multiple chronic conditions" (p. 42).

#### 2.3.3 Snapshot of quality of health care in Canada today.

There are various ways of providing a snapshot of quality of care in Canada. Opinion polls consistently show that sustaining the public health care system is one of the most important priorities concerning Canadians today.<sup>33</sup> Jason Wolf (2014), president of the US-based Beryl Institute committed to improving patient experiences, states, "clinical quality, safety and positive outcomes, while part of the miracle of healthcare, are not exceptions, but rather expectations all consumers now have" (para. 8). In spite of this expectation, measures of health care harm have not significantly lowered – in spite of two decades of copious international efforts to reduce

<sup>&</sup>lt;sup>32</sup> The Francis Report (2013) focused on: poor care and neglect; lack of qualified, experienced and compassionate hospital staff; and the lack of honesty and transparency the leaders from responsible organisations exhibited in the face of these serious care, compassion, and organizational failures.

<sup>&</sup>lt;sup>33</sup> For example, in (2019) Angus Reid reported that 23% of Canadians ranked health care as their top concern.

preventable medical errors.<sup>34</sup> In fact, the Canadian Patient Safety Institute (n.d.-a) states, "patient safety incidents [are] the third leading cause of death in Canada, behind cancer and heart disease" (para. 1).

Quality can also be expressed in terms of spending. Based on CIHI data, Chan and Cochrane (2016) estimate that in 2014–2015 costs to treat patient harm in Canadian hospitals reached \$685 million (p. 29). CIHI (2019a) estimates that for 2019, the total health expenditure in Canada was \$264 billion (CAD), representing 11.6% of Canada's gross domestic product (GDP) (p. 4). Quality of care is often described in terms of comparisons with other hospitals, jurisdictions, and health care systems. For example, the OECD (2019) reports that, based on 2018 data, Canada spends \$4,974 USD per capita, a similar amount to other high-income countries such as Japan, France, Australia and Sweden, and the OECD average. The OECD further states, "Having sufficient health care resources is critical to a well-functioning health system. More resources, though, do not automatically translate into better health outcomes" (p. 32). Dhalla and Tepper (2018) compared the quality of health care in Canada (using all six dimensions in the *Quality Chasm* report) to other high-income countries, and concluded, "the quality of health care in Canada is good, but arguably not great" (p. E1165).

<sup>&</sup>lt;sup>34</sup> Serious patient safety problems persist in many health care systems. For example, a report by the Leapfrog Group (Austin & Derk, 2019) applied 28 measures of patient safety to 2,600 US hospitals and concluded that an estimated 160,000 lives are lost annually from preventable medical errors, with high variability between hospitals. The researchers caution that the 2019 estimates are conservative, and note significant improvement from earlier estimates (in 2016, an estimated 205,000 preventable deaths). These estimates are consistent with earlier reports. For example see (Barach & Johnson, 2018; National Patient Safety Foundation, 2015; Pronovost et al., 2015; Wachter, 2010).

#### 2.4 Emphasis on Patient- and Family-Centred Care

Having explored the ideas, systems and structures of health care, I now turn my attention to patients and families, the users of health care services. In 2001, the *Quality Chasm* report identified patient-centred care as an important dimension of high quality health care. Thus, the patient-centred care and quality movements are intricately linked, and together have impacted the nature of patient–provider relationships and health care reform (Kitson et al., 2013). In what follows, I describe patient-centred care and then expand on aspects of patienthood such as vulnerability and power asymmetries. The roots of the patient-centred care movement arose in the late 1960s with a growing emphasis on the patient's role in health care.<sup>35</sup> This shift paralleled the broader social changes noted above, including citizens' demand to participate as legitimate stakeholders in many areas of society and to hold government and institutions accountable.

Patient-centred care is well described in the literature, with varying descriptions of the core concepts involved (Armstrong et al., 2013, p. 37; Entwistle & Watt, 2013; Gerteis et al., 1993; Institute of Medicine (US) Committee on Quality of Health Care in America, 2001; Kelleher et al., 2006; Kitson et al., 2013; May et al., 2014; Stewart, 1995; Stewart et al., 2013; Travaglia & Robertson, 2018, p. 205). For example, Entwistle and Watt (2013) summarize patients'/citizens' concerns as centring on two main areas: (1) the need to consider patients' interests, autonomy, and subjective illness experiences, thereby correcting tendencies for health care to be too biomedical (technical and disease-centered) and paternalistic; and (2) to design the health care

<sup>&</sup>lt;sup>35</sup> Organizations such as the Picker Institute, Planetree, and the Institute for Patient- and Family-Centered Care have influenced the integration of patient-centred care into health care systems worldwide (G. R. Baker, 2014; Balik et al., 2011; Frampton et al., 2008).

system more around patients, and less around systems and staff (p. 29). Despite a general acceptance of patient-centred care as a shift towards a more collaborative social environment within health care that empowers patients as moral agents (Ells et al., 2011, p. 84; Entwistle & Watt, 2013, p. 3; McClimans et al., 2011, p. 918; Travaglia & Robertson, 2018, p. 205), as noted in Section 2.3.2 tensions arise in how to interpret, balance, and allocate resources to different dimensions of quality (Boothe, 2019, p. 631; Cribb et al., 2019, p. 4). Furthermore, improving the individual experience of care in a meaningful way is one measure of patient centredness (K. Browne et al., 2010, p. 921) and is one of three simultaneous dimensions of improvement in the *Triple Aim* framework (Berwick et al., 2008, p. 760).

As noted above, the term 'patient-centred care' is widely used. Yet many researchers describe confusion about what the term means (Coulter, 2013) and similar terms (including client-, family-, person-, and relationship-centered care) reflect different foci, philosophies, and interpretations according to population or community served, health care setting, discipline, profession, and local culture. For example, *client* is meant to convey a more humanistic and empowering role than patient (Shevell, 2009). Similarly, a recent shift from subject to *participant* in the research domain reflects an intention to respect a more active role (Canadian Institutes of Health Research et al., 2018, p. 14). A central concept of patient- and family-centred care is that the patient's *family* (as defined by the patient) is an essential ally in health, wellness and health care processes (including how they will participate in care and decision-making) (Cené et al., 2016, p. 698; Institute for Patient- and Family-Centered Care, n.d.). Starfield (2011) proposes that the core difference between patient-centred and person-focused approaches is that patient refers to interactions based on discrete clinical visits, whereas *person* integrates

accumulated knowledge in the context of a person's life and interrelationships over time (p. 63). Finally, relationship-centred care, focusing on *relationships* rather than individuals (Beach et al., 2006), is a concept I elaborate on in forthcoming chapters on the basis of my research findings. While acknowledging these important differences, I use patient-centred care to encompass this group of terms and the core concepts (noted above) that rest on involving and collaborating with the users of health care services.

#### 2.4.1 Patienthood.

In 2013, Dubbin et al. stated, "There are some deeply held expectations, beliefs and convictions about what it means to be a patient and what it means to be a provider that can get in the way of providing patient-centered care" (para. 7). Here, I step back from systems, structures, and processes and delve further into characteristics of patients – each with their own experience of interactions with health, health care and the related social world – that may be of relevance in exploring patient/family experience of QI, my phenomenon of interest. The word patient originates from the Latin patiëns, meaning one who suffers, or to undergo suffering (OED Online, 2019a). In the dominant biomedical approach, patients are persons who are sick, and Shevell (2009) situates 'patient' as enhancing otherness, reinforcing passivity and bolstering power asymmetries (pp. 770–771). Furthermore, patients as individual persons is consistent with mainstream bioethics, medical practice and Western political theory, as opposed to a public health context where populations are typically considered (as noted by Baylis et al. (2008, p. 5)). It is in this health care system context that individual persons and groups – as moral agents – receive (or seek to receive) health care.

The concept of moral agency has crucial implications in the sense of enabling patients and families to express their preferences and values, to maintain a sense of self and dignity, and to receive health care accordingly (Entwistle et al., 2010). Two related areas of central concern are rights and interests. Faden et al. (2013) define rights as, "justified claims to something that individuals and groups can legitimately assert against other individuals or groups", and *interests* as, "that which is in an individual's interest – that is, that which supports an individual's wellbeing or welfare in a given circumstance" (p. S20). In my study, the term ethical impact refers to the totality of the effect of an episode of care (or more specific aspects of that care, such as a QI intervention) that may positively (benefit) or negatively (risk of harms and burdens, or risk of being denied benefits) affect the rights, interests and experiences of patients (and families) (Adapted from Faden et al., 2013; Jardine, 2008; M. McDonald et al., 2014). In what follows, I summarize three relevant aspects of patienthood that place individuals in unique situations that impact on their agency, rights and interests when they interact with care providers and health care systems. These aspects include burdens and capacity, power asymmetries, and ideas about vulnerability.

Physician ethicist David Unger (2011) defines capacity, a medical term, as "a person's ability to make decisions about his or her life and his or her medical care" (Ch 2, Capacity to Decide, para. 2), and goes on to state: "transition zones exist in two types of persons: those who are gaining capacity and those who are losing capacity. It is in these grey zones that ethicists and law and policy makers struggle to find clarity" (para. 6). In some cases, an illness itself involves fluctuating capacity, such as for people who live with schizophrenia (Humphrey Beebe & Smith, 2010). Furthermore, of particular interest in my study, it is often the case that illness and

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treatment place burdens on patients and their families beyond their usual circumstances (Boehmer et al., 2016; Gallacher et al., 2018; May et al., 2014; Naik et al., 2009; Shippee et al., 2012). Sociologist Carl May and colleagues (Mair & May, 2014, p. 1; May et al., 2014; Shippee et al., 2012, p. 1043) relate their *Burden of Treatment Theory* to the growing "patient workload" (the burden of symptoms, treatment, self-care and life in general) as health care systems shift responsibilities and tasks over to patients, their families, and their extended relational networks:

The burden continues to increase as healthcare systems shift an ever-growing list of management responsibilities and tasks on to patients and their caregivers. This is real work, which requires considerable effort from patients, their caregivers, and their extended social networks. For many it can be overwhelming—it is time consuming and calls for high levels of numeracy, literacy, and, sometimes, technical knowledge....Such people will struggle to adhere to treatment recommendations, thereby risking poor outcomes and the waste of increasingly scarce healthcare resources. (Mair & May, 2014, p. 1)

Similarly, views of autonomy such as those put forth by Entwistle et al. (2010) and Naik et al. (2009) demand consideration of the context of patienthood in terms of how people's capacity to cope with and execute demands can depend on many factors. In fact, I contend that providers and health care systems might not sufficiently reflect on how additional burdens associated with a new QI intervention – while well intended – may have the potential to further weaken a patient's ability/capacity to express preferences and values, and to enact preferred behaviours.

The complex power dynamics in health care is a second aspect of patienthood that impacts the agency, rights and interests of patients. It is widely accepted that patients and providers are not equal in terms of moral agency and authority (Rodney, Burgess, Pauly, et al., 2013, pp. 92–93; Shevell, 2009, p. 771). Power dynamics in health care are central themes in discussions of autonomy and related areas such as how patients feel about informed consent, unfamiliar

environments (where they do not understand the system, the culture, the language and so on), asking questions of care providers, and truth telling (particularly if the patient is extremely ill) (Agency for Healthcare Research and Quality, 2013; Doane & Varcoe, 2013; Nisker, 2013; The Health Foundation, 2013a). Moreover, health care also includes power asymmetries beyond the patient-provider dyad, such as family–provider, patient–family, as well as between providers, professions, organizations and societal institutions (L. Baker et al., 2011; O'Shea et al., 2019; Reeves et al., 2010; Rodney, Buckley, Street, et al., 2013; Rodney, Burgess, Pauly, et al., 2013; Sherwin, 1992).

## 2.4.1.1 Vulnerability, othering and cultural safety.

Threaded through patienthood, burdens/capacity, and complex power dynamics is the notion of vulnerability. In general language, vulnerability has more recently come to be associated with "a person in need of special care, support, or protection (esp. provided as a social service) because of age, disability, risk of abuse or neglect, etc." (OED Online, 2018b), or as "uncertainty, risk, and emotional exposure" (B. Brown, 2012, p. 40). In ethics, *vulnerability* refers to individuals and groups, who as moral agents are less likely to be able to act in, safeguard, or advance their own interests. In what follows, I describe two layers of vulnerability: situational vulnerability and social or historicized vulnerability, and then explain how ideas about vulnerability connect to concepts of relevance in my study such as othering and cultural safety.

A first layer of vulnerability in health care is situational vulnerability, or what McDonald et al. (2008) describe as the "vulnerability associated with being ill" (p. 36). In this context, individuals or groups are in circumstances that cause them to be vulnerable and/or augment

existing vulnerabilities. In this sense, aspects of patienthood described above, such as burdens of illness/treatment and power asymmetries, apply to patients and families (as individuals and groups) in relation to the increasingly complex health care system, at different times and to different degrees, and depending on the specific circumstances (Baylis et al., 2008, p. 6; Canadian Institutes of Health Research et al., 2018, p. 202; Chan & Cochrane, 2016, p. 9).

Second, social or historicized vulnerability involves individuals belonging to systematically disadvantaged groups or populations that fall outside the mainstream, more powerful social group(s). This is ethically problematic because members of disadvantaged groups are particularly vulnerable to being treated less fairly and less equitably than other members of society, and are thus marginalized from "social goods, such as rights, opportunities and power" (Canadian Institutes of Health Research et al., 2018, p. 8). Both of these contexts of vulnerability (and particularly the second) overlap with *othering*, a sociological concept Griffin (2017) defines as follows:

Othering is a process whereby individuals and groups are treated and marked as different and inferior from the dominant social group. Disenfranchised groups such as women, people of divergent ethnic backgrounds, working-class people, homosexuals, or migrants may all be othered and, in consequence, suffer discrimination.

Johnson et al. (2004) claim that "Othering can reinforce and reproduce positions of domination and subordination" (p. 253), and thus stigmatizing attitudes (e.g., stereotypes and biases), behaviours, and norms (e.g., policies) fail to address central ethical challenges such as autonomy and justice (Cunha, 2018; Gandhi et al., 2020, p. 6). As a result of inequitable social conditions throughout history, a disproportionate burden of ill health and social suffering falls on members of vulnerable groups less able to resist the oppressive treatment of those with more power and privilege (Baylis et al., 2008, p. 9; A. J. Browne et al., 2018; Canadian Institutes of Health Research et al., 2018; Doan & Sherwin, 2016, p. 84). Examples of othering in the context of my study include how hospitals prioritize QI (e.g., improvements benefit dominant groups), and how interventions are shown to be effective (e.g., evaluations reflect management priorities rather than patient/family values and preferences).

In health care, othering has also been described in relation to *cultural safety*. Māori Scholar Irihapeti Ramsden (Ngāi Tahu, Rangitāne)<sup>36</sup> (1993) developed the cultural safety concept as an extension of social justice to explain health disparities between linguistic, ethnic, and cultural groups and to promote Indigenous-settler power-sharing (see also A. J. Browne et al., 2009; Reimer-Kirkham & Anderson, 2010).<sup>37</sup> Cultural safety, as described by Browne et al. (2009), aims to "counter tendencies in health care that create cultural risk (or unsafety)" (p. 169). In this way, the First Nations Health Authority (n.d.-e) in BC urges care providers to "adopt a humble, self-reflective clinical practice that positions them as respectful and curious partners when providing care, rather than as a figure of higher knowledge and authority" (p. 3). In recent years, broader conceptualizations of cultural safety include age or generation, gender, sexual

<sup>&</sup>lt;sup>36</sup> In this dissertation, when writing about and citing Indigenous Peoples, I was guided by *Elements of Indigenous style: A guide for writing by and about Indigenous Peoples* by Gregory Younging (2018). My intent is to honour and transmit Indigenous Peoples' perspectives about themselves in a respectful way. For example, Indigenous People identify with diverse and distinct societies, each with their own histories, languages, cultures and identities (p. 20). Where possible, I refer to an Indigenous person using the names the person uses for themselves (p. 102). Identity is typically expressed in connection to group and place. For example, Gregory Younging describes himself as a member of the Opaskwayak Cree Nation in northern Manitoba.

<sup>&</sup>lt;sup>37</sup> In Canada, the Indigenous context has parallels to that of New Zealand and thus the origins of cultural safety have a particular relevance in our country. For example, Jamieson et al. (2017) highlight current health disparities between Indigenous and non-Indigenous Canadians: "When compared to the general public, First Nations, Inuit, and/or Métis people live on average 5 to 7 fewer years, have infant mortality rates 2 to 4 times higher, and are more likely to have at least one chronic condition" (p. e1).

orientation, ability, occupation and socio-economic status, migrant experience, religious or spiritual beliefs, and individuals/families of people who use illicit drugs (A. J. Browne et al., 2009; Gerlach, 2012; Hawkins, 2013; Pauly et al., 2015; Reimer-Kirkham & Anderson, 2010).

#### 2.4.2 Patient and family engagement: "nothing about me without me."

The practice of engaging patients and families in the health care system is foundational to the patient-centred care mandate that drives health care system improvement (Bombard et al., 2018), and is based on the broader notion of public participation: people have a right to be involved in publicly funded decisions and activities that affect their lives. This insight reflects a paradigm shift from earlier perceptions whereby health professionals and health care leaders held the expertise (World Health Organization (WHO), 2012). Traditionally, patient engagement refers to the shift in a patient's role from passive recipient to active member of their own health care team. Bombard et al. (2018) state, "most commonly, [patient] engagement has focused on the relationship between patients and providers in making care decisions or how to improve patient efforts to manage their own care" (p. 2). Strategies to engage patients and their families typically include informing, educating, and involving patients in self-managing and co-managing aspects of their own health care, including aspects formerly performed by care providers. Coulter and Ellins (2007) describe four areas of patient and family engagement at the direct care level as: (1) becoming health literate; (2) making shared decisions; (3) caring for themselves and managing their health; and (4) reducing patient safety risks.

As Manafo et al. (2018) state, "Including patients' active voices is becoming the espoused healthcare ideology, which has crucial implications for patient experiences, health outcomes, and research and healthcare funding" (p. 2). Delbanco et al. (2001) and Barry and Edgman-Levitan (2012) note that the phrase "nothing about me without me" became a guiding principle associated with embedding aspects of patient-centred care in all levels of the health care delivery system.<sup>38</sup> A second rationale for engaging patients/families in the health care system extended from the recognition that patients and families are credible, reliable and valuable sources of information about improving health outcomes and preventing errors (Bombard et al., 2018; Francis, 2013; National Patient Safety Foundation, 2015), a rationale driven by increased pressure for the accountability and transparency of public spending, services, and outcomes (Armstrong et al., 2013, p. e37; Manafo et al., 2018, p. 2; Travaglia & Robertson, 2018, p. 205). In fact, in 2012, technology consultant Leonard Kish stated, "If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it" (para. 4). Overall, support to engage patients/families across the health care system is based on enhancing improvement efforts to ensure high quality of health care for current patients, future patients, and the broader community.

Engaging patients and families in the health sector is a complex process. Longtin et al. (2017) state, "Various terms such as 'patient participation', 'patient empowerment', 'patient involvement', 'patient collaboration' and 'patient engagement' are used interchangeably" (p. 207). In their highly cited paper,<sup>39</sup> Carman et al. (2013) define patient and family engagement as:

<sup>&</sup>lt;sup>38</sup> Delbanco et al. (2001) and Barry and Edgman-Levitan (2012) attribute the "nothing about me without me" slogan to a participant at the 1998 'Through the Patient's Eyes' conference. Nelson et al. (1998) attribute to same slogan to an earlier disability movement in South Africa, representing an indicator of social change when members of a marginalized group demand to be included.

<sup>&</sup>lt;sup>39</sup> As of July 14, 2020, this *Health Affairs* article has been cited 499 times in the Web of Science Core Collection.

"patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system— direct care, organizational design and governance, and policy making—to improve health and health care" (p. 224).<sup>40</sup> Patient engagement is typically conceptualized along a continuum from one-way provision of information (e.g., fact sheets) to a commitment to implement the individual or group's decision (e.g., ballots) (Bate & Robert, 2006; BC Ministry of Health, 2018; Carman et al., 2013; International Association for Public Participation, 2007). Using the Province of BC (where I conducted my study) as an example, strategies to increase public participation include *Patients as Partners*, an innovative (and ongoing) QI initiative to incorporate patient, family and caregiver voices at all levels of the health care system (Bar et al., 2018; BC Ministry of Health, 2011, 2018; Office of the Auditor General of British Columbia, 2008). In Chapter 3 I elaborate further on patient and family engagement in health care system improvement (see Section 3.3).

#### 2.4.3 Patient and family experience.

Along with the current focus on patient-centred care and patient/family engagement has come increasing interest in how patients and families experience the health care they receive. The OECD (2019) suggests that key features of a positive patient experience include feeling respected, invited and empowered to participate in decisions about their care, and that the steps in their care are well coordinated (p. 40). Despite some progress, high quality care is often described as safe or timely, and many aspects of health care remain organized around health

<sup>&</sup>lt;sup>40</sup> For a summary of various definitions and conceptualizations of patient and family engagement, see Cené et al.'s (2016) Table 1.

conditions (e.g., diabetes) and other priorities (e.g., needs of health care providers) (Bar et al., 2018, p. 51). However, Wolf (2014) states that patients/families do not "draw these forced distinctions. They have but one experience, impacted by the various facets that comprise every healthcare encounter" (p. 11). Furthermore, Entwistle and Watt (2013) note that a central concern for patients and families is that their "subjective illness experiences, particular interests and autonomy" ought to be considered (p. 29).

The *Quality Chasm* report (2001) states that the true indication of a high performing health care system is reflected in patients' and families' experiences and health outcomes, which proved to be a resounding implication of the Staffordshire Hospital scandal (introduced in Section 2.3.2). Canadian studies have reported that hospital patients and their families, when asked, provide valid information about the quality and safety of their care (Daniels et al., 2012; Glickman et al., 2010). Furthermore, there is widespread agreement that knowing how patients and their families experience various aspects of their interactions with the health care system contributes to efforts to set and achieve dimensions of quality such as safety, efficiency, and dignity (Aligning Forces for Quality, 2010; Bate & Robert, 2006, 2007; Coulter et al., 2014; Entwistle et al., 2012; Iedema & Angell, 2015; OECD, 2019; The Health Foundation, 2013c; J. A. Wolf et al., 2014).

Patient experience researchers Paul Bate and Glenn Robert (2007) emphasize that patient experience is a highly complex phenomenon that requires understanding elements such as reflection, awareness, sensation, perception, thought, memory, imagination, emotion and expression, desire, volition, and action and conduct (pp. 41–42). These researchers describe patient experience as appreciating and understanding how people make sense of and construct

meanings about health care they receive on a cognitive and emotional level, which then shapes their attitudes and perceptions (pp. 32–33). As a starting point for conversation, the Beryl Institute (n.d.) offers the following definition of patient experience: "the sum of all interactions, shaped by an organization's culture, that influences the patient perceptions across the continuum of care." Resonating through these definitions is an emphasis on patient experience being part of a series of *integrated human experiences* as opposed to discrete episodes. While the terms 'patient experience' and 'patient satisfaction' are used interchangeably and both refer to feedback that users provide about health services, experts on patient experience point to important conceptual differences between the two (Bate & Robert, 2007, p. 163; Chenail, 2011, p. 1175; The Health Foundation, 2013c, p. 5; J. A. Wolf, 2014, 2019). In what follows, I elaborate on differences between experience and satisfaction, and then describe ways of portraying patient and family experiences in health care settings.

Patient/family *satisfaction with care* describes attitudes about quality of health care, including how patients/families value the services they receive. In this sense, patients are 'customers' giving feedback on how satisfied or dissatisfied they are with certain aspects of their health care experience (e.g., "did you like it?" or "how happy were you?") (Bate & Robert, 2007, pp. 162–164; Chenail, 2011, p. 1175). Satisfaction provides a snapshot, typically based on a rating scale, that is captured at the end of a particular aspect or episode of care (Bate & Robert, 2007). Ratings are thought to be influenced by, for example, age, income, anxiety, education and comorbidity, and therefore measures of patient/family satisfaction without contextual interpretation might provide limited meaningful information (Detsky & Shaul, 2013; The Health Foundation, 2013b; B. Williams, 1994).

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Conversely, patient/family *experience of care* involves a deeper exploration of what happened during a care experience. This exploration seeks to learn what patients did or did not experience during their interactions with care processes and staff, and the impact (emotional and otherwise) the care experience had – and may continue to have – on a person (Aligning Forces for Quality, 2010; Bate & Robert, 2007). As Bate and Robert (2007) explain, experience aims to take an 'inside' view about how certain aspects of a care experience looks and feels. For this reason, patient experience is optimally described qualitatively so patients and families can guide what is important for them to reveal, and can describe impacts of their health care in a way that makes sense to them in the context of their lives. Examples of experience-oriented prompts include, "how did that feel for you?", "what did that look like from your perspective?", "what part of it prompted your response?", and "what happened next?" (pp. 162–64). Experiential information can help health care organizations and systems better comprehend the ethical impacts their care and services have on the rights, interests and lives of patients and families they serve.

In addition to different interpretations of what satisfaction and experience mean, information about patient/family health care experiences is portrayed in different ways. For example, Chenail (2011) suggests experience can be examined in terms of what the results of the care were (outcome), how the care was experienced (process), how processes of care were seen as leading or not leading to outcomes (progress), how patients and providers/staff interact (communication), and patient's sense of self, environment, or valuing of services (p. 1175). Moreover, Murrells et al. (2013) identify how functional, transactional, and relational aspects of care articulate patient/ family experiences. In what follows, I elaborate on functional, transactional, and relational aspects of care.

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First, *functional* aspects of care are heavily task-related. Function depicts work done 'to' patients, such as giving medication, managing pain, wait times, and cleanliness of hospital areas (Adapted from C. Graham et al., 2018; Kelly et al., 2018, p. 174; Murrells et al., 2013). Second, transactional aspects of care are ways in which patients are cared 'for'. Examples include establishing and maintaining channels to exchange relevant, meaningful and useful information on a nominal level for the purpose of coordinating care (such as meeting patient preferences for appointment times) and facilitating goal-directed behaviour (such as explaining how to take medication) (Adapted from Cross, 2014, p. 815; Hilton & Anderson, 2018, p. 16; Murrells et al., 2013; Pittet et al., 2017, p. 211). And third, relational aspects of care are ways in which patients are cared 'about'. Relational aspects include approaching care as part of an ongoing and emotionally supportive relationship, aligning affective and motivational states to create space for patients to discuss concerns or fears and feel listened to, and treating patients with respect, dignity, compassion, and as a unique person rather than a checklist (Adapted from Chew, 2014; Child and Youth Mental Health and Substance Use Collaborative, 2017; C. Graham et al., 2018; Kelly et al., 2018, p. 174; Kornhaber et al., 2016; Murrells et al., 2013, p. 2; Robert et al., 2011). In the pages that follow, I briefly summarize the literature on measuring patient/family experiences and conceptualizing harm. In Chapter 3 I expand on this literature to show that patient/family experience of QI is an understudied area.

## 2.4.3.1 Measuring patient and family experience.

Two central features of portraying patient and family experience are to first identify the components of experience, and to then measure or otherwise describe the components. Measuring health system quality from patients' and families' perspectives is a complex process
that employs quantitative, qualitative and mixed methods (B. Graham et al., 2019; Wong & Haggerty, 2013, p. 16). The most common approach to provide a comprehensive picture of care is to ask patients and families to complete surveys (K. J. Edwards et al., 2015; Health Quality Ontario, 2016, p. 18; OECD, 2019; The Health Foundation, 2013c, 2014a; J. A. Wolf, 2019). For example, CIHI (2019b; Hadibhai et al., 2018) released a high-level summary of results of the first "Canadian Patient Experiences Survey on Inpatient Care (CPES-IC)" and reported that, overall, 62% of patients rated their hospital experience as very good.<sup>41</sup> On a provincial basis, BC uses the "Acute Care Inpatient Sector Survey" to gather patient perceptions and reported experiences across the health care system on mostly four-point response scales, with opportunity for narrative comments (Population Data BC, 2019).

Patient Experience Reported Measures (PREMs)<sup>42</sup> and Patient Outcome Reported Measures (PROMs)<sup>43</sup> are validated measurement instruments that assess quality of care from the patient's perspective. Many Canadian jurisdictions now integrate PREMs and PROMs into mechanisms to assess quality of care, and thus these measures strengthen opportunities for improvement from the patient's perspective (G. R. Baker, 2014, p. 1; Health Quality Ontario, 2016). Other

<sup>&</sup>lt;sup>41</sup> The CPES-IC survey includes data from only 5 provinces, including BC. Key findings included: more than two thirds of patients reported that "doctors and nurses always listened carefully and explained things clearly" (communication and explanation of care); about half of patients "felt that their care was always well coordinated by hospital staff" (coordination of care); and 75% of patients said they had "good planning for discharge from the hospital" (support leaving hospital) (Canadian Institute for Health Information, 2019b).

<sup>&</sup>lt;sup>42</sup> PREMs capture patients' views about their experiences while receiving care, such as during a hospital stay. PREMs are designed to allow comparative performance measurement (Canadian Institute for Health Information, 2019b).

<sup>&</sup>lt;sup>43</sup> PROMs capture information on aspects of patients' health status at a particular point in time; information that is relevant to their quality of life, including symptoms, functionality and physical, mental and social health. PROMs can be condition-specific (e.g., osteoarthritis), procedure-specific (e.g., hip replacement), or 'generic' (e.g., an overall range of physical and psychological domains) (Canadian Institute for Health Information, n.d.). PROMs are also increasingly used as outcome measures in clinical trials (Vodicka et al., 2015).

approaches to assess patient/family experience include patient/family advisory committees, interviews, focus groups, bedside rounding, patient shadowing, post-discharge telephone calls, patient stories, comment cards, complaints and compliments, online ratings, and public meetings (K. J. Edwards et al., 2015; The Health Foundation, 2013b, 2013c; J. A. Wolf, 2019). In recent years, health care organizations have commenced monitoring of social media to track patient/family perceptions of care conveyed in socially shared stories (J. A. Wolf, 2019, p. 31).

In reviewing which aspects of patient experience are (or are not) systematically captured through the diverse approaches I described above, I return to the important distinction Bate and Robert (2007) make between experience and satisfaction. The OECD (2019) highlights the significance of collecting experience data about the components of care that *matter most* to patients, noting that in chronic conditions such as mental health, "a positive care experience influences the relationship with the care team, manifesting in better communication, therapeutic continuity, adherence and health outcomes" (p. 42). Bate and Robert (2007) argue that while many patient surveys claim to measure patient *experience*, they likely measure satisfaction only (p. 169). Moreover, health care leaders advocate that incorporating patient experience data into system improvement is an ethical imperative. For example, Coulter et al. (2014) claim, "It is unethical to ask patients to comment on their experiences if these comments are going to be ignored" (p. 3). On this basis, evaluation measures limited to satisfaction are not able to adequately capture how patients/families experience overall impacts of their health care interactions, including benefits, harms and burdens. In Chapter 3, I review literature about patient/family experiences of QI interventions.

# 2.4.3.2 Conceptualizing and measuring health care harm.

Overall, there has been progress in understanding how patients and families experience health care, with notions of benefit, harm and burden becoming increasingly broad (Canadian Institutes of Health Research et al., 2018; Gandhi et al., 2020; Sokol-Hessner et al., 2018). By harm, I use Faden et al.'s (2013) general definition, "a thwarting, defeating, or setting back of an individual's interests" (p. S20). The TCPS 2 (2018) further interprets harm as: "Anything that has a negative effect on participants' welfare, broadly construed. The nature of the harm may be social, behavioural, psychological, physical or economic" (p. 195), and welfare is seen as, "The quality of a person's experience of life in all its aspects. Welfare consists of the impact on individuals and/or groups of factors such as their physical, mental and spiritual health, as well as their physical, economic and social circumstances" (p. 202). However, one limitation in the quality and patient safety literature (and likely in practice) is that harm is more typically conceptualized in the physical sense, based on ideas within a traditional and dominant biomedical paradigm (Chan & Cochrane, 2016, p. 12; National Patient Safety Foundation, 2015; OECD, 2019; O'Neill, 2016; Sokol-Hessner et al., 2018; The Health Foundation, 2011c; World Health Organization (WHO), 2009b).

Moreover, given the traditional concept of harm, non-physical risks and harms are less likely to be integrated into systems of quality and safety, including estimates of the direct costs health care systems bear to treat *all* preventable harms that impact patients/families and staff, as well as ways to measure patient experience (Sokol-Hessner et al., 2018). Instead, patients/families are more likely to relay information about their experiences of non-physical harms retrospectively

through routes such as complaints, which was what occurred in the Staffordshire Hospital scandal.

# 2.5 Chapter Summary

In this chapter I drew on relevant literature from a number of fields to situate patients and families within the health care ethics and quality landscapes. I focused on health care in Canada and acknowledged that these landscapes are continually shaped by global influences, particularly from the US, the UK and international organizations (such as WHO and OECD). I also described patient-centred care, aspects such as vulnerability and power asymmetries, patient and family engagement in the health care system, and ideas about how patient and family experience of health care is portrayed. In the chapter that follows, I turn to review literature about the QI field, the rationale for involving patients and families in QI, and resulting QI ethical frameworks and research-related questions.

# Chapter 3: Literature Review – Patients and Families, Quality Improvement, and Ethical Frameworks for QI

## 3.1 Chapter Overview

In this chapter, I describe the field of quality improvement (OI). I outline OI's philosophical foundations and the science of improvement, how QI is positioned within the ethical and quality landscapes I reviewed in Chapter 2, strengths QI purports to have, and challenges of its implementation in clinical contexts. As an orientation to the focal area of QI in this study, I outline hand hygiene interventions that involve hospital patients as a means to prevent health care-associated infections. I then summarize the rationale for involving patients and families in QI, and the state of knowledge regarding patient and family experiences of QI. Of particular focus is QI those interventions implemented at the point of care that ask patients/families to take on more responsibility for their own care and safety. Finally, I turn my attention to how new questions about the research-practice distinction (described in Chapter 2) gave rise to ethical frameworks for QI. In particular, I reflect on patterns in the literature about ethical approaches to QI and the potential for benefits, burdens and harms given the paucity of relevant empirical research about patient/family experiences of QI implementation (my specific research question). I outline common ethical frameworks for learning activities that include QI. To close this chapter, I summarize the ethical rationale grounding the need to study the ethical impact of QI interventions on patients and families at the point of care.

# 3.2 Quality Improvement

Health care organizations around the world apply a range of strategies to improve the quality of care they deliver to patients. Since the 1980s, health care administrators and practitioners have used quality improvement (QI) to tackle clinical and operational problems to improve the planning and management of health care services, and thus increase the quality of health care and reduce preventable harm (Health Council of Canada, 2013; J. K. Johnson & Sollecito, 2018b; Parry, 2014). QI is loosely defined as "describing a philosophy or shared attitude about making something better" (Berwick, 2012, p. 2093). Over the last two decades, health care systems have become increasingly focused on QI and safety at the governance and planning levels (Veillard et al., 2012). As part of their professional roles, Canadian health care leaders, managers, and increasingly health care providers, are expected to be trained in improvement approaches and tools and to participate in QI activities (Bar et al., 2018; Health Council of Canada, 2013, pp. 27–28; B. Jones et al., 2019; Mormer & Stevans, 2019; Nicklin & Williams, 2011; Patient Engagement Action Team, 2017; Sherwood & Jones, 2013).

In this section, I first summarize how improvement science and QI are conceptualized and applied in health care, and factors associated with its success. I outline the importance of context and key challenges to sustaining QI interventions.

#### **3.2.1** Improvement science.

QI in health care arose from adapting techniques originally developed by engineers for industrial management. Together with ideas from health care and social sciences, QI formed a pragmatic approach to improve health care quality, including closing the 'quality chasm' between routine

care practices and evidence-based guidelines I described in Chapter 2 (Cribb et al., 2019; J. K. Johnson & Sollecito, 2018b; Koczwara et al., 2018; Scoville & Little, 2014). *Improvement science* describes systems-level partnerships between academics and frontline practitioners to determine effective approaches and tools that health care teams can use in different settings to promote uptake of practices proven to be effective (Andersson & Olheden, 2012; P. B. Batalden & Davidoff, 2007; Koczwara et al., 2018; Marshall et al., 2013; Powell et al., 2009; The Health Foundation, 2011a). In other words, improvement science maximizes the learning from attempts at improvement.

The heterogeneous and fragmented nature of QI is reflected in inconsistent use of terms to describe similar work that depends in part on community, cultural specificities and traditions, and also reflects the complexity and diversity of this field (Burton et al., 2014; Kass et al., 2013; Longtin et al., 2017; Ogrinc et al., 2016; Parry, 2014; Powell et al., 2009; Rubenstein et al., 2014). Moreover, people who implement activities influenced by the QI movement in local practice settings may use terms, apply techniques, and implement interventions in different ways than they were intended. These patterns spark debates about what QI 'is' and QI 'isn't'.

As a concept, QI involves two key areas: embedding a culture of quality and implementing systematic activities to improve aspects of quality. The overarching goal of QI is to provide quality services and products, while minimizing costs; hence the emphases on measuring the effect of interventions and considering trade-offs between aspects of the *Triple Aim* (health outcomes, patient experience, and costs). First, in the broad sense, QI ought to embed a *quality culture*. For example, a QI philosophy encourages health care systems, organizations, and all

health care team members (which includes patients and families) to be actively engaged in a culture of ongoing QI across direct patient care; organizational design and governance; and policy making (Andersson & Olheden, 2012, p. 123; J. K. Johnson & Sollecito, 2018b; Singer & Vogus, 2013; W.A. Sollecito & Johnson, 2013, p. 4). In the fifth edition of McLaughlin and Kaluzny's Continuous Quality Improvement in Health Care, Sollecito and Johnson (2018) identify factors associated with successful implementation of QI in complex systems. They state, "regulatory mechanisms such as accreditation are key factors that have led to greater diffusion of CQI and will continue to do so in the future as a direct result of mandated measurement and improvement of the quality of care" (p. 39). Drawing on theoretical foundations that include Deming's (1986, 1993) classic work on management, Senge's (1990, 2006) concept of learning organizations, and Greenhalgh et al.'s (2005) work on adoption and diffusion of innovation, Sollecito and Johnson (2018) articulate a "culture of excellence" model of QI. This cultural model comprises the following elements: leadership at all levels; vision; constancy of purpose; focus on 'customers' (patients, families and communities); systems and statistical thinking; teamwork; empowerment and intrinsic motivation; and open communication and feedback (pp. 43–47). Furthermore, this model requires ongoing measurement and adjustments: (1) to determine which cultural and process changes are deemed to be improvements; and (2) to sustain positive changes in health care organizations and systems over time.

There is a general consensus in the quality and safety literature that embedding a positive quality and safety culture is an essential requirement to sustain QI interventions (for example, see (Dixon-Woods et al., 2014, p. 114; Illingworth, 2015, p. 22; National Patient Safety Foundation, 2015; Singer & Vogus, 2013). When a quality culture is embedded, care providers are thought to be less worried about being blamed for mistakes and that poor practices will be revealed (Accreditation Canada, 2018; Mormer & Stevans, 2019; World Health Organization (WHO), 2013a). For example, leaders drive a 'positive culture' when frontline care providers, other staff (e.g., those in management or health records), and volunteers<sup>44</sup> feel safe and supported to challenge existing practice and try new ideas; and the responsibility to deliver high quality care is shared between health care leaders and care providers/staff.

The second key aspect of QI, in an applied sense, involves *actions* that ought to improve aspects of quality.<sup>45</sup> A commonly cited definition of *QI activities* is that of Lynn et al. (2007): "systematic, data-guided activities designed to bring about immediate improvement in health care delivery in particular settings" (p. 667).<sup>46</sup> For example, in this sense, QI initiatives are seen as non-research learning activities<sup>47</sup> that share many characteristics with health research (Kass et al., 2013). The general thinking is that the intent of a QI activity is to ultimately benefit individuals receiving care in the same organization; this in contrast to health research in which the goal lies beyond the improvement of the situation of participating individuals. I elaborate on the significance of this QI/research distinction for my study below (Section 3.4.2).

<sup>&</sup>lt;sup>44</sup> Throughout this dissertation, I use the term "volunteer" to refer to those in unpaid, structured roles supporting care in health care settings. Similar terms include peer mentor and peer navigator.

<sup>&</sup>lt;sup>45</sup> *QI activities* (inclusive of similar terms such as initiatives, changes, projects, interventions, etc.) are one of a number of learning activities or strategies to improve the planning and management of health care services related to the health of individuals or communities, which involve people or their health information (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005, p. 5).

<sup>&</sup>lt;sup>46</sup> As of July 14, 2020, Lynn et al.'s Annals of Internal Medicine article has been cited 168 times in the Web of Science Core Collection.

<sup>&</sup>lt;sup>47</sup> Faden et al. (2013) describe *learning activities* as including clinical research, clinical trials, evaluation, comparative effectiveness research, QI research, QI practice, patient safety practice, health care operations, quality assurance, and evidence-based management (p. S19).

Foundational concepts of QI include that it informs specific policies, processes and/or practices identified as needing improvement, which are then tailored for local conditions of the particular health care context (G. R. Baker et al., 2008; J. K. Johnson & Sollecito, 2018b; Lynn et al., 2007; Marshall et al., 2013; Parry, 2014; Perla et al., 2013; Powell et al., 2009; Rubenstein et al., 2014; World Health Organization (WHO), 2013a). Regulatory authorities and health care organizations can mandate QI activities (known as "top down"; for example, see Dekker, 2011; The Health Foundation, 2011, 2014b), and "bottom up" ideas for QI can emerge from the point of care (e.g., care providers, patients). As noted in Section 2.3.1, health care quality is typically situated within optimistic/pervasive and technical/biomedical discourses. QI reflects these discourses in that activities typically center on changing clinical processes, operational processes, and the way health care providers do their work (Bar et al., 2018, p. 51; Cribb et al., 2019, p. 3; Entwistle & Watt, 2013, p. 29; Farmanova et al., 2016, p. 836; Grol et al., 2007, 2013; Harrigan, 2000; Ovretveit, 2014).

Furthermore, QI is closely connected to the overlapping constructs of quality and patient safety. Stevens et al. (2005) distinguish QI and patient safety as follows: QI "raises the ceiling" to achieve a higher level of care, whereas patient safety "raises the floor" so that fewer patients experience poor levels of care and are harmed in the process (p. 133). For example, QI approaches and tools are frequently used to improve specific aspects of patient safety such as hand hygiene (Andersson & Olheden, 2012; Kitto et al., 2013; Whicher et al., 2014; World Health Organization (WHO), 2009c). As I explain in Section 3.2.4, in this dissertation I explore QI methods applied to interventions aimed at improving patient hand hygiene in hospitals where

some of my study participants, such as transplant recipients, saw hand washing as an essential safety measure.

In clinical practice, certain types of QI interventions have shown to have higher levels of success than others. For example, Sollecito and Johnson (2018) comment that interventions involving checklists to prevent errors in intensive care (Pronovost et al., 2006) and surgical (Haynes et al., 2009; Semel et al., 2010) settings have seen relatively widespread adoption, especially when championed by leading clinical experts in the field. Yet, Sollecito and Johnson (2018) (among others such as Dixon-Woods & Martin, 2016, p. 192; Fan et al., 2010, p. 2286) acknowledge that even these well-known, evidence-based checklists are not fully implemented in routine clinical practice, reinforcing that health care is highly variable when compared to other industries such as aviation or manufacturing (p. 48). As such, despite increased use of QI approaches across the health care sector, the evidence base for their effective application and impact (intended and unintended effects) has mixed results. To advance the science of QI and replicate success, the Standards for QUality Improvement Reporting Excellence (SQUIRE) 2.0 (publication guidelines) encourage reporting both successes and failures, using common terms, and providing descriptions of context (D. Goodman et al., 2016; Ogrinc et al., 2016).<sup>48</sup>

<sup>&</sup>lt;sup>48</sup> The SQUIRE 2.0 (2016) guidelines ask authors to consider the following 18 items: title; abstract; introduction (problem description, available knowledge, rationale, and specific aims); methods (context, intervention(s), study of the intervention(s), measures, analysis and ethical considerations); results; discussion (summary, interpretation, limitations and conclusions) and funding (Ogrinc et al., 2016, p. 678).

## **3.2.2** Approaches to implementing QI and patient safety interventions.

Prominent QI approaches and tools each have unique theoretical and operational features, and several approaches are often used together (Powell et al., 2009; Scoville & Little, 2014). The IHI developed the *Model for Improvement* with American manufacturing experts for health care (Scoville & Little, 2014). In this model, one of the most commonly used QI approaches, formal cycles of action and reflection occur as an ongoing, routine part of daily work in different conditions to answer three questions: (1) What are we trying to accomplish? (2) How will we know that a change is an improvement? and (3) What changes can we make that will result in improvement? (Langley et al., 2009). Berwick (1996) describes the *Model for Improvement* as "inductive learning – the growth of knowledge through making changes and then reflecting on the consequences of those changes" (p. 620). *Continuous Quality Improvement (CQI) and/or Total Quality Management (TQM)* was developed in Japan during the 1950s and emphasizes ongoing (as opposed to episodic) QI activity to achieve incremental improvement over time. Rubenstein et al. (2014) explain that essential CQI features are: "systematic data guided activities, designing with local conditions in mind and iterative development and testing" (p. 8).

*Lean Toyota Production System* re-engineering also originated in Japan in the 1950s to streamline and continually improve processes. Such improvements are based on perceptions of what internal and external customers 'value', and minimizing waste, duplication, variability and non-value adding steps (D'Andreamatteo et al., 2015; Scoville & Little, 2014; Waring & Bishop, 2010). Sheps and Cardiff (2017) explain that over the last two decades Lean thinking has been increasingly integrated into many health care systems (e.g., BC health authorities have focused on Lean as well as the IHI *Triple Aim*). And finally, *Six Sigma*, used in industry since 1980 and

more recently in health care, applies statistical tools to distinguish common versus unique processes and thus reduce variation (Powell et al., 2009, p. 12).

# 3.2.2.1 QI tools and techniques.

Over the past thirty years, the quality and patient safety movements have generated a plethora of QI tools, and I describe several of them here. Many QI activities are structured as *projects* with a beginning, middle and end to design and execute specific interventions in ongoing cycles of monitoring, evaluation and action (Hagen et al., 2007, p. e166; Health Quality Ontario (HQO), 2012). Typically, and as was the case in my research, QI projects are led by a project champion, organized by a project team, and guided by a QI *project charter*. The project charter is a tool following IHI's *Model of Improvement* that outlines the project's "rationale and roadmap" (Institute for Healthcare Improvement, 2018, p. 2) (see Appendix A).<sup>49</sup> Often, a *pilot phase* allows the team to assess feasibility, secure funding, define the problem, and inform the design and implementation of a full-scale activity (Canadian Institutes of Health Research et al., 2018, p. 14; OED Online, 2019b; Reed & Card, 2016).

Second, Taplin et al. (2012) define *intervention* as: "a specified strategy or set of strategies designed to change the knowledge, perceptions, skills, and/or behavior of individuals, groups, or organizations, with the goal of improving patients' health outcomes" (p. 3).<sup>50</sup> In response to this

<sup>&</sup>lt;sup>49</sup> Examples of Canadian quality organizations promoting QI project charters include the BC Patient Safety & Quality Council and Health Quality Ontario.

<sup>&</sup>lt;sup>50</sup> A term often used interchangeably with intervention is *initiative*, which the Oxford English Dictionary (OED Online, n.d.) defines more broadly, "that which initiates, begins, or originates; the first step in some process or enterprise; hence the act, or action, of initiating or taking the first step or lead; beginning, commencement, origination."

social complexity (Broughton & Marquez, 2016), organizations generally implement interventions as *bundles*, meaning one intervention consists of a set of interacting, nested technical and non-technical components (Craig et al., 2013; Reilly et al., 2016; Resar et al., 2012).

*Plan-Do-Study-Act (PDSA) cycles* are rapid, iterative tests of change with four stages: (1) identify a plan to test the change; (2) do the test; (3) study the outcomes (observe, analyze, learn); and (4) act on the results (Berwick, 1998; Institute for Healthcare Improvement, 2017; Langley et al., 2009; Reed & Card, 2016; M. J. Taylor et al., 2014). Finally, *run charts* are statistical tools that graph data over time to depict how well/poorly a process performs over time, areas of variation, and the significance of events such as PDSA cycles (Institute for Healthcare Improvement, 2017).

## **3.2.3** Sensitivity to context and implementation science.

# 3.2.3.1 Context, QI, and implementation.

A broad understanding of context in real-world clinical settings has a profound influence on how, and how successfully, QI interventions are implemented (Alexander & Hearld, 2011; Bate et al., 2008; Burton et al., 2014; Clancy & Berwick, 2011; Kaplan et al., 2010; Kringos et al., 2015; Ovretveit, 2011; Taplin et al., 2012; M. J. Taylor et al., 2014; S. L. Taylor et al., 2011; The Health Foundation, 2014b). Moreover, success is perceived differently by different stakeholders. For example, for interventions to work and to be sustained, frontline staff must see evidence of benefit in their setting (Kringos et al., 2015). For these reasons, many QI interventions are designed in a general way and then adapted to local context (Parry, 2014, p. 198; Reed & Card, 2016, p. 147; M. J. Taylor et al., 2014; The Health Foundation, 2014b). This means that *context validity* is not yet established because the criteria for innovation have often not been met in the specific clinical context.

Like QI, *implementation science* aims to improve quality of health care. John Ovretveit (2011), a scholar who studies the implementation of organizational improvements, describes context in the QI field as, "all factors that are not [explicitly] part of a quality improvement intervention itself" (p. pi18). Interpretations of significant areas of context in QI vary, and commonly include: structural context (e.g., "an organisation's financial, material, human, and informational resources") (Robert & Fulop, 2014, p. 37); psychological context (e.g., "readiness for change") (Robert & Fulop, 2014, p. 33); sociocultural context (e.g., "shared mindset, common mission or values espoused") (Bate, 2014, p. 20); and how the people involved (health care leaders, providers, other staff, patients, families) interpret what is going on (Leslie, Paradis, Gropper, Reeves, & Kitto, 2014; May, Johnson, & Finch, 2016; May et al., 2009; Ogrinc et al., 2016).

However, implementation science differs from improvement science in that it evolved from behavioural sciences on the basis that evidence-based practices<sup>51</sup> are ineffective if they are not systematically adopted in practice and policy (M. S. Bauer et al., 2015; Boulton et al., 2020;

<sup>&</sup>lt;sup>51</sup> Evidence-based practices, such as clinical practice guidelines, imply that the criteria for innovation have already been met (Kimble & Massoud, 2017, p. 91).

Eccles & Mittman, 2006; H. Goldstein & Olswang, 2017; Koczwara et al., 2018).<sup>52,53</sup> Implementation science approaches study how care providers go about their routine work to consider how clinical judgement and context shape decisions and actions, and to optimize these interactions, decisions and actions (Debono & Braithwaite, 2015). While implementation science tends to be associated with 'proven' research activities, it is also closely linked to QI interventions that are evidence-based (World Health Organization (WHO), 2013b, p. 11). For example, to facilitate uptake of a new clinical guideline that recommends against routine thyroid screening (Birtwhistle et al., 2019), QI strategies could help to break the pattern of physicians routinely ordering thyroid tests. Further synergies between improvement science and implementation science could make important contributions to sustain all types of health care innovations, bridge gaps in clinical care delivery, and enable learning health care systems to proactively uncover sociocultural structures that maintain inequities and to identify hazards and risks before they harm patients and families (M. S. Bauer et al., 2015; Greenhalgh & Papoutsi, 2019; Illingworth, 2015; Koczwara et al., 2018; Thorne, 2016).

# 3.2.3.2 Difficulty sustaining health care improvement.

Illingworth (2015) notes, "There have been some remarkable successes in recent years to improve patient safety and tackle harm" (p. 4). Yet, despite an intense focus, increased

<sup>&</sup>lt;sup>52</sup> Boulton et al. (2020) state that four commonly used models of implementation science are: Consolidated Framework for Implementation Research (CFIR) (Damschroder et al., 2009); Diffusion of Innovations in Service Organisations (T Greenhalgh et al., 2004); Normalisation Process Theory (NPT) (May & Finch, 2009); and Promoting Action on Research Implementation in Health Services (PARIHS) (Rycroft-Malone, 2004) (p. 3).
<sup>53</sup> Some recent approaches in patient safety include 'resilient health care', 'human factors', 'safety-II', and 'safety differently'. These approaches focus on how people working in health care think and act, and examine the systems with which they interact (Braithwaite et al., 2015; for example, see Carayon et al., 2014; Dekker, 2014; Hollnagel, 2014; Russ et al., 2013; Sheps & Cardiff, 2011).

investment, and pockets of improvement towards improving health outcomes and patient experience, and reducing costs in recent years, an abundant body of literature documents the general difficulty sustaining quality/safety initiatives across a range of topic areas, with many interventions falling short of anticipated benefits (Alexander & Hearld, 2011; G. R. Baker & Black, 2015; Bastian et al., 2010; Gandhi et al., 2020; Illingworth, 2015; May et al., 2009; Moraros et al., 2016; National Patient Safety Foundation, 2015; Pronovost et al., 2015; Wachter, 2010; Wachter & Pronovost, 2009). In what follows, I outline seven distinct ways identified in the health care quality and safety literature that contribute to challenges sustaining QI activities, and thus QI's strengths may not be coming through when implemented in clinical contexts.

(1) Lack of embedded organizational quality culture: Several years ago, a *Healthcare Papers* series shone light on the difficulty Canadian health care leaders experienced in their work to embed QI programs and a quality culture in their organizations (Nicklin & Williams, 2011; Sullivan et al., 2011; Sutherland et al., 2012). In these articles, leaders characterized the approach to improvement in their individual practice contexts using phrases such as: "managing QI initiatives off the side of the desk"; "flavour of the month"; "reinvent the wheel"; "pilotism"; "not integrated into the day-to-day business of the healthcare setting"; "not everyone's business"; and "an add on, not part of what everyone does". More recent research indicates that support for quality cultures at the organizational and system levels (not only in Canada) has increased (Braithwaite, Herkes, et al., 2017). Nevertheless, calls continue for more formal support and infrastructure to enable quality and safety activities to translate into better care for patients in local settings and throughout the continuum of care (Allin et al., 2017; G. R. Baker et al., 2016; Kwok et al., 2019).

(2) QI is complex in ways that routine care is not: QI interventions often involve a higher level of complexity than the discrete care processes that comprise routine health care (Broughton & Marquez, 2016, p. 2). For example, routine nursing assessments for post-operative patients (e.g., changing dressings, managing pain and intravenous fluid) are highly standardized. QI interventions, on the other hand, interact with the predictable and unpredictable aspects of each local setting (Braithwaite et al., 2015; M. J. Taylor et al., 2014). In contrast, a post-operative QI intervention may involve a new discharge handoff protocol to primary care that involves new processes and new interactions between people, organizations and systems (E. L. Jones et al., 2016). Furthermore, the very characteristics of QI that encourage continual improvement and iterative testing can reveal existing structural problems (such as IT infrastructure, administrative practices, interprofessional tensions) and unintended effects (Illingworth, 2015, p. 19; M. J. Taylor et al., 2014).

(3) Pilotism and drift: The fact that many QI activities begin as pilot projects relays the tentative nature of implementation. Jones (2019) notes that QI activities require health care leaders and providers/staff to manage competing priorities, and once an intervention is "up and running" people tend to move on to the next priority (p. 1). Therefore, it is common for QI activities to begin with a period of intense activity and drift (be abandoned or forgotten) over time (Alexander & Hearld, 2009; Bastian et al., 2010; Baxley et al., 2011; Dixon-Woods et al., 2014, p. 112; Fan et al., 2010; Silver et al., 2016; Weaver et al., 2016). This means that QI pilots that result in measurable improvements are not always sustained, and pilot project reports limit evidence of effects to short-term follow-up (van Achterberg, 2012).

(4) Not all QI activities are well-planned, well-executed, or well-supported: Even though QI activities are popular ways to test 'good ideas' and implement evidence-based interventions (World Health Organization (WHO), 2013b, p. 11), there is a range of quality in QI activities. As Marshall et al. (2013) caution, "the urge to act can easily overwhelm the need for evidence to inform that action, to the extent that much quality improvement work is unscientific—it is neither informed by high-quality evidence, nor is it subject to rigorous assessment to establish its effectiveness, costs, and risks" (p. 419). While health professionals are increasingly trained in QI skills, in many areas a gap endures in the expertise that staff need to lead and implement high-quality QI efforts (Dixon-Woods et al., 2014; Mormer & Stevans, 2019), as well as in available supports at the local level (G. R. Baker et al., 2016; Dixon-Woods et al., 2014; Kwok et al., 2019; Marshall et al., 2013; Mormer & Stevans, 2019; M. J. Taylor et al., 2014).

(5) *Limited effectiveness*: Health care leaders and QI practitioners may overestimate the effectiveness of QI initiatives in settings where the intervention has not been evaluated over longer terms, and overlook opportunities to improve quality/prevent harm (Gandhi et al., 2020; Grol et al., 2007, 2013; M. J. Taylor et al., 2014).

*(6) Efficiency constraints*: It is accepted that safer, more efficient health care can reduce downstream costs associated with physical harm.<sup>54</sup> However as noted in Section 2.3.2, most health care systems operate within significant financial constraints. This means that health care

<sup>&</sup>lt;sup>54</sup> For example, in Canada, spending to treat patient harm in hospitals during 2014–2015 was \$685 million (Chan & Cochrane, 2016); and current estimates to manage superbug infections are \$380 million (OECD, 2018a).

organizations are often expected to accomplish well-planned, well-executed, and well-supported QI interventions that require expertise, collaboration, iterative testing and long-term evaluation with inadequate resources (Storkholm et al., 2017; M. J. Taylor et al., 2014).

(7) Change fatigue: In an era of ongoing quality and safety activity, the sheer volume of wellintentioned plans to involve care providers in practice change can lead to change fatigue, a management concept that McMillan and Perron (2013) explain as "the overwhelming feelings of stress, exhaustion, and burnout associated with rapid and continuous change in the workplace" (p. 26). Change fatigue builds from previous experiences, and providers also suffer physical and psychological harms when preventable harm occurs (Gandhi et al., 2020, p. 3; Rodney, 2013). Attitudes and behaviours about new innovations (including QI and patient safety activities) range from enthusiasm, ambivalence to even cynicism (Chung et al., 2017; Dixon-Woods et al., 2012; Hayes & Goldmann, 2018; Health Council of Canada, 2013; W. A. Sollecito & Johnson, 2018).

#### **3.2.4** Improvement context for this study: Patients and hand hygiene interventions.

As I embarked on this exploration of patient/family experience, the focal area of improvement I studied was infection prevention and control through hand hygiene interventions involving patients and families. In health care settings, 'hand hygiene' is understood to include cleansing hands with an alcohol-based hand rub (ABHR) (effective, fast, easily available, well tolerated) and soap and water (if hands are visibly soiled or are contaminated) (B. Henry, 2009; Vermeil et al., 2019, p. 386; World Health Organization (WHO), 2020a). In my research, in order to

understand the experience of patients and their families at the point of care I studied the implementation of QI patient hand hygiene interventions in real time<sup>55</sup> in one acute care hospital.

I chose the area of patient hand hygiene because of its significance. For many years, infection has posed significant burdens and harms to patients, families, and health care systems in Canada, as noted in the Canadian Adverse Events Study (G. R. Baker et al., 2004). According to recent Canadian estimates, bacterial health care-associated infections are too common, currently affecting over 250,000 Canadians every year. Tragically, between 8,000 and 12,000 of these patients die (Canadian Institutes of Health Research (CIHR), 2017; Canadian Patient Safety Institute, n.d.-b). Common health care-associated infections include *Clostridium difficile*, Vancomycin-resistant *Enterococcus* (VRE), and Methicillin-resistant *Staphylococcus aureus* (MRSA) (Canadian Patient Safety Institute, n.d.-b). The greatest threat comes from bacteria that have evolved to resist antimicrobials (so-called 'superbugs'). On average, 404 Canadians die every year because of infections from antimicrobial-resistant (AMR) bacteria (OECD, 2018a, p. 1). The burden of infection impacts health care budgets,<sup>56</sup> the health of populations and, of course, the quality of patient and family experiences.

A separate (but related) aspect of infection prevention and control with significant impacts is viral disease outbreaks such as Severe Acute Respiratory Syndrome (SARS), H1N1, Ebola virus,

<sup>&</sup>lt;sup>55</sup> I use *real time* here to mean my data collection occurred at the same time as the QI interventions were being implemented on different patient care units in the study hospital.

<sup>&</sup>lt;sup>56</sup> Managing superbug infections may generate costs of up to \$380 million in Canada alone (OECD, 2018a). Costs in the OECD (2018b) Report *Stemming the Superbug Tide: Just a Few Dollars More* are expressed in United States dollar purchasing power parity (p. 1) for the purpose of making comparisons between countries.

and, most recently, novel coronavirus (SARS-CoV-2 infection, which causes the respiratory illness Covid-19). Ostwald (2014) estimates that the economic burden of viral outbreaks<sup>57</sup> often impacts society more broadly than the bacterial health care-associated infections described above. Thus, coordinated strategies to prevent and control *all* microbial infections are a global priority (Canadian Patient Safety Institute, n.d.-d; World Health Organization (WHO), 2009c) that is shaped by economic and geopolitical forces (Strathdee, 2019). Promotion of hand hygiene, including via QI interventions, continues to be the primary standard precaution<sup>58</sup> to prevent and limit the spread of virulent infections worldwide (B. Henry, 2009; OECD, 2018b; Vermeil et al., 2019; World Health Organization (WHO), 2009c, p. 6).<sup>59</sup> Furthermore, society's increased awareness of hand hygiene's role in infection control in ordinary circumstances is evident with the increasing availability of hand hygiene supplies and signage in health care facilities and other confined spaces, with cruise ships being at particular risk for transmission (Pavli et al., 2016).

<sup>&</sup>lt;sup>57</sup> For example, Ostwald (2014) states that in 2003/4, SARS had "greater than US\$4 billion impact on Canada, which also resulted in an estimated 28,000 lost jobs" (p. 4). While there were direct medical costs from SARS in affected countries (e.g., in Canada 251 people were infected resulting in 43 deaths), he attributes SARS's significant economic impact to "widespread behavioral changes that significantly constrained economic activity", such as reduced travel and lower workplace productivity (p. 5). At the time of writing, the full enormity of Covid-19's impact on all areas of global society is unknown but likely severe.

<sup>&</sup>lt;sup>58</sup> The World Health Organization (2020a) describes 'standard precautions' as including: "hand and respiratory hygiene, the use of appropriate personal protective equipment (PPE) according to risk assessment, injection safety practices, safe waste management, proper linens, environmental cleaning and sterilization of patient-care equipment" (p. 1).

<sup>&</sup>lt;sup>59</sup> Other key strategies include: stewardship, enhanced environmental hygiene, delayed antimicrobial prescribing, mass media campaigns, and rapid diagnostic testing (known as the OECD SPHeP-AMR model) (OECD, 2018b).

# 3.2.4.1 Hand hygiene interventions involving patients and families in my study.

Situated within this larger context, I studied hand hygiene interventions involving patients and families in an acute care hospital. Well publicized initiatives such as "it's ok to ask" and "speak up" encourage patients/families to ask their care providers to wash their hands (The Joint Commission, 2018; World Health Organization (WHO), 2009c). However, due to power asymmetries between patients and care providers, research consistently demonstrates that despite encouragement, many patients and families are reluctant to ask providers about handwashing because they perceive these interactions as confrontational (Bellissimo-Rodrigues et al., 2016; R. E. Davis et al., 2015; Flannigan, 2015; Kim et al., 2015; Landers et al., 2012; Longtin et al., 2009, 2017; McGuckin & Govednik, 2013; Pittet et al., 2011; Rainey et al., 2015; Reid et al., 2012; Treise et al., 2016). In Chapter 5 (Section 5.5.5.1) I elaborate on my rationale for selecting hand hygiene as the context to understand patient/family experience of QI in this study.

## 3.3 Patient and Family Engagement in QI

Having explored the field of quality improvement in health care, I now turn my attention to patient and family engagement in this field. Armstrong et al. (2013) state, "justifications for involving patients in improvement initiatives are similar to those for involvement in health care more generally" (p. e37) (see Section 2.4.2). In what follows, I first describe how patients/ families are engaged in QI at the organization and system levels. I then review the literature describing how patients/families are engaged in QI at the direct care level (the area of interest in my study), and summarize ethical questions regarding when QI interventions are integrated into patients' routine health care, at the point of care.

Increasing the level of patient and family engagement in mechanisms and initiatives to redesign the health care system and to improve the quality of care is strongly advocated by diverse experts (Armstrong et al., 2013; G. R. Baker, 2014; Balik et al., 2011; Bate & Robert, 2007; Berger et al., 2014; Bergerum et al., 2019; R. E. Davis et al., 2011; S. Davis et al., 2016; Entwistle & Watt, 2013; Greene et al., 2018; Groene et al., 2009; O'Shea et al., 2019; Renedo et al., 2015; Sari et al., 2011; The Health Foundation, 2013b; Travaglia & Robertson, 2018; Wiig et al., 2013; World Health Organization (WHO), 2009d, 2016). Generally speaking, much of the literature referring to 'patient and family engagement' describes involvement at the organizational level, and sometimes at the system level (Carman et al., 2013; Council of Canadian Academies, 2015; Faden et al., 2013). Patient/family engagement within health care organizations includes roles as patient partner/advisor on quality and safety projects to improve policies and procedures, educating health professionals, or in health research (American Hospital Association, 2013; Canadian Institutes of Health Research (CIHR), 2019; Carman et al., 2013; Epstein et al., 2010; International Association for Public Participation, 2007; Longtin et al., 2010; Patient Engagement Action Team, 2017; Patient-Centered Outcomes Research Institute, n.d.; Peat et al., 2010; The Health Foundation, 2013b, p. 18; Travaglia & Robertson, 2018, p. 208). For example, to facilitate patient/family engagement in BC, in 2009 the Ministry of Health created the Patient Voices Network (PVN) (Patient Voices Network, n.d.-a) to develop and support patients and families in a range of roles decision making (for example policy-making, priority-setting, governance, and knowledge translation) at provincial, national, and international levels. Many other organizations worldwide, such as Vancouver Coastal's Community Engagement Advisory Network, Arthritis Society of Canada, and Kaiser Permanente provide a similar function (Travaglia & Robertson, 2018, p. 209).

Reported benefits of patient/family engagement at the organizational and system levels include that services can be more responsive to patient/family needs and priorities, more comprehensive and accountable in terms of planning health care services, and can lead to improved patient experience. Bate and Robert (2007) state that incorporating patient experience into health care design can also result in higher levels of clinician engagement in improvement efforts (p. 178), which helps to address the sustainability challenges I outlined in Section 3.2.3.2. At the same time, concerns have been raised about engaging patients/families in health care system improvement. These concerns include: lack of knowledge about the impacts on patients and families (for example (Bombard et al., 2018, p. 19; Boothe, 2019; Manafo et al., 2018); and conceptual and practical challenges inherent in effective and meaningful attempts to engage patients and families across health care system levels (Abelson et al., 2018; G. R. Baker, 2014; BC Patient Safety & Quality Council & Patient Voices Network, 2017; Liang et al., 2018; Manafo et al., 2018, p. 2; McCarron et al., 2019; National Patient Safety Foundation, 2015, p. 31; Ocloo & Matthews, 2016; Pomey et al., 2015; Shimmin et al., 2017, p. 2).

# 3.3.1 Ethical questions about patients/families and QI activities at the point of care.

The rationale for engaging patients and families in quality and safety at the point of care is that patients/families are entitled and motivated to receive the highest quality and safe health care, and they are in a unique position to notice when things are going wrong (Carman et al., 2013; Longtin et al., 2010; Pomey et al., 2018; The Health Foundation, 2013b; World Health Organization (WHO), 2009d, 2017, p. 14). It is important to note that while many QI interventions occur at the direct care level, the focus of improvement tends to be internalized on provider-focused processes (see Section 3.2). Furthermore, patients and families are typically

engaged in direct care QI through retrospective, passive mechanisms such as patient surveys, exit interviews and focus groups. This means that the majority of these QI initiatives neither directly engage current patients at the point of care, nor emphasize patients'/families' roles in their own health care (Leape et al., 2009, p. 426; The Health Foundation, 2013b, p. 18; Travaglia & Robertson, 2018).

However, some QI initiatives do occur at the point of care and are integrated into patients' health care in real time (the actual time during which care processes occur). To illustrate how QI interventions can involve patients to lesser and greater degrees, in Appendix B I describe six scenarios of QI interventions that involve hand hygiene – whether patients/ families are aware of the processes, if the processes are categorized as routine or QI, or what aspects of the processes are studied and measured. Furthermore, a subset of QI initiatives at the point of care deliberately engages patients/families in *new roles* that include taking *new responsibilities* for aspects of the quality and safety of their own health care, therefore increasing responsibility for their own wellbeing (Coulter & Ellins, 2007, p. 24; Landers et al., 2012, p. S12; Patient Engagement Action Team, 2017, p. 21; The Health Foundation, 2013c, p. 26; Travaglia & Robertson, 2018, p. 208). Thus, QI and patient safety interventions involving patients/families parallel areas where patients/families participate in their own health care. Examples include hand hygiene (e.g., the "it's ok to ask" intervention described in Section 3.2.4.1), medication reconciliation, and falls prevention. As I will explain in Chapter 5, the primary QI intervention I studied in this study is similar to Scenario Five in Appendix B.

Because QI processes at the point of care are *not* thought to be transparent or observable to patients and families, quality leaders and providers often presume that: (1) patients/families are unaware of the role of QI in their health care; and (2) QI interventions have little or no impact on patient/family experiences (Baily et al., 2006; Faden et al., 2013; Kass et al., 2008). As noted in Section 2.3, to date, an integral feature of the quality movement has been the assumption of benefit. While I acknowledge the vital importance of increasing quality, patient safety and patient engagement, as well as the benefits that QI approaches offer, QI leaders and those who implement QI interventions involving patients and families at the point of care tend to *assume* interventions are a beneficial extension of routine medical care. At the same time, QI leaders tend not to recognize potential downsides or ambiguities QI interventions could have for patients and families (Berger et al., 2014; Canadian Institutes of Health Research et al., 2018; Pomey et al., 2018; The Health Foundation, 2013b). For example, given the situatedness of patients and families (see Section 2.4.1), the cumulative burdens from illness and treatment can impact their capacity to cope with further demands at the point of care (May et al., 2014).

In the context of my study, a QI intervention encouraging patients to ask their providers about handwashing could increase patient workload, cause patients to feel an undue burden for their own safety, and undermine trust (Landers et al., 2012, p. S12). Furthermore, given underlying political and managerial motivations to engage patients/families in their own care (Batt, 2017; Duncan et al., 2014; May et al., 2014, pp. 2–3), QI interventions may involve – or be perceived by patients, families, health care staff and the public to involve – competing interests if the interventions' goals extend beyond patients' immediate interests (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005; Baily et al., 2006; Duncan et al., 2014;

Grady, 2007; Paley, 2014; Radnor et al., 2012). Thus, involving patients and families in QI at the point of care raises ethical questions about unexamined wider impacts on this stakeholder group, some of whom may be in vulnerable circumstances.

Furthermore, the widespread assumption of QI's benefit has resulted in little clinical or ethical foci in evaluations of the wider impacts that QI interventions have on patients/families. Almost 20 years ago, Vincent and Coulter (2002) critiqued the patient safety field for largely ignoring patients, patients' perspectives, and patients' roles in the safety of their own care (p. 76). To be sure, the more recent developments to engage patients and families in the health care system and in their own health care have brought many benefits. While most of the (limited) research on patient/family experience of QI applies to engagement at the organization/community level, Bombard et al. (2018) state, "The limited evaluation of patients' experiences is particularly ironic given the intent of these services to be patient-centered. Additional evaluative metrics should be developed to examine patients' experiences" (p. 19). Thus far research examining benefits and harms of patient and family involvement in QI at the point of care provides limited evidence of benefit in terms of patient outcome or patient experience (Cené et al., 2016; Pomey et al., 2018; Wachter, 2010). Where patient/family perceptions of QI activities are sought, this information is typically quantitatively-focused and superficial, aligning more closely with satisfaction with care than with experience of care (Bate & Robert, 2007, pp. 162–164). Furthermore, Berger et al.'s (2014) systematic review of patient engagement in safety and quality initiatives (including initiatives such as hand hygiene and rapid response systems) reported, "None of the included studies evaluated harms of interventions or surveys [on patients and families]" (p. 552).

Based on my review of diverse sources of relevant literature, I conclude that knowledge encompassing broader interpretations of the benefits, harms and burdens that patients and families experience as a result of their care – including 'learning activities' such as QI interventions – is not systematically captured. This, I argue, is an important moral consideration. Therefore, the primary issue of concern in this study is the paucity of research about patient/family experience of QI interventions *integrated into their own care, at the point of care.* I am particularly interested in the gap in knowledge about patient/family experiences of QI interventions specifically designed to increase the role of patients/families in the real-time safety of their own care, which is a power-laden situational context. It is my premise that this gap is the result of an optimistic, positivist framing of QI as 'routine clinical care'. Thus far, this framing has provided little incentive to study patient and family experiences of QI at the point of care, and has created an ambiguous ethical status for QI activities, which I elaborate on in Section 3.4.

In a related domain, ethicists McDonald, Cox and colleagues studied experiences of research participants in their groundbreaking *Centering the Human Subject in Health Research* study (Cox et al., 2019; Cox & McDonald, 2013; M. McDonald et al., 2008, 2014; M. McDonald & Cox, 2009; Townsend et al., 2014). Their findings have two particular areas of relevance for my study. First, clinical trial participants with chronic illnesses experienced profound emotional impacts from quality-of-life questionnaires that researchers considered to be standard 'minimal risk' research procedures (M. McDonald et al., 2014, p. 117; Townsend et al., 2014). Second, the

"protective imagination"<sup>60</sup> of researchers and REBs regarding benefits, burdens and harms did not always correspond with the impacts described by participants. These empirical findings reinforce the importance of investigating the nuances of the ways patients and families understand and experience the components that make up a QI intervention as the intervention is happening. However, unlike research procedures and routine care processes that are typically easy to isolate, QI activities at the point of care are often complex and highly integrated into routine practice. In turn, this characteristic makes patient/family experience of QI difficult to isolate, measure, and report on (Dixon, 2017, pp. 7–8). Therefore, the assumed benefits of QI activities, the challenges to isolate the phenomenon of experience at the point of care, and the complexity of measuring related outcomes are likely some of contributors to why important questions regarding ethical impact of QI interventions on patients/families remain unasked and unanswered. On the basis of this critical review I argue that patient and family experience of QI interventions at the point of care is an understudied phenomenon.

# 3.4 Ethical Frameworks for QI

Having explored the complex ethics and quality landscapes in which patients and families receive health care in Chapter 2 and the state of knowledge regarding patient and family experience of QI in this Chapter, I now turn my attention to how QI is positioned within the ethical and quality landscapes. In so doing, I examine ethical frameworks that currently apply to

<sup>&</sup>lt;sup>60</sup> Cox, McDonald, Townsend and colleagues (2019; 2014) report that REB members use their "protective imaginations" that align with biomedically-based risk guidelines, assumptions, personal experiences, common-sense understandings, and best guesses. This tendency de-emphasizes the need to study impact that participation in research studies *actually has* on research participants. These findings are consistent with a growing body of research, see for example (Dresser, 2016; Pritchard, 2011; Stark, 2011).

QI. In the current ethics paradigm, different oversight requirements are set out for learning activities based on the distinction between research and practice (see Section 2.2.3). On this basis, most types of research *do* require explicit ethics oversight. On the other hand, QI is categorized as practice and *does not* generally require explicit ethics oversight on the assumption is that QI activities are guided by implicit ethical norms of health care providers. Thus, research requires an arbiter and protector of participant interests but QI does not. However, QI's ambiguous ethical status means that people from different fields can frame what seem to be similar learning activities in different ways.

Furthermore, the focus of ethics oversight remains on labelling and sorting QI from research activities, rather than on patient/participant rights, interests and welfare. In what follows, I summarize literature outlining challenges in the current approach to ethics in the health research domain, revisit the practice/research distinction as QI became commonplace in health care, and review several ethical frameworks developed for QI activities.

# 3.4.1 Challenges in research ethics oversight mechanisms.

In my study of patient/family experience of QI interventions, the significance of existing ethical oversight approaches for research and practice is paramount. As I described in Chapter 2, REBs are an important part of the ethics review process in Canada and elsewhere. In what follows, I summarize challenges in the current system of research ethics that are of particular relevance for my study. Observers note that many aspects, including the policy documents and the high levels of expertise and dedication, work very well (M. McDonald et al., 2011). Yet, the research community (especially researchers, REB administrators and REB members) call for

improvement in several areas, including the need for: increased funding and collaboration to support timely reviews and approvals; research ethics education; additional clarity on proportionate review;<sup>61</sup> and more consistency and transparency between the decision-making of different REBs that all follow the same set of standards (Cox et al., 2019; Dawson et al., 2019; M. McDonald et al., 2011; Nicholls et al., 2015; Oberle & Storch, 2013; Page & Nyeboer, 2017; Unger, 2011 Chapter 8). In recent years, while several areas in Canada report progress (albeit slow) with multi-jurisdictional REB reviews to make it less cumbersome for researchers and funders to conduct multi-site research, calls for a pan-Canadian approach continue (Nicholls et al., 2018).

A separate concern is how the REB structure and the ethics review process is situated within the research ethics lifecycle (J. A. Anderson et al., 2011; Canadian Institutes of Health Research, 2018), the broader learning health care system (Faden et al., 2013), and the ethical concerns of participants and communities (Boilevin et al., 2019, p. 12). Specifically, there is growing concern that, in general, REBs' vigilance to the prospective aspects of research projects (e.g., ideas about risk, consent form wording) do not carry through to the monitoring and retrospective aspects (Cox et al., 2019; Dawson et al., 2019; M. McDonald et al., 2011; Nicholls et al., 2015; Unger, 2011 Chapter 8). For example, as part of the continuing review process, REBs review information provided by researchers and funders such as numbers of participants enrolled in the study and adverse events. But, "REBs are not equipped to keep researchers accountable to

<sup>&</sup>lt;sup>61</sup> The *TCPS 2* (2018) specifies that a *proportionate* approach to REB review requires assessing the ethical acceptability of a research project. Specifically, this assessment involves considering the foreseeable risks, the potential benefits and the ethical implications of the research (Article 6.12).

actually follow their proposed research protocols" (Boilevin et al., 2019, p. 12). Therefore, REBs do not learn things such as how consent *discussions* between researchers and study participants occur initially or on an ongoing basis (Canadian Institutes of Health Research et al., 2018, p. 33; Humphrey Beebe & Smith, 2010), or how diverse participants are empowered in research relationships (Cascio & Racine, 2018). And, despite more recent inclusion of data from PREMs and PROMs in research design, REBs do not learn about the *ethical impacts* research activities actually have on participants (Boilevin et al., 2019; M. McDonald et al., 2014). On this basis, McDonald et al. (2011) argue, "REB review is anecdotally based rather than evidence based" (p. 44).

Researchers who work in ethics reiterate that an effective ethical oversight system for health research must operate *over the entire research lifecycle* (J. A. Anderson et al., 2011; Canadian Institutes of Health Research, 2018; Dawson et al., 2019; M. McDonald et al., 2011, 2014; Nicholls et al., 2015). Furthermore, Reimer-Kirkham and Anderson (2010) state that not considering the influence that power and justice have on formulation of research questions contributes to ongoing inequities. Importantly, the lack of retrospective information about research activities and the emphasis on the REB review stage hinder achievement of key ethical objectives, and deprive research communities, research participants and society as a whole from opportunities for system learning.

Finally, not all individuals and communities in Canada (especially, though not only, for groups that are marginalized) have found that institutional REBs in fact consistently protect or are able

to protect their rights, interests, and welfare.<sup>62, 63</sup> Furthermore, despite *TCPS 2* guidance such as the "proportionate approach" to ethics review (p. 9) and a chapter dedicated to qualitative research (Chapter 9), Van den Hoonard and Hamilton (2016) offer the perspective of social science researchers who argue that the biomedical and clinical roots that legitimately drove highly scrutinized research ethics policies and reviews for individual participants are often inappropriately applied to other disciplines, and qualitative research in particular. I elaborate on this challenge in the next section on disentangling the practice/research distinction.

#### 3.4.2 QI on the ethical map: disentangling the practice/research distinction.

When QI emerged in the health care sector in the 1980s, QI activities fell under the domain of practice/clinical ethics and were seen as simply part of care provision. As such, the interests of people immediately involved in QI activities (typically health care staff, and to a lesser extent patients and families) were seen to be upheld by professional codes of ethics, privacy laws and consent laws rather than requiring particular ethical scrutiny; scrutiny that *is* required in the research activities as I described above (see Section 2.2.3.2). However by the early 2000s, QI methods became more sophisticated and "scientific" (for example, using cluster designs and randomization, altering standard practice, and collecting systematic data (World Health

<sup>&</sup>lt;sup>62</sup> Between the years 1982 and 1995, Nuu-chah-nulth First Nation provided a UBC researcher with blood samples for DNA testing to study the high incidence of rheumatic disease, an area of concern in their community. Years later, the community learned that the researcher relocated to different universities in two different countries, had taken the specimens with him, and had conducted research that was not part of the original consent. In response, the Nuu-chah-nulth-aht developed research protocols that were responsive to context of their unique communities (Arbour & Cook, 2006; Dalton, 2002; Nuu-chah-nulth Tribal Council Research Ethics Committee, 2008).
<sup>63</sup> Boilevin et al. (2019) released "A Manifesto for Ethical Research in the Downtown Eastside" to share local knowledge and expertise on community ethics. The report outlines the pitfalls and the potential of research in Vancouver's Downtown Eastside, and advocates for a Community REB. These authors position research as a "tool of colonialism", and state that university-based REB members "might be using ideas of 'risk' that make more sense to middle or upper class, white, settler folks than they do to community members" (p. 12).

Organization (WHO), 2013a, p. 13), and thus QI projects began to resemble traditional research activities (Baily et al., 2006, 2006; Bellin & Dubler, 2001; Casarett et al., 2000; Kofke & Rie, 2003; Lynn et al., 2007). Over the past twenty years, research, QI, and practice are perceived as being increasingly intertwined (World Health Organization (WHO), 2019).

Significant attention has been given to the issue of whether a particular QI activity integrated into routine care is more like practice because it incorporates "proven" practice changes at the local level, or, whether the particular QI activity is more like a research activity that tests changes and systematically collects data – one of the hallmarks of research. Furthermore, some QI activities seemed to be contributing to generalizable knowledge<sup>64</sup> (another hallmark of research) because results were published, which foregrounds the question of whether the activities were designed to help patients, to generate new knowledge, or both. These changes in the nature of QI as a field have made it increasingly difficult for practitioners and oversight bodies alike to distinguish QI from research activities, and therefore to comply with the ethical oversight rules in place to protect individuals and institutions.

In Chapter 2 (Section 2.2.3), I outlined the rationale for the initial practice/research distinction in the 1970s, which flowed from pressure to protect research participants. Introducing systematic QI activities into health care more clearly illuminated a competing interest; that of the health care organizations undertaking QI to "serve the interests of the individuals who are cared for in these

<sup>&</sup>lt;sup>64</sup> James Anderson (2010) argues that as a concept, generalizable knowledge suggests a "decontextualized picture of knowledge and knowledge seeking" that is in itself problematic (p. 48). Anderson's critique would seem to apply to both research and QI.

same organizations" (World Health Organization (WHO), 2013a, p. 11). Health care ethicists including (Baily et al., 2006; Grady, 2007; Lynn et al., 2007, p. 667) argued that along with health care organizations' and systems' notions of service and the obligations to improve quality, came an interest in whatever motivated the QI effort. For example, health care improvements can be driven by efficiency, regulatory and/or accreditation reporting purposes (Stein, 2002; World Health Organization (WHO), 2013a, p. 11). Therefore, ethicists posed new questions concerning whether QI could threaten to interfere with, or put at risk, something that current patients are owed as part of their normal, routine health care.

# 3.4.2.1 The catalyst: The Michigan Checklist Study.

A pivotal catalyst to the discussion on how QI fits into health care ethics oversight structures was what I refer to as the "Michigan Checklist Study". In 2006, Peter Pronovost and colleagues published results of their intervention to reduce life-threatening infections in intensive care units across Michigan<sup>65</sup> in the *New England Journal of Medicine*.<sup>66</sup> A Johns Hopkins University IRB determined the project to be QI, and thus as a non-research activity it was exempt from ethics review (H. A. Taylor, Pronovost, & Sugarman, 2010). An anonymous whistleblower accused the project leaders of conducting the study without having received appropriate ethics review. As a result, the Michigan Checklist Study became the target of an Office for Human Research

<sup>&</sup>lt;sup>65</sup> The six components of the Michigan Checklist Study intervention implemented as a "bundle" were: (1) clinicians were educated about practices to control infection and harm resulting from catheter-related bloodstream infections; (2) a central-line cart with necessary supplies was created; (3) a checklist was used to ensure adherence to infection-control practices; (4) providers were stopped (in nonemergency situations) if these practices were not being followed; (5) the removal of catheter- related bloodstream infection at monthly and quarterly meetings. (Pronovost et al., 2006, pp. 2726–2727)

<sup>&</sup>lt;sup>66</sup> As of July 14, 2020, Pronovost et al.'s *NEJM* article has been cited 2,433 times in the Web of Science Core Collection.
Protections (OHRP) investigation that sparked extensive discussions in the medical and bioethics literature (Baily, 2008; Kass et al., 2008; Kuehn, 2008; Miller & Emanuel, 2008; Savel et al., 2009; H. A. Taylor, Pronovost, & Sugarman, 2010) as well as the mainstream media (Gawande, 2007a, 2007b).

The ensuing discussion about the Michigan Checklist Study was an important one that exposed the ambiguous ethical status of QI, particularly the complexity of differentiating QI from research activities according to current regulations and guidelines. The two central questions were: (1) Should the IRB have classified the project as research, requiring it to undergo research ethics review from each of the 70 hospital IRBs?;<sup>67</sup> and (2) Should patients and care providers have given informed consent for data being collected after introducing a checklist, given that the procedures addressed in the checklist had already proven to be safe? In response, Baily (2008) stated:

You know you are in the presence of dysfunctional regulations when people can't easily tell what they are supposed to do. Currently, uncertainty about how the OHRP will interpret the term "human-subjects research" and apply the regulations in specific situations causes great concern among people engaged in data-guided activities in health care, since *guessing wrong* may result in bad publicity and severe sanctions. (p. 768 *emphasis added*)

These discussions also raised important concerns about what was considered research; the unintended consequences that ethical oversight mechanisms could have on patients and health care systems, such as slowing down and therefore undermining necessary efforts to improve health care services and prevent harm; and what type of ethical oversight was appropriate for various activities (Baily, 2008, p. 768; Kass et al., 2013; Miller & Emanuel, 2008, p. 766;

<sup>&</sup>lt;sup>67</sup> In an interesting paradox, Pronovost and his research team were granted an IRB exemption for the "QI study" yet *NEJM* published their results as "original clinical research."

Nicholls et al., 2019). Furthermore, despite attempts to disentangle the practice/research distinction, Kass et al. (2013) claim that "the research-practice distinction leads to overprotection of the rights and interests of patients in some cases and to underprotection in others" (p. S5). At present, questions and concerns continue regarding how the range of learning activities (e.g., research, QI, program evaluation, pragmatic trials) are conceptualized, labelled and evolve, and how they fit into current ethical oversight mechanisms.

#### 3.4.3 Ethical models/frameworks for QI.

Since the Michigan Checklist Study, many authors (for example, Dixon, 2017; Faden et al., 2013; Fiscella et al., 2015; C. E. Goldstein et al., 2018; Hagen et al., 2007; Kass et al., 2013; Klingler et al., 2020; Lynn et al., 2007) have put forth rationales and models for ethical oversight of QI (usually grouped with other 'non-research' activities such as program evaluation). In this section, I briefly outline two well-known models; (1) the project ethics approach, and (2) the learning health care system approach.

The first model involves a separate ethics process for QI projects (Babalis et al., 2011; Dixon, 2017; Hagen et al., 2007; Lynn et al., 2007) that requires first sorting QI from research.<sup>68</sup> In the mid 2000s, the Alberta Research Ethics Community Consensus Initiative (ARECCI, now named

<sup>&</sup>lt;sup>68</sup> Hall et al. (2020) provide a Canadian summary of popular tools to sort QI from research (p. 65). Examples of the many guidelines to assist with this sorting process include: (1) ARECCI's *Ethics Screening Tool* (Alberta Innovates, 2017b) (see Appendix C); (2) US Office for Human Research Protections' *Human Subject Regulations Decision Charts* (U.S. Department of Health and Human Services, 2016); (3) UBC's *Checklist for quality improvement/quality assurance/program evaluation/ curriculum development studies requiring ethical review* (UBC Behavioural Research Ethics Board, 2011); and (4) Ogrinc et al.'s *Instrument to differentiate between clinical research and quality improvement* (2013).

A pRoject Ethics Community Consensus Initiative) was struck to guide the health care community on the research/QI dilemma (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2005). The ARECCI group developed two ethics decision-support tools: the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2017b), which helps to determine the ethical review stream (i.e., research or QI) and ethical risks of a particular project (see also Appendix C); and the *ARECCI Ethics Guideline Tool* (Alberta Innovates, 2017a), which helps project teams consider the ethical implications of QI.

The second model, proposed by a group of US ethicists (Faden et al., 2013) incorporates an Ethics Framework for a Learning Health Care System approach. This framework applies a common ethics framework across the range of activities aimed at generating knowledge to improve health care and safety. Importantly, this model rejects the justification to distinguish research and non-research activities on the basis that the distinction has no moral or scientific basis (Faden et al., 2013; Kass et al., 2013). For example, the authors challenge the assumptions that care providers in clinical practice make treatment decisions solely to advance the welfare and interests of each patient (Faden et al., 2013, p. S20), and that routine care is safer, less risky, with fewer burdens – when in fact many 'routine' therapies, tests and interventions are of unproven value and may actually be harmful (Kass et al., 2013, p. S8). The authors argue that bringing all learning activities under one ethical umbrella changes these basic assumptions about perceived ethical differences between practice and research activities (Kass et al., 2013) and thus represents a paradigm shift. Another interesting element of the Learning Health Care System framework is the obligation of patients to "contribute to the common purpose of improving the quality and value of clinical care and health care systems" (Faden et al., 2013, p. S18) in such a

way that prevents off-loading of responsibilities that are not necessarily positive or equitable. This obligation reflects other proposals for reciprocity within civil society (Council of Canadian Academies, 2015, p. 89). In chapters 7 through 9 I discuss patient/family obligations to participate in QI activities in the context of my findings.

As I have noted above, in Canadian health care organizations QI activities (and other forms of systematic inquiry to inform changes in local practice/policy) are not considered research, and as such are not required to undergo REB review unless the project contains an element of research (Canadian Institutes of Health Research et al., 2018, Article 2.5). Notwithstanding progress studying these issues, ethical assessment for QI activities is often suggested, but is not a requirement or norm in BC's health authorities,<sup>69</sup> in Canada, or beyond (BC Patient Safety & Quality Council, 2019; Flaming, 2017; Nerenz, 2009; H. A. Taylor, Pronovost, Faden, et al., 2010; H. A. Taylor, Pronovost, & Sugarman, 2010). Some exceptions in Canada include: (1) BC's Interior Health Authority;<sup>70</sup> (2) BC's First Nations Health Authority;<sup>71</sup> and (3) Public Health Ontario's learning health care ethical process (Klingler et al., 2020; Ondrusek et al., 2015; Willison et al., 2014). In addition, authors from Canada and other jurisdictions have reported that activities labelled as QI undergo REB review on an ad hoc basis for reasons such as uncertainty

<sup>&</sup>lt;sup>69</sup> In this context "health authorities" in British Columbia refer to structures responsible for delivering health care services to the public on a regional or province-wide basis (BC Ministry of Health, n.d.-b).

<sup>&</sup>lt;sup>70</sup> Interior Health (2014) has a policy requiring ARECCI Decision Support Tools for every QI project involving "people and their private information" (p.1).

<sup>&</sup>lt;sup>71</sup> First Nations Health Authority's (n.d.-a) 7 Directives emphasize "Community-driven and Nation-based", and the "First Nations principles of Ownership, Control, Access and Possession (OCAP®)" guide a form of ethical review for both research and QI projects.

or to satisfy requirements of academic journals (see, for example Ezzat et al., 2010; Jeffrey et al., 2019; Patel et al., 2013; Patenaude et al., 2008)

## 3.4.3.1 Questions about ethical frameworks for QI.

In what follows I briefly outline several of my observations that spurred my initial interest in this study regarding characteristics of patienthood in the context of QI activities. These observations include the need to examine areas such as the focus on *risk* (e.g., ex ante "risk screening", and the use of "minimal risk" terminology), a feature of health research ethics oversight that has been applied to newer ethical frameworks for QI. Potential downsides of taking on similar notions of risk (harms and burdens) include that: (1) such an overemphasis on risk of harm may not fully consider the benefits to which current (and future) patients are potentially being denied from successfully implemented QI activities (Jardine, 2008); and (2) the new models may replicate one of the flaws identified by McDonald, Cox et al. (2014) and others: ex ante expert notions of participants' experiences are not the same as adequate accounts of actual participant experiences. On the other hand, advantages of applying a health research ethics approach are that this approach aligns with the procedural REB model familiar to many health personnel, and may offer a valuable contribution to maximizing benefits and minimizing risks to stakeholders in QI, including patient/family participants.

Building on my discussion of harm in Section 2.4.3.2, I note that Paul Slovic (1999) argues that because risk is socially constructed (meaning shaped by, for example, psychological, social, cultural and political factors), "Whoever controls the definition of risk controls the rational solution to the problem at hand" (p. 699). This means that an ex ante assessment of risk without reconciliation of actual experience raises important questions such as: Whose ethics? Who defines risk? Who defines harm? Who has control? In QI and patient safety, a strong focus is on changing care processes and provider behaviours. As I have explained above, patients and families are also key stakeholders in quality, safety and QI. For example, some hand hygiene programs involve asking patients to document if staff used proper hand hygiene (Canadian Patient Safety Institute, n.d.-c). Questions to ponder include, when patient partners are included on QI project teams, do these individuals have the same perspectives about risk and benefits as the patients/families who are actually impacted by the QI activities? Moreover, it is unclear whether existing processes for QI implementation adequately contemplate ethical issues of import to patients/families, such as: if the QI activity will change their access either to the QI or routine care; how patient/family data will be represented and shared; if patient choice will be respected; and how other areas of their health and health care could be impacted. Overall, as a result of the concerns I have raised regarding the voluntary nature of ethical assessment of QI, I find it troubling that QI activities are not more fully evaluated for efficacy or impacts on patients/families, staff, and organizations.

#### 3.5 Summary of Literature Framing Patient/Family Experience of QI

In this chapter I summarized health care QI as a vital tool in health care that originated from industry and aims to improve the quality of health care at the systems level. Key characteristics of QI include organizational leadership, frontline engagement, and process and provider-focused interventions implemented as rapid leaning cycles, and measurable results. The main issue I have addressed in this review is the failure to grasp the ethically significant issues (strengths and tensions) that arise in health care QI from the perspective of patients and families, and how these gaps in knowledge have potential to improve health care. Moreover, I have noted that patient and family experiences of QI interventions at the point of care are poorly understood, especially from a values-based perspective. Of particular concern is the subset of QI interventions that require patients/families to take on additional burdens and/or assume new roles requiring them to enact more agency in health care interactions. When patient experience data regarding QI initiatives is gathered, it is often quantitatively-focused and superficial. That there continues to be a paucity of robust evidence about how patients and families experience QI reflects a deeply embedded bias in health care that QI generates positive benefits, even though the criteria for innovation have often not been met. In addition, this bias leads to not fully exploring potential downsides for patients and families at the point of care – care contexts with known burdens, asymmetries of power in a hierarchical system, and competing interests at stake.

At the same time, at the health care system level, QI is assumed to be ethically unproblematic, given that the implementation of QI interventions does not generally require formal ethical attention, or oversight, or explicit informed consent from patients/families or staff. In practice, then, patients and families often are unaware that QI interventions are being tested as part of their hospital care. Therefore, the many quality and safety initiatives ongoing in health care systems in Canada and worldwide may introduce potentials for benefits, burdens and/or harms without sufficient clarity about their distribution, as well as other relevant ethical issues for patients/families such as feeling respected. Furthermore, despite some encouraging progress, as a result of suboptimal sustainability of QI initiatives, insufficient learning, and varying levels of ethical attention, we may unintentionally be achieving lower levels of improvement, causing harm, wasting scare resources and/or entrenching disparities.

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In conclusion, involving patients and families in QI at the point of care raises ethical questions about unexamined wider impacts on this stakeholder group, some of whom may be in situations of significant vulnerability. The dearth of research into patient/family experiences of QI is a problematic gap in the literature, and poses tensions between competing goals to improve the individual experience of care, improve population health outcomes, and reduce costs. Thus, there is an urgent need to explore and understand these wider impacts using a values-based ethics lens to study patients' and families' perspectives. In Chapter 4, I describe the theoretical structure grounding my research to explore how patients and families experience health care QI interventions in the power-laden situational contexts in which these experiences occur.

## **Chapter 4: Theoretical Structure**

#### 4.1 Chapter Overview

In Chapter 4, I describe the theoretical structure that I have chosen to address my research questions and frame this applied ethics research. The purpose of outlining the theoretical perspective informing any study is to "explain how it provides a context for the process [of design and analysis] and grounds its logic and criteria" (Crotty, 1998, p. 7). Reeves et al. (2008) further explain that theory helps make sense of a complex social reality. Thus, in my study I outline the theoretical structure to study patient and family experience in the context of QI implementation at the point of care.

In what follows I explicate my constructionist epistemological orientation for the purpose of this research, a view that people socially construct all knowledge and all reality (Crotty, 1998, p. 42). I then discuss this orientation in relation to my goals: to understand patient and family experience and create new knowledge for others to apply in practice. I position constructionism in relation to alternative epistemological perspectives. I also explain why the concept of *context* is a significant aspect of this study, specifically in relation to patient/family experience, the implementation of quality QI, and ethics. To articulate context and its role at the intersection of human experience, QI, and ethics, I then argue why *values-based* framing to study patients and families, as moral agents in context, is an understudied approach to exploring experiences of QI interventions at the point of care. I link the need to acknowledge context and values-based framing with contextual ethical theory.

In Figure 4.1 I provide an illustration of *relational ecological theory*, the theoretical framework I developed to represent my interpretation of the key theories informing my study and the relationship between them. A theoretical framework is defined as, "any empirical or quasi-empirical theory of social and/or psychological processes, at a variety of levels (e.g., grand, mid-range, and explanatory), that can be applied to the understanding of phenomena" (Given, 2008, p. 871). First, I explain why I used Doane and Varcoe's (2013, 2015) values-based *relational inquiry* (context, power) as one key approach. Then I describe how Bronfenbrenner's (1979, 1993) *ecological systems theory* (micro, meso, exo, macro, chrono) enhanced my contextual inquiry of patient and family experience of QI.



Figure 4.1 Study theoretical framework: Relationship between relational and ecological theories emphasizing the role of context to study patient and family experience of QI.

#### 4.2 Assumptions About the World: A Constructionist Epistemological Orientation

In this discussion of theoretical structure I begin by acknowledging the grounding assumptions about reality ("a way of understanding and explaining how we know what we know" (Crotty, 1998, p. 3) that I brought into this dissertation. Guba (1990) situates assumptions as reflecting a world view and a "basic set of beliefs that guides action" (p. 17). Guba and Lincoln (2005) subsequently articulate four fundamental philosophical dimensions that, together, define an inquiry paradigm:

- "What is the nature of ethics?" (p. 200). What roles do human subjectivity, context and values play in the logic of inquiry and generating knowledge? What is of value to us? (axiological);
- "What is the nature of reality?" (p. 200) (ontological);
- "What is the nature of knowledge and the relationship between the knower and the would-be knower?" (p. 200) (epistemological); and
- "How can the knower go about obtaining the desired knowledge and understandings?" (p. 200) (methodological).

Social research scholar Michael Crotty (1998) defines constructionism, the inquiry paradigm I use in this study, as: "the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (p. 42).<sup>72</sup> As a researcher, I situate myself in this study within a constructionism-oriented theory of knowledge because it positions me to interpret how patients/families construct their experiences of QI. In claiming a constructionist orientation, I implicitly reject alternative epistemological

<sup>&</sup>lt;sup>72</sup> As a point of conceptual clarity, I draw from Crotty (1998) and Burr (2015) to distinguish construct**ion** ism (defined above) from construct**iv** ism, "primarily an individualistic understanding of the constructionist position" (Crotty, 1998, p. 58). Many authors appear to use these two terms interchangeably and inconsistently in the literature (see for example (Creswell, 2013, p. 61). However, the distinction is an important one because different assumptions about reality "give rise to different research programmes, address and solve different types of research questions" (Talja et al., 2005, p. 92).

Construct*iv*ism focuses exclusively on "the meaning-making activity of the individual mind" (Crotty, 1998, p. 58), viewing the agent as more in control of this construction process (Burr, 2015, p. 22). On the other hand, construct*ion* ism fosters a critical spirit. Constructionism focuses on how structural or interactional social forces, such as power arrangements, collectively generate and transmit meaning (Burr, 2015), emphasizing "the hold our culture has on us" (Crotty, 1998, p. 58).

perspectives such as foundationalism (objectivism) and relativism (subjectivism) for this study. In Figure 4.2, I illustrate constructionism in relation to these alternative perspectives.<sup>73</sup>



Figure 4.2 Where my study fits on an epistemological continuum of research perspectives.

Constructionism can be contrasted with a foundationalist<sup>74</sup> perspective, as constructionism is based on the assumption that "there is no theory-free knowledge and, accordingly, no foundation on which to adjudicate different claims to knowledge. This means that no interpretation or construction of reality can be judged as uniquely right or wrong" (Given, 2008, p. 460). Constructionism is also distinguished from relativism<sup>75</sup> in that relativism does not provide grounds for inter-subjective knowledge and value claims, thus leaving researchers without grounds for collective action. In adopting a constructionist perspective in this study, I claim that it is possible to describe and interpret the significance of personal meaning relative to a specific

<sup>&</sup>lt;sup>73</sup> Figure 4.2 draws on the work of Lincoln and Guba (2000), who are known for their work articulating competing paradigms in qualitative research (in particular, see tables 6.1 and 6.2). Guba and Lincoln use the term constructivism in their tables comparing aspects of different paradigms. As explained above, in this study I use the term constructionism.

<sup>&</sup>lt;sup>74</sup> Smith (in Given, 2008, p. 460) describes foundationalism whereby knowledge claims are based on a 'foundation' of interpreting the reality of the world from a privileged position.

<sup>&</sup>lt;sup>75</sup> Burr (2015) describes relativism whereby knowledge claims are 'relative' to something else, and "the view that there can be no ultimate truth, and that therefore all perspectives are equally valid" (p. 238).

context (e.g., a particular setting and time) (Given, 2008, p. 750), while allowing for a critical approach (considering social structures such as attitudes and power, positionality, representation, and the production of situated knowledges (Bhavnani et al., 2014). This approach describes a modified or critical realism perspective; one that is neither realist nor antirealist (Burr, 2015, p. 9; Crotty, 1998; Thorne, 2016, p. 56).

My constructionist perspective in this study also reflects Vivien Burr's (2015) four key assumptions: "a critical stance toward taken-for-granted knowledge; historical and cultural specificity; knowledge [...] sustained by social processes; and knowledge and social action together" (pp. 2–5). The link between context and action in constructionist epistemology aligns with two aspects of my study purpose: to understand the phenomenon of patient and family experience of QI interventions; and to apply these new understandings to improve the efficacy and ethics of QI in practice.

#### 4.2.1 Understanding patient and family experiences.

My understanding of *patient experience* as a concept was shaped by two well-known advocates, Paul Bate and Glenn Robert (2007), who seek to understand patient experiences and then to use this new knowledge to improve the quality of health care services. In describing their concept of patient experience, Bate and Robert (2007) suggest that it is necessary to appreciate and understand the way patients make sense of and construct meanings about the health care they receive, both cognitively and emotionally. These constructed meanings, moreover, affect patients' attitudes, perceptions, behaviour, and, most specifically, the enactment of their values. A constructionist view assumes people *make sense of* and *construct meanings* "as they engage with the world they are interpreting" (Crotty, 1998, p. 43). Research scholar Sally Thorne (2016) also describes *constructed meaning* in the context of interpreting experiences: "apprehending experience as reflected in the perspective of others, while simultaneously accounting for the (very real) cultural and social forces that may have shaped that perspective" (p. 55). Similarly, Bate and Robert (2007) describe the process of studying patient/family experiences as "trying to make sense out of how other people make sense" (p. 35). In other words, two levels of 'constructing meaning' are involved: with this in mind, I employed constructionism-oriented theory in support of my research to make sense of and construct meanings about patients and families, and, in turn, to construct meanings of QI interventions.

#### 4.2.2 Towards applying new knowledge in practice: the importance of context.

Applied researchers in the practice disciplines, including health care administration, have an obligation to consider the contexts in their research in order to increase the likelihood that findings can benefit real-world clinical contexts with all of their "inherent social, political, and ideological complexities" (Thorne, 2016, p. 57). In my study, a constructionist approach allowed me to interpret experiences of personal meaning during specific QI interventions by linking context and action. Similarly, Bate (2014) notes that contextualizing inquiry is important because: (1) meaning and action can only be described and interpreted in relation to the complex contexts in which they occur; and (2) contextualizing inquiry can allow people working in health care to "see the familiar in unfamiliar ways" as well as "see the unfamiliar in familiar ways" (p. 26).

Increasingly, both philosophers and scientists acknowledge the need to contextualize inquiry (Bate, 2014, p. 8). Yet much of health care research and practice has traditionally been presented as acontextual, reflecting the positivist theoretical perspective of an objective reality. Research processes such as "bracketing" (Bate, 2014, p. 4) and "controlling for" (Thorne, 2016, p. 34) help to identify which factors, variables, events, processes (etc.) are relevant for a study. Context – and related terms such as environment and setting – are often used interchangeably and with a wide array of definitions that tend to lack specificity (Bronfenbrenner, 1979; Ovretveit, 2014).

While I approached this study realizing that contextual inquiry was crucial for my purpose, I acknowledged that I did not know (or fully know) the context at the outset, or what the impacts of the various contexts would be, or what features of context were ethically significant (Greenhalgh & Papoutsi, 2018; McLaren & Hawe, 2005, p. 7; Ogrinc et al., 2016; Robert & Fulop, 2014, p. 56; Thorne, 2016, p. 141). This is not to say that I subscribed to a fully relativist view; rather, I adopted an epistemological middle ground (see Figure 4.2), acknowledging that each person has their own unique life experiences (Cox & McDonald, 2013, p. 226), and "as well as being a social thing, 'context' is also a very personal thing [and] there is no common or universal set of contextual interpretations shared by everyone" (Bate, 2014, p. 8). In the sections that follow, I explain the relevance of context for the three main conceptual themes in this study, illustrated in Figure 4.3.



Figure 4.3 Context in relation to the three main conceptual themes in this study.

## 4.2.2.1 Context in relation to patient/family experience.

A *patient's or family member's experience of* health care is the first key aspect of context in this study. As a researcher, health care consultant and patient/family member, I have some understanding of the meanings patients/families draw from their experiences as shaped by the unique life of each patient and that individual's surrounding environments (Doane & Varcoe, 2013, p. 150). Moreover, based on my extensive review of the literature and on information gathered within different health care settings, I have learned that many diverse factors contribute to how patients/families experience their situations. Some scholars have cautioned that without formal contextual inquiry research methods, "…experience research is actually little more than a conversation that anyone might have had, … words and stories without analytic frameworks do not speak for themselves" (Bate & Robert, 2007, p. 32). Context in relation to personal experience, according to Doane and Varcoe (2013), ought to consider, "those elements that cue certain behaviours and responses, for example [often] health care contexts contain strong messages about what is not of importance, driven by economic and cost-efficient values" (p. 151).

Travaglia & Robertson (2018) state, "measuring CQI from the patient perspective is more complicated than it may initially appear. It is also clear that patient experiences, satisfaction included, can be highly individual, contextual, and fundamentally phenomenological in character" (p. 208). However, as noted in Chapter 3 (Section 3.3.1), reports of patient and family 'experiences' of QI at the point of care, as described in much of the literature, tend to be superficial or lack context. As I will describe in Chapter 5, in my study I made an important distinction from typical patient and family experience studies of QI by studying patient and family experiences of the implementation of a QI intervention in real time, at the point of care. Calabrese (2013) emphasizes the significance of such research, noting that if we are to "explor[e] health experiences in their natural context [then] we can learn important things from paying attention to those contexts" (p. 20). For example, patients and families could describe their experiences of the QI intervention as they happened and in the context of their current circumstances, rather than describing more distantly past experiences, thus improving the reliability of their reports.

## 4.2.2.2 Context in relation to implementation of QI.

The second aspect of context relevant for my research relates to *the implementation of QI* interventions within the complexity of dynamic health care settings. In Chapter 3 (Section 3.2), I noted that much of the quality and safety literature frames QI interventions as temporary, tentative, changeable or adaptable, in transition, unpredictable, and highly sensitive to the local conditions of the particular health care context. For example, see (G. R. Baker & Black, 2015; Illingworth, 2015; May et al., 2009; National Patient Safety Foundation, 2015; Pronovost et al., 2015; Wachter, 2010; Wachter & Pronovost, 2009). My main interest in this study was regarding

how the contextual features of QI project implementation may be shaping patient and family experiences of QI and health care more generally.

## 4.2.2.3 Context in relation to health care ethics.

The third aspect of context relevant for my research is in relation to *health care ethics*. In Chapter 2 (Section 2.2.4), I described contextual approaches to ethics and the sociopolitical complexity, which Rodney, Burgess, Pauly, et al. (2013) note is "necessary if those of us engaged in health care ethics are to better understand and deal with the complex sociopolitical climates in which health care is delivered and in which resources for health are embedded" (p. 96). Similarly, Varcoe et al. (2012), analyzing moral distress among care providers, observe, "it is evident that the extent to which context is considered in understanding moral distress is crucial" (p. 52). And, the *Tri-Council Policy Statement* (2018) explicitly mentions the intersection of context and ethics, stating that "It may be necessary to consider the various contexts (e.g., social, economic, cultural) that shape the participant's life, to properly evaluate the implications of the research in terms of the core [ethical] principles" (p. 10).

As an extension of context in relation to health care ethics, this study is concerned with patient and family experiences and *moral agents acting in context* (Doane & Varcoe, 2013; Rodney, Kadyschuk, Liaschenko, et al., 2013; Sherwin & Feminist Health Care Ethics Research Network, 1998). The agents of focus are the patient and family and their experience of care in relation to a new QI intervention. A *moral agent* in this study is defined as an individual situated in specific contexts, with the capacity to direct their actions to some ethical end (adapted from Storch, 2013, p. 10).<sup>76</sup> Agents are seen as interacting with *structures*, described by William Sewell (1992) as, "sets of mutually sustaining schemas and resources that empower and constrain social action and that tend to be reproduced by that social action" (p. 19). In other words, having agency means having the capacity to make free choices and to act upon them (Burr, 2015, p. 235; Rhodes et al., 2016, p. 279). Given the dynamic nature of the agent–structure relationship, in order to understand human experience of a phenomenon, I needed a contextual approach to ethics to obtain a deeper understanding of patients and family members as embodied<sup>77</sup> individuals, not just abstract moral actors. Taken together, these understandings emphasize the importance of context in this study as a significant aspect of my theoretical framing. In what follows, I argue why values-based framing is also needed in this study, and I explain the theories I selected to guide my exploration of values in context.

#### 4.3 Need for Values-Based Framing

Studying patient/family roles in QI and health care raises significant values-based questions and tensions. In the context of my study, central questions about experiences of QI related to moral agency and structures included: what perceptions and realities shape a patient/family or care provider's ability to choose to participate in a QI intervention, or to decline to participate, and to then act on this intention? What considerations influence a patient's or family member's

<sup>&</sup>lt;sup>76</sup> In a recent Institute for Healthcare Improvement (IHI) paper, Hilton and Anderson (2018) further describe agency: "**Agency** is defined as the ability of an individual or group to choose to act with purpose. Agency has two key components: 1) **power**, or the ability to act with purpose; and 2) **courage**, or the emotional resources to choose to act in the face of difficulty or uncertainty. Together, courage and power are the primary drivers for activating people's agency, or the ability of an individual or group to choose to act with purpose." (p. 7)

<sup>&</sup>lt;sup>77</sup> Referring to, for example, an individual's age, gender, sexual orientation, ethnocultural background, socioeconomic status and/or health status.

willingness to engage or intervene in their own health and health care, or that of a loved one? How do interactions between family members and care providers shape decision making on behalf of patients? How do fiscal pressures impact patient/staff ratios in hospitals? What kinds of QI initiatives get prioritized – those with a focus on health outcomes, cost savings, patient/family experience, staff experience, a combination of these, or something else? Such questions highlight the importance of values in this study, and it was therefore essential for me to attend not only to ontology and epistemology, but to the issue of *axiology*. Attention to axiology is a relatively new way of conceptualizing inquiry, and reflects a growing understanding that different values and preferences shape human experience (Guba & Lincoln, 1994, 2005; Heron & Reason, 1997; Lincoln & Guba, 2000). An explicit linkage to values-based inquiry proved to be highly important for my study of patient and family experiences in the context of QI.

Values-based questions that may arise during research, such as those listed above, suggest that tensions in the agency/structure relationship can be productive. QI can be positive if an intervention results in improvement through balancing the *Triple Aim* of health care system improvement (Berwick et al., 2008). Yet, as I noted in Chapter 2 (Section 2.3.2) one frequently mentioned tension is that of cost savings – a commonly stated, and sometimes feared objective of health care QI efforts (Dixon, 2017, p. 20). This inherent tension in the agency–structure relationship can be problematic if one goal is compromised (such as patients' trust in care providers) at the expense of another (such as a hospital's fiscal accountability). Philosopher Richard Rorty's (1999) perspective is closely aligned with this type of ethical thinking, and reinforces the health care ethics imperative to focus on *values* in addition to the idea of economic *value-added*. For example, if individuals (patients, families, and/or care providers, administrators

and other health care staff) are put in positions where they make decisions that are not consistent with their values and preferences, they may suffer loss of meaningful agency.

#### 4.3.1 Enhancing existing ethical frameworks through values-based inquiry.

As described in Chapter 3 (Section 3.4), ethical frameworks applied to QI projects do exist, and seem to be based on the four prima facie bioethics principles, which are modelled after reviews of research projects. And yet, despite the values-based questions that (ought to) arise when QI interventions are integrated into patient care, ethical inquiry into patient/family *experience* of this 'improvement' remains undertheorized and limited. Given my commitment to studying agents enacting values in context, I aim to enhance what we understand about applying axiology and forming questions about how core ethical principles and ethical constructs emerged in my data regarding the QI intervention and patients' and families' experiences of care.

#### 4.4 Theories Employed to Study Values in Context

Applying relational inquiry and social ecology together as a guiding *relational ecological theory* allowed me to explore values and contextual levels of influence in my study of patient and family experiences of QI in a way that is consistent with constructionist epistemology and axiological aims. This theoretical framing still allowed for inductive data description, analysis and interpretation. In what follows I review these two theoretical approaches.

#### 4.4.1 Relational ethical theory: Key relational terms.

In defining three terms that convey my relational ethics perspective (relational, situational, and sociopolitical contexts) for the purposes of this study, I have drawn on Susan Sherwin's (1998)

feminist analysis of relational ethics, which views people as products of their environment and focuses on power dynamics. As well, I have drawn on other Canadian authors who have written about relational ethics, notably: Françoise Baylis, Vangie Bergum, Gweneth Hartrick Doane, Nuala Kenny, Patricia Rodney, and Colleen Varcoe. Sherwin's view in particular aligns with my interpretation of a constructionist perspective.

First, I use the term *relational* "of, relating to, or characterized by" (OED Online, 2017c) in Sherwin's (1998) broad sense: "the full range of influential human relations, personal and public" (p. 19). It is important to note that my use of *relational* in this dissertation applies beyond interpersonal relationships to a wider range of contextual influences (self/context/others). Specifically, I use the term *relational view* as one that considers the full range of intrapersonal, interpersonal, and contextual relations (Doane & Varcoe, 2013, pp. 150–151; Rodney, 2013, p. 314; Rodney, Burgess, Pauly, et al., 2013, p. 85; Sherwin & Feminist Health Care Ethics Research Network, 1998, p. 19). Second, the term *situational* refers to a person's "situation or situations; dependent on, determined by, or in relation to position, situation, or circumstances" (OED Online, 2018j) "with particular people and particular relationships in particular contexts" (Rodney, Burgess, Pauly, et al., 2013, p. 85). Third, my use of the term sociopolitical contexts is taken from Rodney (2013) and refers to the "ever-widening layers of relationships of power and influence; from the individual through to the global" (p. 314). These sociopolitical (social, cultural, political, and historical) processes are connected to notions of an embodied individual, including aspects such as age, gender, sexual orientation, ethnocultural background, socioeconomic status and/or health status (Doane & Varcoe, 2013, p. 151).

In other words, taken together, the terms relational, situational, and sociopolitical contexts are important because they establish that individuals interpret their experiences via their location within their families, communities, larger society, and so on. Social ecology theory provides a useful analytic adjunct to explore these layers of influence and the different situations in which people, as relational beings and moral agents, find themselves. This in turn informs how different situations and contexts shape human responses, including attitudes, knowledge, and behaviour, and ethical concepts such as autonomy and vulnerability. I argue that a relational inquiry approach, developed in the nursing literature, has been missing from the improvement science literature. In the context of my study, this gap is most apparent in accounts of patient/family experiences of QI, specifically when patients are asked to take on new responsibilities to improve the quality and safety of their health care. In what follows, I elaborate on relational inquiry and describe how, along with social ecological theory, the two theoretical approaches frame this dissertation.

## 4.4.1.1 Relational inquiry.

Theoretical framing that I found to be highly applicable to my study was Doane and Varcoe's (2013) values-based perspective of *relational inquiry*. To engage in relational inquiry, Doane and Varcoe (2015) point to an understanding of the *relational interplay* that occurs at three levels. The authors describe these levels as: intrapersonal (within all the people involved); interpersonal (among and between people); and contextual (the structures and forces that are influencing the situation and shaping the intrapersonal and interpersonal responses) (see Table 4.1).

Analytic lens	Level of Relational Interplay		
	Intrapersonal	Interpersonal	Contextual
Interpretive	How are people making meaning of their situations?	How are different interpretations shaping situations?	How are people variously situated and constituted?
Power	How do relative positions of power shape understanding?	How are power dynamics shaping each interpersonal relationship?	How are social structure and arrangements shaping people, situations, and interpersonal relationships?

 Table 4.1 Doane and Varcoe's interpretation of relational inquiry.

Table 4.1 from © G. H. Doane and C. Varcoe. (2015). *How to Nurse: relational inquiry with individuals and families in changing health and health care contexts.* Philadelphia: Wolters Kluwer. Page 41. By permission from publisher.

Doane and Varcoe's (2013) interpretation of relational inquiry takes "multiple contexts and relationships into account", particularly with regard to health care (p. 144).

As is evident in Table 4.1, Doane and Varcoe apply two analytic lenses. The first is the *interpretive* lens, derived from hermeneutic phenomenological theory of people and their lived experiences, and how those experiences are meaningful and interpreted. The interpretive lens extends Bergum's (2005) ideas about the context of relationships at the individual level. The second analytic lens is the *power* lens, connected to critical theory and feminist ethics. The power lens explores how the power-laden contexts of people's lives shape their experiences and interpretations, similar to Sherwin's (1998) ideas about relational autonomy and relational ethics. Overall, the relational inquiry structure helped me to understand my data in relation to connections with others and within the social, cultural, political and historical processes shaping the specific health care setting (Rodney, Burgess, Pauly, et al., 2013).

#### 4.4.2 Social ecology theory.

As a strategy to facilitate my exploration of the complexity of the sociopolitical contexts in which moral agents were operating in my study, I further theorized contextual layers of influence using social ecology theory. Social ecology draws from natural ecosystems, "composed of all the organisms found in a particular physical environment, interacting with it and with each other (OED "Ecosystem, n.," 2017). Bronfenbrenner (1979, 1993) is one of the pioneers of social ecological models. Bronfenbrenner views "environments" (1993, p. 39) as interactional social contexts of human development and behaviour. With the individual at the centre, Bronfenbrenner (1993) colourfully describes, "The ecological environment is conceived as a set of nested structures, each inside the other like a set of Russian dolls" (p. 39): (1) microsystem (interpersonal relationships with significant individuals and groups); (2) mesosystem (interventions between microsystems); (3) exosystem (social settings in which individual does not have an active role); (4) macrosystem (social forces such as ideologies, values, norms); and (5) chronosystem (time in relation to individual's life course and sociohistorical circumstances).

I chose the ecological (multilevel) framework as a way of operationalizing systems thinking to understand the layers of context and to interpret the dynamic complexity of both patient/family experience and the implementation of QI interventions in health care settings. Social ecological models have had widespread influence on the way psychologists and other disciplines approach the study of human beings and their environments, and are also common in health care including QI.<sup>78</sup> For example, Taplin et al. (2012) state, "The notion that multiple levels of contextual influence affect behaviors through interdependent interactions is a well-established ecological view" (p. 4) in relation to layering in the context of cancer care.

Finally, as an ethical inquiry, social ecology is a useful way for me to examine values in context. As noted in Table 4.1, Doane and Varcoe's (2015) approach reflects social ecology in that it examines layers of relational inquiry. Other ethicists make more direct connections between ethics and ecology. For example, Marck (2013) contends that connections between morality and ecology may allow a deeper exploration of agents in context (p. 225). Bergum (2013, p. 130) integrates ecological layers in stating that an ecological consciousness considers the importance of managing oneself, as well as living together in larger and larger senses of community. The QI intervention case studies utilized in this study (described in Chapter 5, Section 5.5.5) are embedded in a larger societal commitment to goals such as patient safety, patient/family-centred care, and high quality publicly funded health care. During my analyses, I considered environments as contexts of patient/family experience, specifically in relation to pilot QI interventions at point of care. Overall, individuals bring with them their own unique biography and history to interact with different types and levels of context. As I have explicated above, in

<sup>&</sup>lt;sup>78</sup> Examples of social ecology framing in health care include: Greenhalgh's (2009) calls for a wider approach to coping with chronic illness; the IHI's model of patient and family engagement (Carman et al., 2013b; International Association for Public Participation, 2007); Mackintosh et al.'s (2017) depiction of patient and family involvement in decision making (p. 5), and interprofessional models to implement QI (J. K. Johnson & Sollecito, 2018a). Social ecology has also been used to frame accounts of patient experience by describing interactions between patients and their surrounding systems. For example, Ginter and Braun (2014) and M. E. Williams (2016) describe the role of support groups for patients with cancer and their families. Other studies describe the role the built or physical environment plays on patient–provider interaction (for example, see Sweeney, 2008).Ecological perspectives have also been adopted in fields such as epidemiology (e.g., (Baral et al., 2013), health promotion (e.g., (Richard et al., 2011), public policy (e.g., (McGinnis & Ostrom, 2014)), music therapy (e.g., (Crooke, 2015), environmental management (e.g., (Benessaiah & Sengupta, 2014), and animal behaviour (e.g., (Lu et al., 2008).

this study, ecological systems theory informed my inductive understandings of models of health care, applied ethics and relational inquiry, and human experience.

# 4.5 Chapter Summary: Applying *relational ecological theory* to a study of patient and family experience of QI interventions

A priori ethical analytic framing and a constructionist epistemological orientation were major elements of the theorizing that guided my inductive inquiry. In employing relational inquiry and ecological systems theory, I used interpretive and power-based analytic lenses to explore levels of relational interplay operating within the nested social contexts of human development and behaviour. I refer to my unique use of these two frameworks in this study as *relational ecological theory*, illustrated in Figure 4.4.



Figure 4.4 *Relational Ecological Theory*: Doane and Varcoe's (2015) values-based relational inquiry overlaid with Bronfenbrenner's (1993) ecological systems theory.

Note: In Figure 4.4 on page 119, blue denotes level of relational interplay; green denotes analytic lenses (interpretive and power). Figure 4.4 by permission from BMJ Publishing Group Limited. "Ecological perspectives in health research," by L. McLaren and P. Hawe, 2005, *Journal of Epidemiology and Community Health*, 59(1), p. 10. Copyright 2005; Figure 4.4 adapted with permission of © McGraw-Hill Education, from *A topical approach to life span development*, J. Santrock, 4th ed. 2008, Page 33; permission conveyed through Copyright Clearance Center, Inc.

Taken together, these theories serve to organize my subsequent inductive analyses of ways in which moral agents enact or hold back from enacting their values and preferences; the reciprocity between agents and complex sociopolitical structures; and how traditions and interactions at the individual and institutional levels shaped experience and decision making. In my findings and discussion chapters I convey how using a relational ethical approach to guide my analyses of the different layers and connections of context helped me operationalize systems thinking to better understand the role that the QI intervention's implementation – itself a changing entity – was or may have been playing shaping patient/family experience. In this way, the concept *relational* applied beyond interpersonal relationships through and within social ecological levels of influence in order to further explore these layers in relation to my research questions. Indeed, I believe that the theoretical framing I have developed and deployed is a novel approach to studying the complexity inherent in patient and family experience in the context of real-time implementation of a QI intervention at the point of care. In the following chapter, I outline how I implemented the study based on this theoretical framing.

## **Chapter 5: Implementing the Study**

#### 5.1 Chapter Overview

To operationalize the relational ecological theoretical perspective discussed in Chapter 4, I designed a coherent plan to learn how moral agents manoeuvre in complex sociopolitical contexts. In this chapter I describe how I implemented the study. I first describe the qualitative paradigm, and its application through interpretive description methodology and reflexivity. In so doing, I explain why this approach is consistent with the purpose of my research and the theoretical structure. I then describe the actual processes I used to conduct this interpretive description study, which entailed an exploratory phase (e.g., developing a research partnership, selecting case studies) and a data construction phase (e.g., collecting and analyzing study data to come to an understanding of what observed behaviours and interactions meant to those enacting them at both superficial and deeper levels). Finally, I outline strategies I employed to manage data and confidentiality throughout the conduct of my research.

#### 5.2 Orientation to Inquiry: The Qualitative Paradigm

As I indicated in Chapter 4, the qualitative methodological plan outlining the actions I took during this study was informed by answers to a set of interrelated axiological, ontological and epistemological questions. This methodology reflects a world view and set of basic assumptions that guided my inquiry within the qualitative inquiry paradigm (Guba, 1990, p. 17). It is important to note that my qualitative approach is consistent with the *relational ecological* theoretical approach I described in Chapter 4.

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John Creswell (2013), an applied research methodologist, defines qualitative research as follows:

Qualitative research begins with assumptions and the use of interpretive/theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem. To study this problem, qualitative researchers use an emerging qualitative approach to inquiry, the collection of data in a natural setting sensitive to the people and places under study, and data analysis is both inductive and deductive and establishes patterns or themes. The final written report or presentation includes the voices of the participants, the reflexivity of the researcher, a complex description and interpretation of the problem, and its contribution to the literature or a call for change. (p. 44)

Historically, many quantitative researchers deemed qualitative research to be diametrically opposed and inferior to quantitative methods and ways of knowing. Despite this perception, the qualitative paradigm gained prominence in the 1960s and is now increasingly valued as a powerful approach to inquiry in many fields, including in the health and social sciences and implementation science (Boulton et al., 2020; T Greenhalgh et al., 2016). In particular, a qualitative approach provides a structure to discover unanticipated, new or emergent information (Calabrese, 2013). With qualitative researchers and research methodologists adding important contributions to the literature over the several decades since qualitative inquiry first came to research prominence, the usefulness of this important paradigm has become increasingly apparent. In 2013, Creswell (2013) stated that even compared to 10 years previously, "qualitative research today involves closer attention to the interpretive nature of inquiry and situating the study within the political, social, and cultural context of the researchers, and the reflexivity or 'presence' of the researchers in the accounts they present" (p. 45). These characteristics are particularly important in studies such as mine, which are aimed at gaining an understanding of multifaceted processes in complex sociopolitical contexts (Creswell, 2013; Rodney, 2013), including QI (Boulton et al., 2020; Leslie et al., 2014; Ovretveit, 2014).

Several features of qualitative approaches are of particular importance in my study. First, qualitative research attends to the socially constructed element of human experiences (Crotty, 1998), acknowledging that human experiences are part of multiple constructed realities that may vary over time and circumstance (Crotty, 1998), and that appreciation of context is central (McLaren & Hawe, 2005, p. 7). My inquiry therefore captures perspectives at a point in time, and in some cases, trajectories of perspectives over time. Another important feature of qualitative research is the orientation toward collecting data in natural settings that allowed me, as much as possible, to immerse myself in the context in which research participants behave, act, experience and interpret the phenomenon being studied (Creswell, 2013, p. 45; Punch, 2014, p. 126). This immersion exposed me to authentic scenarios so I could collect contextualized data about patient/family experiences of QI at the point of care.

#### 5.3 Interpretive Description Methodology

I chose interpretive description, which is a qualitative methodology developed in the nursing profession by Sally Thorne from the UBC School of Nursing (Thorne, 2008, 2014, 2016; Thorne et al., 1997, 2004). This methodology enabled me to study the patient/family experience of QI at the point of care through a relational ecological set of lenses. Related to his research on the ethics of humanitarian health policy and practice, Hunt (2016) describes interpretive description as "aim[ing] to identify patterns and linkages amongst individuals who have first-hand experience of a phenomenon of interest, while also accounting for variations between individuals" (p. 3). As

with other 'emergent designs',<sup>79</sup> interpretive description works as an iterative cycle of data collection and analysis based on what is learned from study participants and events observed in the field (Canadian Institutes of Health Research et al., 2018; Given, 2008).

In its ancestry, interpretive description draws from three main qualitative traditions originating in the social sciences: ethnography; grounded theory; and phenomenology (Thorne, 2014, 2016, pp. 29–30); all of which have been used to study patient/family experience of health care (Bate & Robert, 2007; Chenail, 2011; Ziebland et al., 2013). In *ethnography*, researchers seek to understand a social or cultural scenario from an insider's perspective, and how people make sense of behaviour within a cultural context (Chenail, 2011; Given, 2008; Punch, 2014). Ethnography has anthropological and sociological origins, and focuses on prolonged fieldwork (direct observation and interviewing) and fieldnotes (Hammersley & Atkinson, 2007; Thorne, 2016, p. 31). Researchers use grounded theory to discover or construct explanatory theory that is grounded in data (Given, 2008; Punch, 2014); and is thus a method of inquiry as well as a product of that inquiry (Given, 2008). Grounded theory has sociological origins, and the integrity of coding data is a central feature. Chenail (2011) describes *phenomenology*, with its philosophical origins, as helping researchers learn "how people make meaning in their lives by examining relationships between what happened and how people have come to understand these events" (p. 1180). In phenomenological studies of patient and family experience, researchers

<sup>&</sup>lt;sup>79</sup> Given (2008) describes emergent design as: "data collection and analysis procedures that can evolve over the course of a research project in response to what is learned in the earlier parts of the study" (p. 245). In my proposal (per Article 10.5 of *TCPS 2* (2014)), I stated I would "consult with the REB when, during the conduct of the research, changes to the data collection procedures may present ethical implications and associated risks to the participants."

typically conduct in-depth interviews focusing on how participants immediately experience a phenomenon, rather than categorizing or reflecting on the phenomenon (Given, 2008) or its context.

As I explain below, researchers in many applied disciplines in health care and human services have increasingly used interpretive description as a methodological framework.<sup>80</sup>

#### 5.3.1 Rationale for selecting interpretive description.

Over the past twenty-two years, interpretive description has evolved as a widely respected methodology to respond in useful ways to questions about "complex experiential clinical phenomena" that arise in the applied disciplines in practice (Thorne, 2008, 2016; Thorne et al., 1997, 2004). Interpretive description projects typically arise from conversations amongst clinicians, and proceed to explore or test practices and processes, with the aim of improving practice (Liska et al., 2018; Polit & Beck, 2012).<sup>81</sup> Thorne (2016) states that when research questions arise in the applied disciplines such as nursing and health care administration, action is often required before a problem is completely understood or even articulated (p. 35). In coming to this research with my disciplinary orientation as a health care administrator, interpretive

<sup>&</sup>lt;sup>80</sup> For example, recent doctoral dissertations using interpretive description include those in counselling psychology (Huminuik, 2017; Rostam, 2013), education (West, 2016), epidemiology (Blair, 2017), medical ethics (Hunt, 2008), and social work (Dotolo, 2017). Other researchers have selected interpretive description methodology to answer ethical research questions about clinical practice. Recent examples include Williams and Haverkamp's (2015) study of eating disorder therapists' perceptions, Bollig et al.'s (2016) study of ethical challenges in nursing homes, and Bélanger et al.'s (2019) study of Québec palliative care physicians' perspectives regarding voluntary active euthanasia.

<sup>&</sup>lt;sup>81</sup> In this way, interpretive description research can be seen to be consistent with the goals of QI, in that QI projects can also arise from conversations amongst clinicians, and proceed with efforts to explore or test practices and processes, with the aim of improving practice.

description was harmonious with my values-based theoretical framing and goals, and enabled me to engage with and join in on an interdisciplinary conversation with published literature.

#### 5.4 Reflexivity in Research

In their guidelines for qualitative research, Cohen and Crabtree (2006), define reflexivity as, "an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process" (para. 1). As well, Berger et al. (2014) describe reflexivity "as a means to monitor the tension between involvement and detachment of the researcher and the researched as a means to enhance the rigor of the study and its ethics" (p. 221). Throughout this study, I maintained an awareness of reflexivity as a critical component of rigorous qualitative research. Reflexivity is both a mindset and a process of reflective practices with the goal of fostering fuller engagement with and analysis of the data (Berger et al., 2014, p. 221).

#### 5.4.1 Epistemological and ethical aspects of reflexivity.

Reflexivity involves "critical reflection of how the researcher constructs knowledge from the research process – what sorts of factors influence the researcher's construction of knowledge and how these influences are revealed in the planning, conduct, and writing up of the research" (Guillemin & Gillam, 2004, p. 275). Reflexivity is typically considered in epistemological terms as a precursor to rigorous research. In keeping with my interest in studying patient and family experience of quality/safety interventions through an ethical lens, ethical aspects of reflexivity were central in this study. As noted by Guillemin and Gillam (2004):

Being reflexive about research practice means a number of things: first, an acknowledgment of microethics, that is, of the ethical dimensions of ordinary, everyday research practice; second, sensitivity to what we call the "ethically important moments" in research practice, in all their particularities; and third, having or being able to develop a means of addressing and responding to ethical concerns if and when they arise in the research (which might well include a way of preempting potential ethical problems before they take hold). (p. 276)

In light of these cautions, I strove to be present and intentional during interactions with

participants and with the emerging data.

## 5.4.2 Role of the researcher.

Recognizing the researcher as a research instrument is a common characteristic of qualitative

research. Given (2008) expands on this role, suggesting:

The researcher brings his or her views, values, beliefs, feelings, and assumptions to the research. When the researcher is the instrument, all of these have an effect on how the research is conducted. In addition, the gender, race/ethnicity, age, sexual orientation, and politics of the researcher will accompany him or her into the research setting. The researcher has a place in the research. That place needs to be made explicit. (p. 737)

That is, a researcher's background always influences the types of research questions asked,

methods chosen, and how and what data are collected, analyzed and disseminated (Berger et al.,

2014). Indeed, Thorne (2016) argues that the researcher as key instrument is legitimate in applied

practice research because the purpose is to convey a phenomenon that can be recognized and

understood by those in the field (pp. 96-97). In this sense, I was the key instrument in this

doctoral study since I was the only person collecting data, as I will explain below.

## 5.4.2.1 Locating myself in the research: Researcher's statement.

As I embarked on this study, I was aware that I had a responsibility to locate myself as the researcher and to recognize my privileges or "cultural capital" (R. Henry et al., 2017, p. 184).

This responsibility aligns with my *relational ecological theory* framework, of which the relational ethics aspect "reminds us to be reflective about our own positionality, and to embrace complexity and diversity" (Rodney, Burgess, Pauly, et al., 2013, p. 96). Thus, as the researcher in this study, the purpose of my "researcher statement" is to convey self-awareness that my biases, values and experiences with the phenomenon may have shaped my interpretation of the complexity of human experience and my construction of study data (Creswell, 2013, p. 216; Dwyer & Buckle, 2009, p. 60; Thorne, 2016, p. 153). Indeed, as described in Chapter 1, this research project originated from experienced-based questions and frustrations that arose during my career as a health management consultant and REB member.

Selecting a relational inquiry approach to guide this study sensitized me at the outset to how relative positions of power, privilege and social structures shape understanding, relationships and situations (Doane & Varcoe, 2013). As a researcher who is a white, settler, middle-aged, middleclass, educated, professional, heterosexual married woman and mother, I was aware that some study participants (patients, family, hospital staff, volunteers) might view me to be in a position of relative privilege and power, and participants might feel much more or less comfortable with me because of these characteristics. Patient and family participants showed me during my research fieldwork how complicated it can be to negotiate the invisible forces of social privilege and power inside relational encounters.

As I engaged with research participants and the data, I understood that participants' willingness to share more – or less – information could depend on their perception of their position in relation to me (Berger et al., 2014). For example, during a lengthy interview, Chloe, a patient-
participant (who will be introduced further in Chapter 6) shared with me how kidney failure and dialysis changed the way she thought of herself as a sexual being. I interpreted this disclosure as Chloe being more comfortable discussing her sexual experiences with another woman (and perhaps a woman with whom she could relate) than if I had been male, or a younger person. At the same time, this example brought to mind the possibility that there were data that I was *unable* to see, hear, or sense in this study, given my location. To mitigate this challenge, I strove to identify mannerisms and words in my communication that might interfere with participants' ability to 'be themselves', and to experience and express their thoughts and feelings. This is an example of how I was reflexive about my own positionality in relation to the patients, family and staff I interacted with, and how I attempted to be aware of the impact that my positionality might be having on the research process, mistrust, over-rapport, and my data (Chenail, 2011; Creswell, 2013; Guillemin & Gillam, 2004; H. A. Taylor, Chandros Hull, & Kass, 2010; Thorne, 2016).

## 5.4.2.2 Researcher's personal experiences.

During my study period I had several experiences of my own as a family member in hospital settings. Honouring and reflecting on my own experiences furthered my interpretation of the complexity of my observations in the field. Experience-based design researchers Bate and Robert (2007) state:

The general idea is that the more I, the experience researcher, engage, question and help people to reflect on their experiences from this outside-inside position, the more I shall be able to imagine myself in these experiences, and the more I become able to understand them. (p. 44)

I found this outside-inside position to be the case; my personal experiences provided context for the meaning of relational patterns and themes and for the way these themes can impact on a person's experience. At the same time, I took cautions to preserve the integrity of my study data (e.g., stating that insights from personal experiences were not study data). Marshall et al. (2010) describe the process of drawing on personal experiences "not as an end in itself, but as a springboard for interpretations and more general insight. As a result, links between knowledge claims, personal experiences of both participant and researcher and the social context become more explicit" (p. 22). Personal insights enabled me to reflect and expand upon on what was written in the literature, what was emerging from my data, and how my role (as the research instrument) might be informing my inclusion and interpretation of data. All these factors served to enhance my appreciation of the social context I was exploring.

#### 5.5 Exploratory Phase: Developing Research Partnership and Entering the Field

The first of my study's two phases was an exploratory phase. As the *Tri-Council Policy Statement* (2018) notes, the exact beginning of the qualitative research is often difficult to pinpoint:

It is sometimes difficult to ascertain the beginning and end of a qualitative research project. Access to particular settings and populations often develops over time, and it is not unusual for researchers to be passive observers, or simply passively interested in a setting for some time, before any formal effort is made to establish a "research" relationship. (p. 137)

An important part of developing my research proposal was networking. For example, I initiated many face-to-face, telephone and email dialogues with people representing quality, patient safety, and patient-centred care portfolios in health care organizations across Canada. I actively sought to meet with patient and family advocates in BC, a strategy that is recommended by many researchers involved in patient-focused health care quality and safety (for example, see G. R. Baker et al., 2016; Coulter, 2016; Renedo et al., 2015; The Health Foundation, 2013b). It soon

became clear, through this networking, that I wanted to learn about what was happening for patients and families when they were exposed to QI interventions *at the point of care*. Figure 5.1 summarizes and provides a timeline of the decisions I made regarding choice of method and analysis to ensure the rigour and significance of my research. I describe these decisions in the sections that follow.



Figure 5.1 Study activities and timeline.

#### 5.5.1 Overview of gaining entry.

In qualitative research, gaining entry refers to the ethical and academic processes the researcher undertakes to access and engage with research participants and the broader professional and institutional community (Given, 2008). To implement my study, I needed to build trust in a health care organization at various levels from senior leaders to unit staff and patients and families so I would be "invited in"<sup>82</sup> to a health care delivery setting to which I would not

<sup>&</sup>lt;sup>82</sup> I use the term "invited in" to refer to the research process whereby I, as a researcher outside the community or organization, gained access to the research setting. This invitation evolved in a way that meant I felt the communities I interacted with had a supportive and collaborative approach to working with me in the study.

otherwise have access – a critical process in qualitative studies (Canadian Institutes of Health Research et al., 2018, p. 136). For example, health care staff may have feared I had a hidden agenda to reveal poor practices (Thorne, 2016, p. 129; World Health Organization (WHO), 2013a). Despite such cautions noted in the literature, I was surprised at the ease with which I gained entry to the health care partner (referred to as the Study Hospital).<sup>83</sup>

## 5.5.2 Health care partner.

In my study, the health care partner, or Study Hospital, was a university-affiliated acute care teaching hospital in BC's Lower Mainland.<sup>84</sup> Over six months, I developed a research partnership through informational meetings to assess the feasibility of my research. I wanted to conduct my fieldwork at this hospital because it was known for continuous QI and patient and family-centred care – two values-driven philosophies of importance in my research. In addition, the people I met with at the Study Hospital conveyed interest in my research area and support for graduate students. As a researcher, building on established professional relationships (both mine and those of my committee members) helped me gain entry to the organization. Because I was not affiliated with the hospital, I signed a confidentiality agreement that precluded me from disclosing personal information concerning patients and staff, as well as internal organizational records and documents without permission.

<sup>&</sup>lt;sup>83</sup> I discuss gaining entry or access to patient care units (study units) and study participants in Section 5.5.6.

<sup>&</sup>lt;sup>84</sup> The Lower Mainland is an urban region surrounding and including Vancouver that covers the southwest corner of BC, and provides service to over 60% of the provincial population (BC Ministry of Environment, n.d.).

#### 5.5.3 Individual research sponsor.

An important part of negotiating entry was identifying a primary contact person within the organization to facilitate my research study and help me gain access to the research setting(s) and a specific community. Creswell (2013) describes a gatekeeper role as, "one or more individuals in the group who will allow the researcher in" (p. 95). Amir (pseudonym)<sup>85</sup> offered to 'sponsor' my research because my area of interest was related to his professional interests. Amir's involvement from our initial discussions through to knowledge translation was important to my study in several ways that I elaborate on throughout this dissertation. To acknowledge Amir's unique role in my doctoral study we formalized a *Consultant to Doctoral Committee* role.

Well-known and respected in the organization, Amir leveraged his connections, reputation and resources to facilitate my research in three important ways. First, Amir was instrumental in facilitating operational approvals, introductions, as well as opportunities to observe and present at meetings spanning several levels of the organization in relation to my study. Second, Amir assisted in identifying case studies appropriate for my research focus (described in Section 5.5.5.1). And third, Amir provided a health care partner perspective in diverse areas, including feedback on my study materials (e.g., must be concise), an insider's knowledge of the organizational culture (e.g., how quality/safety initiatives gain traction at an organizational level), and updates related to my topic (e.g., plans to spread hand hygiene interventions to different units). Regular conversations and doctoral committee updates, particularly during the

<sup>&</sup>lt;sup>85</sup> In Section 5.7.2, I explain that use of pseudonyms, composite stories, and altered details protects individual and institutional confidentiality.

phases of my gaining entry and data collection, created a reflective and supportive research arrangement. Taken together, Amir's contributions helped me navigate organizational systems and structures, and interpret the context and significance of hospital patient and family experiences. As noted by Bate and Robert (2007), these same attributes of Amir's status in the organization that helped me gain entry might have made it more difficult for him (and others in leadership roles) to get close to the staff, patients and families "inside" patient care units to gain an understanding of patient and family experience in context. As a researcher supported by Amir, I had opportunities to understand some of the complexity of organizational influences that I would not otherwise have appreciated.

## 5.5.4 Forming a patient advisory group.

As I developed my thesis proposal, I spent a lot of time thinking and writing from my disciplinary orientation as a health care administrator and REB member. The literature I reviewed in Chapters 2 and 3, and informational meetings I had with patient advocates in BC emphasized the roles patients do, and could, play in health care improvement. Consistent with my theoretical and methodological patient-centric commitments, I recognized that interacting in a rigorous manner with patient/family participants as advisors would shift the power dynamics by acknowledging patients as co-knowers in my journey. In turn, this approach would enable me to co-construct meanings from the data about patient/family experience in a way that aligned with my goal to influence real-world practice. In fact, I came to believe that I would be unable to justify embarking on such a project without patient partners.

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While I was awaiting ethics and operational approvals, the hospital submitted a request to BC's *Patient Voices Network* (PVN)<sup>86</sup> to engage two patient partners to collaborate<sup>87</sup> on my research team (see Appendix D). PVN matched me with two patient partners, Carol and Marie-Thérèse (pseudonyms), and facilitated an orientation to establish expectations. Both patient partners signed confidentiality agreements with the Study Hospital.<sup>88</sup> Carol was a long-standing member of PVN, while Marie-Thérèse was embarking on her first experience as a patient partner. In my study, I hoped to learn from patient and family participants with backgrounds representing diverse health care experiences, age, gender, ethnocultural and social demographics. Yet my two patient partners were white, middle-class, professional women with families, living in urban environments, and so were not representative of the full range of patients and families I interacted with. While the three of us shared these similarities, important differences were that my patient partners were older adults, retired, with different health care experiences. In addition, one grew up outside North America.

I formed my patient advisory group just prior to beginning my observation on patient units. Over a period of three years I met on 17 occasions with my two patient partners together and separately, and we met once together with my full doctoral committee. My descriptive and reflective notes taken during our meetings became fieldnotes. I solicited feedback from my

<sup>&</sup>lt;sup>86</sup> I described PVN's role in Section 3.3. The PVN recommends a minimum of two patient partners so the 'patients' feel more comfortable at a table of health care workers (Patient Voices Network, n.d.-b).

<sup>&</sup>lt;sup>87</sup> Based on the International Association for Public Participation's (2007) spectrum of patient engagement, an intention to *collaborate* meant seeking our patient partners' input and guidance about the research approach, observations and findings, and including their interpretations as much as possible.

<sup>&</sup>lt;sup>88</sup> The content of the patient partner confidentiality agreement was similar to the one I signed as a researcher (described in Section 5.5.2).

patient partners on study documents,<sup>89</sup> articles on QI and hand hygiene, and attitudes, knowledge and behaviours about hand hygiene initiatives that involved patients/families. Engaging with patient partners throughout this study was particularly useful to understand perspectives of those who might perceive themselves to be on the wrong side of the power equation. I incorporated patient partner suggestions from our early conversations into my methodology, particularly with respect to developing rapport with patients and families on patient units. These suggestions included elements such as ensuring that patients "see that the hospital approves" of what is happening and the researcher "has the right to be there" (Fieldnote #1), and that patients might be more likely to engage with me if I wore "cheerful clothing" to contrast with the "bland and depressing hospital environment" (Fieldnote #2). This input prompted me to clearly display my name badge and wear colourful clothing to gain credibility with patients and families while on the study units. As I will highlight throughout this dissertation, my patient partners' reflections on my emerging findings informed my interpretation of study themes and conclusions.

<sup>&</sup>lt;sup>89</sup> Prior to recruiting patients and families in the hospital, my patient partners reviewed the consent forms and participant materials for this study. My consent forms for patients and families included the following sample wording taken directly from the UBC guidance notes, "We do not think taking part in this study will help you" (UBC Behavioural Research Ethics Board, 2012, 2018) (see Appendices H and J). My patient partners objected to this 'no promise of benefit' statement because they believed: (1) patients and families did benefit from the opportunity to voice their opinion about their hospital care, and asking patients and families about their experiences in a sincere and meaningful manner shows respect for and empowers patients and families; (2) this statement might de-value the vital role patients/families could play in adding to the general knowledge of health care; and (3) reinforce paternalism (Fieldnotes #1 and #2). I was curious about my patient partners' interpretation of reciprocity between researcher and research participant. After discussing this with my supervisor, I decided to retain the statement in the consent form as written, and to reflect on the assumptions embedded in the statement after my analysis. During my study, several patients and families expressed to me that they viewed participating in my study as a privilege and an opportunity to improve the health care system. Other patients described how participating benefited them. Further research about patient/family perspectives on the benefits and downsides of health care system improvement research at the point of care may be warranted. After my dissertation is published. I plan to share this study observation with UBC's Office of Research Ethics.

## 5.5.5 Case study methodology.

My use of case studies as a strategy to organize social data in the qualitative tradition (Creswell, 2013; Punch, 2014) were consistent with my theoretical and methodological framing because they allowed me to describe and interpret specific real-life contexts in which agents were experiencing the phenomenon of interest: how patients and families experienced a hospital's implementation of a QI intervention. Yin (2014) describes the scope of a case study as "an empirical inquiry that investigates a contemporary phenomenon (the "case") in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident" (p. 16). Stake (1995) further emphasizes the case researcher's role as interpreter: "the researcher is the agent of new interpretation, new knowledge, but also new illusion" (p. 99). Case studies typically occur with researchers gathering data from within the naturally existing 'social fields' in which the phenomena of interest are located (Lincoln & Guba, 1985). Thorne (2012) encourages the use of case-based research in interpretive description studies as a way to challenge assumptions in the data (p. 282).<sup>90</sup>

Bioethicists have long employed case studies as a way of sharpening their focus on specific issues and attending to contextual details in moral deliberations (Sherwin, 1992). While cases are a useful tool in bioethics, Michael McDonald cautions, "there are however risks in creating and resorting to paradigm cases in that we then ignore contextual differences and neglect other pressing matters" (personal communication, August 2018). Furthermore, Kean (2018) observes

<sup>&</sup>lt;sup>90</sup> Recent research combining interpretive description and case study methodologies include, for example, Hakanson and Ohlen's (2016) study of illness narratives of people who are homeless; Hogan et al.'s (2014) study of school-based physical activity policy; and Moll's (2014) study of support for health care workers with mental health issues.

that ethical case studies emphasize facts and action over contextual details such as the reasons behind decisions and behaviour. I focused my research using cases with real-life issues in real time (Center for Practical Bioethics, n.d.) with the objective that an in-depth exploration of patient/family experiences could identify themes and conclusions that may be relevant to enhance QI in other settings. Thus, McDonald's and Kean's cautions are an important consideration when I discuss the implications of my findings, and further accentuate the importance of paying attention to the details of context in my study.

## 5.5.5.1 Selecting case studies.

In this study, a *case* is a QI intervention that involves patients and families in their own safety – specifically, giving patients/families a new opportunity for patient hand hygiene. Informed by Yin's (2014, p. 95) guidance on selecting case studies, to answer my research questions I set six criteria to select the QI interventions at the Study Hospital I would focus on:

- The health care organization and project team consider the project to be a QI activity (Alberta Innovates, 2010; Cooper & McNair, 2015, p. 210);<sup>91</sup>
- The intervention follows commonly accepted improvement approaches/tools (e.g., PDSA cycles) and/or is based on a widely implemented initiative provided by safety/quality organizations (e.g., *Inpatient Sepsis Toolkit* (BC Patient Safety & Quality Council, 2016);
- The intervention focuses on a priority area of patient safety;

<sup>&</sup>lt;sup>91</sup> This criterion is particularly important in my study exploring how QI is actually implemented at the point of care, consistent with my real-world approach.

- The intervention involves patients (or families) at the point of care taking on specific, new responsibilities integrated within their own health care;
- Ideally, patient partners are involved in planning the intervention; and
- The intervention is implemented within the timeframe and budget of this unfunded doctoral study.

As described in Chapter 3 (Section 3.2.4), the focal area of improvement I studied was infection prevention and control through hand hygiene interventions involving patients and families. Early in the gaining entry phase, through discussions with the Study Hospital's quality and safety leaders, I narrowed my case study topic area to two *hand hygiene* interventions that met the case study criteria outlined above. I provide my detailed rationale in Table 5.1.

Reason	Rationale			
Priority	Hand hygiene is an ongoing infection control priority in Canada and worldwide			
Choices	A wide array of hand hygiene QI interventions is frequently encountered in health care			
	settings in Canada and worldwide			
Patient/family	Hand hygiene interventions increasingly involve patients and families			
Relatable	Hand hygiene is an accessible topic that patients and families can readily understand			
	and relate to; therefore, talking about hand hygiene could serve as a catalyst to			
	stimulate some of the broader ethical questions I aimed to explore			
Relevance	Understanding features of hand hygiene interventions may be relevant to other priority			
	areas of quality and safety, such as medication safety or falls prevention			
Benefit	Hand hygiene is thought to be obviously of benefit			
Masking	Due to the array of hand hygiene interventions common across diverse organizations			
_	they are easily masked to assist in maintaining confidentiality			
Feasible	The Study Hospital had several hand hygiene interventions involving patients			
	underway			

Table 5.1 Rationale for hand hygiene as case study focal area.

This focus on patient hand hygiene interventions set the context of care I was studying,

established common ground between myself as a researcher and the study participants, and

launched my researcher journey of studying participants in context. I selected two hand hygiene initiatives as cases:

• Case A: Patient Hand Wipes (pilot intervention, see below)

• Case B: Organization-Wide Hand Hygiene (group of ongoing interventions, see below) As this study was an exploratory understanding of patient and family experience of QI interventions, an exhaustive evaluation of the cases (e.g., mission and goals, hypothesis, evidence base, baseline data, theoretical framework) was not conducted ex ante (Thorne, 2016). Using a theoretical sampling approach (discussed below), if patient and family data raised questions about certain aspects of the intervention's design, implementation, or impact, then I would explore these aspects to understand their significance for my research questions. In what follows, I describe my two case studies and the relationship between them.

## 5.5.5.1.1 Case A: Patient Hand Wipes (pilot intervention: 2 projects on 2 units).

The overarching goal of the *patient hand wipes* intervention was to decrease microbe transmission, particularly antimicrobial-resistant organisms, by having staff and volunteers help patients clean their hands with alcohol-based hand wipes before eating and drinking. While I was gaining entry to the Study Hospital, two different multidisciplinary (primarily nursing) QI project teams were planning to implement a pilot *patient hand wipes* intervention on two different acute care units. Prior to receiving research ethics approval, I received operational approval to 'shadow' several of these planning meetings over a period of five months in order to better plan my study. On Study Unit 1 (an outpatient dialysis unit), the motivation for the *patient hand wipes* intervention was a concern brought forth by a patient partner, who had noticed patients eating with visibly soiled hands in a different area of the hospital. On Study Unit 1, the unit manager's stated aims to participate in the intervention were to change the culture to increase care provider hand hygiene compliance and to alter patient hand hygiene behaviour before eating both inside and outside the dialysis unit. On Study Unit 2 (a complex medical unit), the catalyst for the *patient hand wipes* intervention was a recent increase in infections reported on the unit. This project team's primary aim was to increase staff engagement in hand hygiene by assisting their patients with hand hygiene before meals. Both projects shared hand hygiene compliance, staff engagement, and patient engagement as discrete and intersecting motivations, as quality leaders positioned patient hand hygiene as a new way of controlling infection on hospital units.

As noted in Chapter 3 (Section 3.2.2), QI approaches and tools such as PDSA cycles are designed to facilitate nimble adaptation of improvement interventions so they work in different contexts (Perla et al., 2013). The *patient hand wipes* intervention was implemented differently by the two project teams on two different units (Project #1 on Unit #1; Project #2 on Unit #2. The study units are described below). Table 5.2 outlines the key similarities and differences between how Case A (*patient hand wipes*) was designed for each study unit:

 Table 5.2 Case A: Key similarities and differences between the patient hand wipes intervention on the two study units.

Respond to a patient hand hygiene concern identified by a patient partner (Unit #1);		
the unit (Unit #2).		
both study units); to		
).		
patient and family-		
es per day, only a		
patient medical unit		
ervice (Unit #2).		
ee/snack (both study		
vipe before each meal		
s to offer each patient		

# 5.5.5.1.2 Case B: Organization-Wide Hand Hygiene (group of ongoing interventions).

To complement Case A, Case B, *organization-wide hand hygiene*, was comprised of a set of ongoing interventions to promote hand hygiene. These interventions aimed to raise awareness about the role of hand hygiene in infection control, increase hand hygiene practices of staff, patients, families and other visitors, and change the culture associated with hand hygiene in health care environments. Interventions in this group fell into two categories: information (e.g., signs and brochures) and supplies (e.g., hand rub). Table 5.3 provides common examples of these interventions in Canadian health care settings and represents the types of ongoing interventions in the Study Hospital during my study period.

Category	Examples			
Hand Hygiene Information				
- Information, reminders and	- Campaigns: <sup>92</sup>			
instructions	o "It's ok to ask" (original campaign: UK National Patient			
- Various forms including posters,	Safety Agency, 2004 (Pittet et al., 2011))			
signs, brochures, organization	• "Save lives: clean your hands" (original campaign: (World			
website, organizational reports	Health Organization (WHO), 2009c))			
- Target patients, family and staff	<ul> <li>"Stop! Clean Your Hands" (Canadian Patient Safety</li> </ul>			
	Institute, n.dd)			
	- Posted statistics about staff hand hygiene compliance and			
	infection rates			
	- Annual reports about infection control and prevention strategies			
Hand Hygiene Supplies				
- Means to clean hands	- Alcohol-based hand rub (ABHR) dispensers			
- Typically accompanied by	- Sinks			
signage	- Soap			
- Target patients, family and staff	- Hand wipes in canisters			

 Table 5.3 Case B: Examples of common organization-wide hand hygiene interventions.

Due to their public visibility, I identified many of these organization-wide hand hygiene interventions as I was gaining entry to the hospital. For example, I observed hand hygiene supplies and signage while walking in public areas of the Study Hospital (e.g., entrances, hallways, waiting areas, stairwells, elevators, washrooms, cafeteria) as well as on patient care units. Information such as patient brochures and annual reports was available on the Study Hospital's public website.

Of note, the aim of "it's ok to ask" and similar interventions (described in Chapter 3) is to create a comfortable environment for health care providers to be reminded by staff and patients/families members to wash their hands, and/or for patients/families to raise the topic of hand hygiene with

<sup>&</sup>lt;sup>92</sup> Organizations such as Canadian Patient Safety Institute, The World Health Organization, Centers for Disease Control and Prevention, and Institute for Healthcare Improvement routinely launch hand hygiene campaigns with free access to materials.

their providers (R. E. Davis et al., 2015). Given my theoretical framing of relational ethics and power imbalances between patients/families and providers, interventions promoting interaction between patients/families and providers were of special interest in my study. At the early stages of my observations, I wondered how patients and their families felt about asking care providers about hand hygiene. I will revisit these questions in Chapters 6 to 9.

## 5.5.5.1.3 Relationship between Cases A and B.

In the health care improvement field, connected and complementary interventions are typically rolled out together to increase the potential for impact (Resar et al., 2012; World Health Organization (WHO), 2009a). This feature also increases the complexity of assessment. My plan was to select *two cases* in the same priority improvement area. This strategy allowed me to expand my conversations with participants, understand what was common and unique between the cases, and understand the larger context of the QI intervention and what this meant to patients and families (Yin, 2014, pp. 57, 63–64). Together, connected cases allowed for deeper study of the phenomenon of interest and the relationship between the phenomenon of interest and the context in which each case was embedded (Punch, 2014, p. 123).

I selected Case A (*patient hand wipes*) to be the lead case because it was a new intervention being piloted in two different acute care settings and provided opportunities for qualitative comparison of possible similarities and differences including: (1) patient population; (2) unit culture; (3) how patient safety and QI worked on different units; and (4) how different project teams implemented a similar intervention (Thorne, 2008; Yin, 2014). To situate Case A, Case B (*organization-wide hand hygiene*) provided information about the range of hand hygiene

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interventions that patients/families and staff/volunteers encountered in the Study Hospital. Therefore, as illustrated in Figure 5.2 Case B formed part of the overall context in which Case A was implemented by hospital staff/volunteers and was experienced by patients and families.



Figure 5.2 Relationship between Case A (patient hand wipes) and Case B (organization-wide hand hygiene).

#### 5.5.6 Gaining entry to the patient care units (Study Units).

Two specialized patient care units were identified as study units because they were the units on which Case A was being implemented during my data collection period. In other words, study units were not selected based on features of staffing, clinical area, or patient population. Rather, the QI project teams drove selection of my study units. My first requirement, once I had identified the two patient care units, was to seek organizational and research ethics approvals, and to gain entry to these patient care units.

## 5.5.6.1 Organizational approvals.

In health care settings, researchers typically require formal approvals at the unit, department and senior leadership levels to conduct fieldwork. The literature emphasizes the importance of researchers first building trust with unit staff before attempting to engage patients and families

(Creswell, 2013; Given, 2008, p. 2; Nind, 2008). As Nind (2008) notes, "Before gatekeepers are likely to help they will need to be convinced of the benefits for the people who they will often regard as in need of their protection" (p. 9). Depending on the context, in my study gatekeepers included clinical and administrative leaders, care providers, and patients/families. Guba and Lincoln (2003) state, "Achieving trust demands forthrightness, clear and fair explication of the purposes of the research, and authentic presentation of the researcher's self-conditions which require time to fulfill" (p. 231). The assistance of Amir (my research sponsor) was very important in this process. Without Amir's "in", it would have taken me longer to be "invited in" to the patient care units and to gain rapport with participants (patients, families, point-of-care staff and volunteers, and leaders). Nevertheless, as Henry et al. state (2017), "While gatekeepers can provide the connections, it is up to the researchers to build the relationships" (p. 190), and I was aware of this throughout the process of gaining entry. Once unit managers of Study Units #1 and #2 and a member of the hospital's senior leadership granted the operational approvals for my study, the next step was obtaining research ethics approval.

## 5.5.6.2 Research ethics approval.

Once all elements of my research were confirmed, I applied for and received research ethics approval via delegated review from the UBC REB.<sup>93</sup> This study was deemed to be minimal risk and did not target particularly vulnerable populations, ask extremely sensitive questions, use deception, observe medical exams or sensitive procedures, or report identifying data to hospital

<sup>&</sup>lt;sup>93</sup> The *TCPS 2* (2018) specifies that when a research project is deemed to be low risk, the REB/REB Chair can *delegate* the research ethics review to one board member instead of requiring a full board review (Article 6.12).

authorities, and participants were provided off-site options for interviews. The study was conducted in accordance with *TCPS 2* (Canadian Institutes of Health Research et al., 2018). In terms of the guiding principles and values of research ethics, this study was implemented as planned and I had no evidence or suggestion that any serious ethical concerns arose during the conduct of this research.

In qualitative research, negotiating entry sometimes requires modifications to the study design (Thorne, 2016), thus I submitted any changes with the potential to impact my research study to the REB as amendments. For example, my original plan was to observe patients and families via shadowing clinical staff on study units. In the opinion of one of the study unit managers, patients and families typically feel "at home" on the unit given the chronic nature of their illness and long-term relationships with staff. The manager suggested two changes to how I planned to introduce myself, a visiting researcher, to the unit: (1) shadow patients and families instead of staff; and (2) add a photograph and short biography to my "study unit poster" (see Appendix E) (Fieldnote #3). The manager's expressed reasons for these changes were to better respect patients'/families' integration into the running of the unit and to build trust. In addition, the manager predicted that if I started off shadowing staff, patients/families would think I was evaluating the staff and would therefore be less likely to provide me with honest feedback. Upon reflection, I came to recognize that the unit manager's suggestions improved my study because they echoed my theoretical approach (described in Chapter 4) and my ideas about the researcher as instrument (described in Section 5.4.2).

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## 5.5.6.2.1 *Ethics of QI*.

As I explained in Chapter 1, key areas of interest in this study were learning more about the ethical and practical implications of health care system improvement projects falling into the research or non-research category, and reflecting on the adequacy of ethical approaches that health care organizations commonly employ for QI interventions. One of my case selection criteria (described above) was that the organization and project team considered the primary case study to be a QI activity. While it was not required by UBC or the Study Hospital, as part of my study procedures I completed the ARECCI Project Ethics Course (Alberta Research Ethics Community Consensus Initiative (ARECCI), 2010) and applied the ARECCI screening tools (Alberta Innovates, 2010) (see also Appendix C) to the patient hand wipes QI projects before commencing observations on patient care units. The ARECCI screening determined that the patient hand wipes projects were QI or program evaluation (in other words, not research, and therefore not requiring REB approval). I obtained an ARECCI risk score of three,<sup>94</sup> indicating that the *patient hand wipes* projects posed minimal ethical risk to people and the organization. In such situations, the ARECCI framework recommends that QI project leaders use the ARECCI guidelines to identify and manage ethical risk consistent with local policies. To my knowledge, the *patient hand wipes* projects I observed did not undergo any sort of ethical assessment or oversight. In Chapter 9 (Section 9.3.4.2), I reflect on my initial application of the ARECCI ethical screening tools given what I learned in this study.

<sup>&</sup>lt;sup>94</sup> The purpose of the *ARECCI Ethics Screening Tool* is to help "determine the primary purpose of the project, the types of ethical risks, and the appropriate type of ethics review" (Alberta Innovates, 2017b). A score of 3 was applied to my response to Question 23, "Special populations or any individuals or groups in a socially vulnerable position?"; to which I responded "Some patients on the study units will include frail elderly, persons with disabilities, unstably housed" (Alberta Innovates, 2010).

## 5.5.6.3 Recruitment and consent.

Once I had begun establishing trust on the study units, another important part of this research study was welcoming feedback about my study from hospital staff, patients and families. To conduct these observations, my presence on each unit involved arrival, observing, recruiting and shadowing staff, patients, and families, recruiting patient and family interview participants, and leaving the unit (Gill et al., 2014). To negotiate and navigate access to the study units and study participants I developed relationships with key leaders on each unit. I used a *primary consent process* consisting of recruitment letters and consent forms that were tailored for each participant group (explained in Section 5.6.1). For clarity in the writing of this dissertation, I typically describe data using the terms such as 'patients' or 'care providers' (instead of participant) in order to distinguish the group of research participants I am referring to.

A *secondary consent process* consisted of group disclosure and verbal introductions by unit staff, and included study posters (see Appendix E) displayed in unit hallways, waiting areas, and staff lunchrooms. The purpose of this information was to disclose to patients, families, and hospital staff what my study was about, and that it involved observational activities on the unit. In addition, unit leaders sent out emails to regular staff members and volunteers. These methods of communication are accepted forms of group disclosure for patient safety studies involving participant observation (World Health Organization (WHO), 2013a).

## 5.5.6.4 Overview of study units.

As noted above, the two study units were the patient care units on which Case A was being implemented during my data collection period. Both study units are specialized clinical areas, each with a unique context of care that treat an adult patient population with serious and chronic conditions.<sup>95</sup> Additionally, on both of these units, health care-associated infections are especially prevalent. Both study units are known for their specialized, long-term tenure, interprofessional and uniquely engaged staff, and for conducting a range of learning activities including research and QI projects.

## 5.5.6.5 Study Unit #1: chronic illness – outpatient dialysis.

Unit #1 is one of five in-hospital dialysis centres located in BC's Lower Mainland (BC Renal Agency, n.d.). This specialized chronic illness unit has several dozen dialysis stations and operates 24 hours a day, 7 days a week. Patients tend to be older adults receiving long-term treatment for kidney failure; have other chronic conditions; and are otherwise a heterogeneous group in terms of gender, complexity/severity of health condition(s), ethnocultural background, and social situation. A smaller group of patients in this unit receive dialysis on a temporary basis while awaiting a kidney transplant.

Unit #1 is staffed with up to 25 registered nurses at any one time, along with a team of specialized physicians, and other professionals dedicated to the unit including dietitians, licensed practical nurses, nurse practitioners, pharmacists, and social workers. It is common for patients and family members to be engaged in processes such as weighing themselves. A family advisory

<sup>&</sup>lt;sup>95</sup> Nolte and McKee (2008) define chronic disease as: "Conditions that require a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment" (p. 1).

committee meets regularly and has staff support (e.g., administrative support and one clinical staff member attends each meeting). Additionally, a core group of approximately 50 volunteers in the renal program is organized through the Study Hospital's volunteer department. Most volunteers serve for at least one year. Volunteers provide a snack service to patients/ families each day. I chose Unit #1 as the "primary study setting" because Case A was actively being piloted on this unit. This meant that I began theoretical sampling (explained below) with patients/families on Unit #1 and planned to sample most heavily from this unit.

## 5.5.6.6 Study Unit #2: chronic illness – complex medical.

Unit #2 is a specialized chronic illness unit with over 25 inpatient beds. The context of care is unique because the unit primarily serves patients prone to serious infections. These patients include a population of immunocompromised patients marginalized by society<sup>96</sup> with significant challenges related to socioeconomic hardship, substance use, and disability. Unit #2 is staffed with up to 8 registered nurses at any one time, as well as multiple teams of consulting physicians, other professionals dedicated to the unit including dietitians, licensed practical nurses, nurse practitioners, pharmacists, and social workers. Health profession students completing practicums are a regular presence on this unit. A core group of volunteers organized through Study Hospital's volunteer department provides a daily coffee and tea service. Additionally, peer mentoring and other social supports are highly integrated into the unit.

<sup>&</sup>lt;sup>96</sup> To avoid inadvertently stigmatizing through language, I use terms such as 'marginalized by society' and 'person experiencing problems with substance use' rather than 'marginalized patient' or 'addict' (Broyles et al., 2014).

In my study, I found that most patients on the complex medical unit were much sicker and with a different set of health and socioeconomic challenges than those on the outpatient dialysis unit. The patients were otherwise a heterogeneous group in terms of age, gender (in general, more males), complexity of health conditions, and ethnocultural background. Unit #2 had completed their 4-week pilot study of Case A (the patient hand wipes) two months prior to my on-unit observations. Due to this timing and because hand hygiene had recently been an area of QI focus on this patient unit, I considered Unit #2 to be the "secondary study setting". This meant that I planned to sample fewer patients/families from Unit #2 and explore the similarities and differences between the two study units.

#### 5.6 Constructing Data Phase: Sampling, Collecting and Analyzing Data

In this section, I describe how constructing data from both study units included the following activities: creating a sample, collecting data, and analyzing data. As Thorne (2016) states, "from the outset of your study, you are not 'collecting' data as much as you are constructing an understanding of what constitutes data and how you will articulate it as such" (p. 133). As an iterative process, interpretive description methodology required me to continually reflect on what I was observing, consider what my role was in constructing meanings, and return to the literature.

#### 5.6.1 Creating a sample.

In qualitative studies, a small number of data sources are selected from a defined larger population for intense analysis (Given, 2008, p. 799). In this section I describe my theoretical approach to sampling, and the different groups of participants in this study. Participant groups include the primary sampling frame, which was comprised of patients and families, and a secondary sampling group, comprised of hospital staff and volunteers.

## 5.6.1.1 Sampling approach.

This study primarily employed *theoretical sampling*, which "explicitly builds the sampling strategy from the evolving theoretical variations that derive from the data as the study is being conducted" (Thorne, 2008, p. 91). Selecting participants and contexts was predominantly driven by ongoing analysis of the data and theoretical insights and directions that led back to the key focus of the study (Creswell, 2013, p. 158; H. A. Taylor, Chandros Hull, & Kass, 2010, p. 208; Thorne, 2008, p. 91). In my study, theoretical sampling guided by my ethical framing drove my decisions regarding where to sample next (what to pay attention to) – that is, participants in the context of study units, unit contexts, and participant contexts (e.g., age, familiarity with unit).

I also employed *convenience sampling*, where participants were selected for pragmatic reasons because they were readily available, particularly as I launched the study (Thorne, 2016, p. 98). For example, when staff members or patient/family participants asked to talk with me about the study, I always agreed with the primary aim of promoting inclusivity. Any person (patient, family, or staff) who was not fluent in English was excluded from the study because I did not have funding to hire interpreters or to have materials translated. No exclusions were made on the basis of age, gender, class, or ethnicity (apart from language fluency).

## 5.6.1.1.1 Estimating sample size.

*Sample size* was not confirmed a priori for reasons that include variation between participants, and how my interactions with participants unfolded (Thorne, 2016, p. 106). In addition, factors influencing participant observation in health care settings include medical emergencies and staff illness (Creswell, 2013; Gill et al., 2014). Initially, my plan included the following estimates:

- 168 to 216 hours of participant observation on two acute care units over four months, shadowing 8 to 10 staff and/or 8 to 10 patients and family members;
- 20 to 25 in-depth interviews with patients and family members; and
- 6 to 8 informational meetings with and presentations to groups of hospital staff and patients to further understand significance of data gathered from patients and families. These initial estimates of observation and interview procedures were consistent with recommendations for qualitative studies (Sandelowski, 1995; Thorne, 2016, p. 103) and published research of a similar scope (e.g., Hunt, 2008; Kalengayi, Hurtig, Ahlm, & Ahlberg, 2012; Rodney, 1997; Rostam, 2013). For example, Sandelowski (1995) states that a sample size of 15 participants who have unique and extensive knowledge of the subject area can provide a coherent and convincing account of a phenomenon. For studies using grounded theory methodology, the concept of theoretical saturation is important because it signals the point when the researchers are satisfied they have collected enough data to develop their model (Creswell, 2013, p. 89; Given, 2008, p. 875). However, Thorne (2008) asserts that theoretical saturation should not be a goal of interpretive description studies such as mine, especially because "[individuals] theoretically represent infinite variation in relation to their experiences with health care" (p. 98). In this study, my findings and interpretations are based on a perspective built on the study plan described in this chapter.

## 5.6.1.2 Describing the study sample obtained.

Qualitative research using participant observation captures direct and indirect observations and interactions (Creswell, 2013; Maxwell, 2013; Punch, 2014; Thorne, 2016). In my study, I interacted with patients, families, staff, and volunteers in different ways over a prolonged period, resulting in a large data set from which to describe and interpret findings. In what follows, I describe how I bounded my study sample. Given that the data in this study was co-created by the researcher and participants, my study is not directly reproducible (Cohn, 2015; Thorne, 2016).

## 5.6.1.2.1 Participant characteristics.

The participants with whom I interacted during this study are summarized in Table 5.4 (the main sample: patients/family members who were receiving care on the study units) and Table 5.5 (outside the sampling frame: hospital staff/volunteers who acted as key moral agents shaping the context of the patient/family experience). The types of data collected for each research participant and the summaries reported here were driven in part by theoretical sampling, meaning that the focus is on areas that emerged as conceptual areas of significance. For example, in keeping with my theoretical sampling approach and to build trust with participants, I collected demographic data (e.g., age, gender, ethnocultural background, and occupation) *in relation to the context* of my broader conversations with and observations about the participant (American Psychological Association, 2003; A. J. Browne et al., 2014). I anticipated my final primary study sample to be a heterogeneous patient/family group in terms of age, gender, complexity of health condition, and experiences of health care.

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Reporting participant characteristics includes participants' own descriptions, information relayed to me by others (e.g., patients, family members, staff, volunteers), and details observed and interpreted by me as a participant observer (e.g., list of patients, diagnoses etc. displayed on a whiteboard inside the nursing station). For example:

- *Gender* is reported as male, female, or not specified. This was not a question posed to
  participants; I did not ask "how would you describe your gender?" Rather, I noted gender
  in my fieldnotes based on a combination of inputs including what participants told me
  directly ("I'm a 50-year old man") and indirectly ("I'm a mother" or "as a woman"), how
  others referred to a participant ("Mr. Smith"), and my own observations ([Fieldnote #4]).
- Age is reported as a range. Participants frequently brought age and age-related information into conversations in relation to their experiences. For example, "I was 3 years old when World War II started". Where exact age was not obtained during data collection, it was estimated.
- *Ethnocultural background* is reported as it too was often brought into conversations in relation to patient and family stories about cultural-based values and habits, particularly by non-Caucasian patient and family-participants ("My grandmother was born in Singapore and she taught me the importance of handwashing"). Ethnocultural background is reported according to Statistics Canada (2018) groupings.

(a) Sampling frame: Primary focus (Patients and Families). The inclusion criteria for my main sample, where I began theoretical sampling were patients and families members who: were receiving care on one of the units (#1 and #2) where Case Study A (*patient hand wipes*) was implemented; understood the purpose of the research study; and freely consented to

participate. The sample of patient and family participants was composed of 25 patient participants ranging in age from middle 30s to early 90s, and eight family member participants ranging in age from early 20s to early 90s. Table 5.4 summarizes patient and family participant characteristics including how I interacted with these participants (e.g., via shadowing [see Section 5.6.2.1] or interviewing [see Section 5.6.2.2]).

Sampling Frame/Primary	Focus (Patients and Family Members)
A. Patients n=25	
Туре	Description
Age range	Middle 30s to early 90s
Gender	Male (18), female (7), not specified (0)
Ethnocultural background	Caucasian (13), Non-Caucasian (visible minority) and Aboriginal people (12) including Aboriginal, Black, Chinese, Japanese, Filipino, Latin American, South Asian
Residence; Housing	Reside in local urban centre (25); unstably housed (5)
Employment	Work full or part-time (5), retired or disability (10), unknown (10)
Overall health situation	At least 10 patient participants had mobility challenges (wheelchair, cane, walker); majority had several serious concomitant illness besides reason they were receiving treatment in hospital
Familiarity with study unit	Highly familiar (20), moderately familiar (2); new to unit (3) Note: 1 patient was highly familiar with both study units
Study unit	Outpatient dialysis unit (19), complex medical unit (5), both study units (1)
Interaction with researcher	Via shadowing (signed consent form) (9), via interview (signed consent form) (8), via group disclosure/ verbal consent (10) Note: 2 patients were both shadowed and interviewed
B. Family Members n=8	
Туре	Description
Age range	Early 20s to early 90s
Gender	Male (2), female (6), not specified (0)
Ethnocultural background	Caucasian (3), Non-Caucasian (visible minority) and Aboriginal people (5) including Chinese, Filipino, Latin American, South Asian
Residence; Housing	Reside in local urban centre (8); unstably housed (0)
Employment	Work full or part-time (2), retired (4), student (1), unknown (1)
Relationship to patient	Spouse of a patient (5), child of a patient (3)
Study unit	Outpatient dialysis unit (7), complex medical unit (1), both study units (0)
Interaction with researcher	Via shadowing (signed consent form) (3), via interview (signed consent form) (2), via group disclosure/ verbal consent (3)

Table 5.4 Summary characteristics of patient and family member study participants.

# (b) Outside the sampling frame: Agents shaping context (Hospital Staff and Volunteers).

To study real-world situations in which patients and family members receive health care, the context of those health care settings is integral to describing and interpreting the patient and

family experience (Bate & Robert, 2007; Thorne, 2016). Rodney, Kadyschuk, Liaschenko, et al. (2013) situate hospital staff acting as moral agents in direct patient care (p. 164). In my study, I considered that point of care providers, volunteers and unit leaders acted as key moral agents who shaped the context of the patient and family experiences of QI interventions, and therefore formed an important part of my study sample even though they were "outside" the sampling frame. Hospital staff and volunteer participants played two different roles in my study, *unit research mentors* and *research facilitators*.

*Unit Research Mentors* included 15 point of care providers (mostly nurses) and 6 volunteers who agreed to be 'shadowed' (described below) while they went about their regular routines on the patient care units where the targeted hand hygiene intervention was implemented. *Research Facilitators* were 17 hospital staff who played a role in my study in terms of helping me gain entry (to organization-wide meetings, project team meetings, study units, and to the patient/family participants themselves) and helped me to interpret the significance of my findings. *Inclusion criteria* were hospital staff and volunteers who understood the purpose of the research study and freely consented to participants.

Outside the Sampling Frame/Agents Shaping Context (Hospital Staff and Volunteers)						
C. Point of Care Providers (Unit Research Mentors) n=15						
Туре	Description					
Age range	Early 30s to late 50s					
Gender	Male (2), female (13), not specified (0)					
Ethnocultural background	Caucasian (8), Non-Caucasian (visible minority) and Aboriginal people (7) including Chinese, Filipino,					
	Latin American					
Professional group	Nursing (14), other (1)					
Years in role	Majority 10+ years					
Study unit	Outpatient dialysis unit (3), complex medical unit (12)					
Interaction with researcher	Via shadowing (signed consent form) (10), via interview (signed consent form) (0), via group disclosure/					
	verbal consent (5)					
D. Volunteers (Unit Research Mentors) n=6						
Туре	Description					
Age range	Early 20s to late 50s					
Gender	Males (3), females (3), not specified (0)					
Ethnocultural background	Caucasian (3), Non-Caucasian (visible minority) and Aboriginal people (3) including Chinese					
Professional group	Majority students aspiring to be health care professionals					
Years in role	Several months to many years					
Study unit	Outpatient dialysis unit (4), complex medical unit (2)					
Interaction with researcher	Via shadowing (signed consent form) (1), via interview (signed consent form) (0), via group disclosure/					
	verbal consent (5)					
E. Quality/Safety Leaders of	r Patient Care Unit Leaders (Research Facilitators) n=17					
Туре	Description					
Age range	30s to 60s					
Gender	Males (5), females (12), not specified (0)					
Ethnocultural background	Caucasian (12), Non-Caucasian (visible minority) and Aboriginal people (4) including Filipino, Japanese,					
	Latin American, South Asian					
Professional group	Nursing (9), other (2), quality/safety (4), volunteer (2)					
Years in role	Majority 10+ years					
Study unit Outpatient dialysis unit (7), complex medical unit (4), organization-wide (6)						
Interaction with researcher	Via shadowing (signed consent form) (1), via interview (signed consent form) (0), via group disclosure/					
	verbal consent (16)					

## Table 5.5 Summary characteristics of hospital staff and volunteer study participants.

# 5.6.1.2.2 *Quantifying the study sample.*

My study sample can also be described in quantitative terms (see Table 5.6). During this study,

my research included:

• 11 hours of participant observation and informational meetings at the beginning to

negotiate the study;

- 79 hours of participant observation on two acute patient care units over 8 months including: (1) shadowing 11 staff/volunteers ("unit research mentors") with each instance ranging in duration from 1 hour to 3.5 hours; (2) shadowing 12 patients and family members<sup>97</sup> [9 patients and 3 family] with each instance ranging in duration from 20 minutes to 3.5 hours; and (3) informal interactions with 13 patients and family members [10 patients and 3 family] and 22 staff/volunteers;
- 8 audio recorded interviews with 10 patients and family members [8 patients; 2 family], totalling 13 hours; and
- 34 hours of informational meetings, knowledge translation and presentations with approximately 17 individuals outside the sampling frame (e.g., unit staff, quality and safety leaders, patient/family advocates and patient partners) to understand the context and significance of patient/family stories and emerging findings.

<sup>&</sup>lt;sup>97</sup> Several patient/family interactions involved patient-participants together with family member-participants. Out of 12 patient/family shadowing interactions, 1 interaction included patient and family member together. Out of 8 audio recorded patient/family interview interactions, 2 interactions included the patients and family members together.

Table 5.6 Quantitative summary of research hours.

A. Negotiating the Research: Gaining Entry (Before Research Ethics Approval)						
Туре	Hours	Date Range				
Informational meetings; Participant Observation: QI project team meetings	11	March 4, 2015 to August 19, 2015				
B. Constructing Data (After REB Certificate of Approval August 21, 2015)						
Туре	Hours	Date Range				
Participant Observation						
Patient care units	77	August 26, 2015 to March 16, 2016				
Organization-wide	2	August 26, 2015 to March 16, 2016				
Audio recorded Interviews						
Patient/Family	13	January 24, 2016 to March 16, 2016				
(8 interviews; 10 participants)						
Consultation, KT Meetings						
Internal to organization	3.5	September 16, 2015 to January 28, 2016				
External to organization	3	February 25, 2016 to May 25, 2018				
Research sponsor	5	September 16, 2015 to March 9, 2018				
Patient partner consultation	21	July 31, 2015 to October 16, 2018				
Informational meetings	1	September 15, 2015				
Total Study Hours	137					

#### 5.6.1.3 Differences between estimated and actual sample.

In my study, the final sample in terms of participants and number of observation hours was lower than estimated. As I progressed in the study, my doctoral committee and I determined that I had sufficient data and did not require as many participants/observation hours as originally estimated. Reasons for this decision included aspects such as trust building; participant interest; my access to patient/family participants; and the theoretical sampling approach I used. For example, given my relational orientation to being attuned to how power shapes understanding and relationships, I anticipated that patients/families could be sensitive talking about their care. However, I was surprised both by my 'feeling' of privacy while talking with patients/families at the bedside as well as the seeming candour of many patients and families. In my study, collecting more data at the bedside reduced the number of hours needed for participant observation and the number of formal audio recorded interviews, compared to my initial estimates. Overall, these aspects resulted in adequate numbers and sufficient diversity in patient and family participants. Finally, I found that the theoretical sampling and framing and the case study approach used in this study were an effective and efficient means of generating theoretical insights (Given, 2008).

## 5.6.2 Collecting data.

Gathering data from multiple sources is particularly important when the phenomenon is understudied, and there is minimal literature to draw on. As I will discuss below, triangulating methods and sources (e.g., participant observation and interviews) of participant data along with documentary analysis (e.g., organizational reports, patient materials) enabled me to capture relational data and accounts of people's actions (see, for example Bate & Robert, 2007; Chenail, 2011; Hawkins, 2013; Thorne, 2016, p. 266). In an attempt to understand "the patient's role" in the quality and safety of their own health care, the central interactions of interest in this study became those interactions between patients, families and their care providers (e.g., nurses, doctors, volunteers) in the context of target QI interventions. For the purpose of this study, I use Wolf's (2017) definition of *interaction* in health care situations:

the orchestrated touch points of people, processes, policies, communications, actions, and environment. These touch points reach beyond the clinical realm to reinforce the concept that experience in healthcare occurs at a multitude of places, primarily between one human being and another. Interactions are the basis for any experience one has in healthcare organizations. (pp. 5–6)

In what follows, I describe the data collection methods I used: participant observation; formal interviews and informational meetings with patients, families, hospital staff and volunteers; reflexive memos and fieldnotes; and documentary analysis. Together, these methods enabled me

to foster interactions to listen to patient and family voices and interpret their experiences of QI interventions.

## 5.6.2.1 Participant observation.

Patients' health experiences have been studied using observational methods in many settings including telemedicine, primary care and pharmacy (Stevenson, 2013). Given (2008) defines participant observation as, "emergent design involving a variety of methods including direct observation of human behavior and the physical features of settings, informal interviewing, and document analysis" (p. 598). In my study, the purpose of observing everyday activities on patient care units was to gain "a holistic view" of the activities, processes and interactions that shed light on patient/family experiences of QI interventions (Canadian Institutes of Health Research et al., 2018, p. 138). I aimed for what Punch (2014) describes as "the insider's perspective on those events, actions and contexts" (p. 128) shaping what patients, families and hospital staff and volunteers did, instead of what they said or thought they did, as well as what I (the researcher) thought they did (Given, 2008, p. 598; Stevenson, 2013, p. 29; Von Stamm, 2008, p. 491; World Health Organization (WHO), 2013a, p. 23).

## 5.6.2.1.1 Process of participant observation.

Creswell (2013) recommends the first few sessions of observation as "times in which to take a few notes and simply observe" (p. 168). An initial observation period on each unit enabled me to gain a general understanding of context/nature of the unit, build trust with unit staff, and develop

an observational protocol (a method for recording notes in the field that includes prompts,<sup>98</sup> descriptive notes, and reflective notes [see Table 5.7 and Appendix F]) (Creswell, 2013, pp. 166– 171; Thorne, 2008, p. 80). Following this initial observation period, I maintained a regular presence on the two study units over approximately eight months, with exposure to various times of day and days of the week. My ability to spend considerable time observing and interacting with staff, volunteer, patient and family participants in the Study Hospital relied on "maintaining positive field relations for research access" (Calabrese, 2013, p. 23). In the role of participant observer I "engage[d] to some extent in the activities taking place, either in order to better understand the local perspective or so as not to call attention to [myself]" (Mack et al., 2005, p. 18). For example, at the beginning of my fieldwork on patient care units I felt uncomfortable taking notes about my observations in view of patients, families and staff. However, as described in my field note: "I feel comfortable 'charting' (making notes in my study binder) on this unit because everyone seems to always be writing things down; sense of documentation" (Fieldnote #5). In fact, simply being on the unit without 'doing' anything made me stand out rather than blend in.

#### 5.6.2.1.2 Shadowing.

Bate and Robert (2007) describe shadowing people as they go about their day-to-day activities as a research technique that allows "experiential learning, as a means of recording behaviour, and as a means of understanding roles or perspectives" (p. 89). At the outset of my study I wondered if

<sup>&</sup>lt;sup>98</sup> An example of prompts I asked myself while observing included: What types of verbal and non-verbal language are patients and staff expressing during interactions?
hospital staff in a gatekeeping role might be selective about relaying information to me, or even block access to potential patient and family participants I was interested in talking to. I thought staff may have had concerns about being too busy, suspicious of my research, protective of their patients, concerned about being judged personally or about exposing issues outside their unit (Creswell, 2013, p. 171; Gill et al., 2014; Nind, 2008, p. 9). My strategies to minimize this potential challenge included prolonged observation in each unit to develop trust with staff, patients and families, shadowing several people on each unit, and triangulating data collection techniques (Given, 2008, p. 431; Yin, 2014, p. 241). As I described above, my experience was that I was highly supported by the unit staff to approach patients and family members.

My data collection began while shadowing Amir on patient care units. As my study progressed, I continued to shadow him at meetings related to my case studies throughout the organization. Most of my time collecting data occurred shadowing patients, families, staff and volunteers over eight months on the two patient care units where Case Study A was implemented. As Gill et al. (2014) state, "Perhaps more intensely than any other research method, [shadowing] is a physically and mentally demanding activity" (p. 76). After each shadowing shift I spent considerable time journaling and writing analytic memos to engage with and understand my data better (Creswell, 2013, p. 168).

#### 5.6.2.1.3 Shadowing patients and family members (sampling frame/primary focus).

DiGioia and Shapiro (2012) further explain the nature of shadowing patients and families as "the direct, real-time observation of patients and families as they move through each step of a Care Experience in any health care setting" (p. 4). In this context, these authors define care experience

as, "the patient's and family's journey through a specific cycle of care" (DiGioia & Shapiro, 2012, p. 2). Sitting with patients and families and looking at the experience through their eyes allowed me to gain valuable insight into "This is how it feels,' not just 'This is how it looks'" (DiGioia & Shapiro, 2012, p. 8; Institute for Family-Centered Care and Institute for Healthcare Improvement, 2008, p. 77; Royal College of Physicians, 2012, p. 3).

On Unit #1, typically, the unit leader facilitated recruitment by approaching the patient/family member, providing them with a study information sheet (see Appendix G), and asking if they were interested in talking with me. To minimize undue influence or stress on the patient–provider relationship, staff did not recruit patients and families directly (Canadian Institutes of Health Research et al., 2018, p. 135). I subsequently approached patients and families who expressed interest to explain the study and review the consent form (see Appendix H). Interested patients and families signed the consent form and we negotiated when and where the shadowing would start and finish.

#### 5.6.2.1.4 Shadowing hospital staff and volunteers (agents shaping context).

On Unit #2 (and also on Unit #1 to a lesser extent) I shadowed point of care unit staff ("Research Mentors") as a way of learning about patient and family experience as well as understanding the perspectives of agents shaping context of the QI interventions being studied. The unit manager's criteria for pairing me with staff appeared to be based on the nurse's patient assignment (e.g., infectious contact precautions, patient stability, type of care processes that needed to be done) and the nurse's interest in mentoring me. Occasionally I set up shadowing sessions directly with specific staff members in advance. For those staff who agreed to be shadowed, I reviewed the

consent form and obtained their written consent to function in a *research mentor role* (see Appendix I). The research mentors then explained my study and role to other staff, patients and families verbally and via unit communications (e.g., email and study materials, see Appendix E and Appendix G).

#### 5.6.2.2 In-depth interviews.

The interview – talking with a person by asking questions and receiving answers – has long been the mainstay of qualitative research (Punch, 2014, p. 144; Thorne, 2016, p. 136). "It is a very good way of accessing people's perceptions, meanings, definitions of situations and constructions of reality" (Punch, 2014, p. 144). Participants are more likely to express what they want to tell researchers about their perspectives and experiences during open-ended interviews (Bate & Robert, 2006, 2007; Kvale, 2009; Mack et al., 2005; Thorne, 2016). After conducting many hours of participant observation that included informal conversations with patients and families, shifting to in-depth semi-structured<sup>99</sup> interviews allowed me to better understand individuals' life contexts, and what patient and family attitudes and behaviours meant to those enacting them. These formal interviews also allowed me to challenge existing patterns and build new patterns in my data.

<sup>&</sup>lt;sup>99</sup> Given (2008) describes a semi-structured interview as "a qualitative data collection strategy in which the researcher asks informants a series of predetermined but open-ended questions. The researcher has more control over the topics of the interview than in unstructured interviews, but in contrast to structured interviews or questionnaires that use closed questions, there is no fixed range of responses to each question" (p. 810).

#### 5.6.2.2.1 *Recruiting and interviewing patients and families.*

I approached recruiting patient and families for interviews in the same way I approached shadowing – primarily using theoretical sampling and with some convenience sampling (as described above in Section 5.6.1.1). I also asked several patients whom I had previously shadowed or talked to informally on the unit if they would like to participate in a formal interview. For those patients/families who expressed interest, I explained the study, reviewed the interview consent form (see Appendix J), and scheduled the time and place for the interview. In my study, all interviews were conducted face-to-face, as recommended by qualitative research theorists (e.g., Taylor, Chandros Hull, & Kass, 2010). In other researchers' interview-based studies about patient experiences and health care system improvements, some interviews were held at the bedside at the time of discharge (e.g., Daniels et al., 2012) and others were conducted at home, post-discharge (e.g., Kemp et al., 2016). In my study, I gave participants a choice about where the interview was held (e.g., in hospital; at their home) to give patients and family members an opportunity to reflect on their care experience(s) in its entirety, to feel more comfortable relaying their experiences. Two of eight interviews were held in patient homes.

At the time of the interview, I obtained and documented consent. As part of the informed consent discussion, I asked participants to give permission for audio recording and to alert me to anything they did not wish to be recorded. No participants declined recording or asked that anything be left out. Each patient/family interview consisted of an in-depth, semi-structured interview ranging in duration from 21 minutes to 2 hours and 6 minutes. Interview duration depended on factors such as my rapport with the interviewee(s), the interviewee's apparent

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interest in the conversation, and in one case, the interviewee's capacity to participate due to their fluctuating medical situation.

#### 5.6.2.2.2 Trigger questions and the process of interviewing.

To operationalize the perspectives and thinking discussed in Chapter 4 in my research interviews, I used a series of open-ended trigger questions developed for this study (Appendix K) in collaboration with my doctoral committee and with input from my research sponsor and patient partners. Collen (2006) describes a trigger question as "a prompt posed by the researcher to elicit a self-report from the participant. It is an initial direct question that sets into motion the self-reporting process of data collection" (p. 341). Questions included, for example, "I'm wondering what patients notice about what [Study Hospital] is doing to promote cleanliness at the hospital?" I used questions to signal the concepts of interest in my study while "giv[ing] the speaker the opportunity to take it somewhere else" (Bate & Robert, 2007, p. 85). Where possible I incorporated the participant's own language (words and phrases) to probe further.

Interview procedures varied for each patient/family situation. I considered the patient's or family member's health condition, comfort level talking about their care experiences, location preference, and whether the participant was alone or with someone else. As I explored patterns and themes in my data over the course of the study, my phrasing of trigger questions evolved. I aimed to, as Jacob and Furgerson (2012) advised, "trust [my] instincts and be ready for surprises" (p. 4). Despite my best intentions, I acknowledge that some study participants may have felt judged or unhappy with their interactions with me. Other than my interview with

patient-participant Evelyn (a situation I describe in Chapter 6, Section 6.2.2.2), I do not have specific examples of this in my data or my observations.

#### 5.6.2.3 Fieldnotes, reflexive journaling, and an audit trail.

As described above, I used fieldnotes extensively. For each one of my formal research interactions at the study site (for example, observing a project team meeting, shadowing a patient or nurse, interviewing a patient, or presenting an update about my research to staff) I captured my notes on a *data collection form* (see Appendix F) that was guided by my observational protocol (Creswell, 2013). I integrated reflexivity into my fieldnote process to learn about possible triggers for my thoughts and emotions, and to explore content areas I was more (or less) comfortable with, emphasizing, or avoiding. Using Doane and Varcoe's (2015) framework to "observe the relational interplay", I posed continual questions to myself about what I was observing, and my own thinking and responses to what I was observing (Berger et al., 2014, p. 221). Fieldnotes capturing complex forms of social interaction such as facial expressions and non-verbal cues formed an important part of my analysis. For example, the following excerpt from my fieldnotes in Table 5.7 describes the interplay between my observations about a patient-participant's non-verbal cues and my reflexive process about my role in this observation (Fieldnote #6):

Table 5.7 Example of researcher observations and reneetions as documented in neumotes.	
Researcher Observation	<b>Researcher Reflection</b>
Patient had eye contact with me most of the interview,	This eye contact was interesting,
except when he was thinking, then he looked up.	because I felt like I didn't want to
	interrupt it and look down at the trigger
Some non-verbal facial gestures when he was talking	questions. I did glance down
about nurses who made him feel uncomfortable - his	occasionally and that seemed to work
eyes sort of narrowed and he looked off to the side.	ok.

Table 5.7 Example of researcher observations and reflections as documented in fieldnotes.

At the end of each interaction I asked myself a series of reflective questions on the shadowing experience, such as awkward moments, what worked well and what worked less well. During this study, in addition to fieldnotes, I wrote a series of reflexive notes related to epistemological, interpersonal and ethical aspects of the research (Guillemin & Gillam, 2004) and how my personal experiences may be shaping my interpretation of the data. Thorne (2016) states that an audit trail of reasoning is "essential to being able to ask yourself later on 'how is it that I came to that understanding?' and to produce a reasonable and credible answer" (p. 153). Incorporating reflexive journaling into my iterative data collection and analysis process aided me in helping participants to reflect on their experiences, to notice what I paid attention to and how I constructed meaning from my study data, and to imagine myself in patients' and family members' situations in order to better understand them more fully. Thorne (2016, p. 239) suggests including excerpts from interview transcripts and fieldnotes to serve as part of the audit trail and internal logic to connect a study's purpose, process and context, and I have done so in Chapters 5 and 6.

#### 5.6.2.4 Utilizing documentary evidence.

I collected organizational documents (e.g., plans, reports, policies, signage, brochures) and studied these data to provide context about the general concepts of interest to me in this study: quality, safety, patient/family-centred care, and hand hygiene (Balik et al., 2011; Bate & Robert, 2007, p. 84; Punch, 2014, p. 159; Rubenstein et al., 2014; The Health Foundation, 2014a). I also recorded and photographed organizational details including signage (e.g., such as wall posters) and objects (e.g., such as hand dispensers and sinks) located in public and patient care areas of the Study Hospital to capture information that patients and families are exposed to in the hospital environment (Bate & Robert, 2007, p. 90; Given, 2008, p. 620). As recommended by qualitative research methodologists (Given, 2008, p. 621), I used some of these photographs as visual prompts during conversations with patient and families to help focus on hand hygiene and aid participant recall so I could more fully explore meanings attached to them.

#### 5.6.3 Constructing meaning and knowledge.

Analysis allows researchers to make sense of all the data they collect. Consistent with Thorne's (2016) interpretive descriptive methodology, I constructed patterns and themes from the data; they are a synthesis of what I observed together with my pre-informed (reading, perspectives) thinking. Written data sources (interview transcripts, fieldnotes, and reflexive notes), and other documentary material (such as organizational reports or patient material on infection control) were securely saved in Microsoft Office programs and NVivo 10. These software programs provided a structure that helped me to organize the analysis.

Audio recorded interviews were transcribed verbatim by one transcriptionist who noted features such as speaker overlaps and emphasis on particular words and syllables. I listened to all interviews in their entirety to confirm accuracy of the transcript and altered each transcript to mask participant and Study Hospital identity (described further in Section 5.7.2). I added further contextual notes to document what "may have been communicated nonverbally but quite clearly in the interactional moment" (Thorne 2014, p. 109) such as tone of voice, emphasis, pauses, laughter (Given, 2008, p. 41) and I made reflexive notes in response to my experience of engaging with each interview again.

The theoretical justification for this study supported using a relational ecological frame to guide the iterative process of data analysis. As noted above, I continually interrogated my thinking according to this theoretical frame, and evaluated what was revealed about the patient and family experience of (as well as the process of) QI interventions, and what patient and family experiences revealed about ethical strengths and tensions in QI. I reviewed my progress with my doctoral supervisors and my whole doctoral committee at regular intervals. In what follows, I describe how I constructed meaning from the data using an interpretive description design (Thorne, 2016), whereby analysis occurred in three overlapping phases: description, analysis and interpretation.

#### 5.6.3.1 First analytic phase: Describing data.

The description phase involved becoming familiar with and staying close the discrete data; for example, by listening to interview recordings and reading transcripts and fieldnotes several times. Miles and Huberman's (1994) analytic framework (data condensation, data patterns and themes, and drawing and verifying conclusions – see Figure 5.3) and mind mapping exercises (Tattersall et al., 2011) were helpful in organizing the data for patterns and ideas, and assigning temporary labels to groupings of meaning. Data patterns included patient and family perceptions such as patients who perceived care providers as "busy". Data patterns also related to the patient hand hygiene QI implementation. For example, early on in my data collection I noted some inconsistency in what I had heard in the QI project team planning meetings about how the *patient hand wipes* intervention was going to be implemented, and what I saw happening while observing on the patient units. I also began to form ideas about patients' and families' general

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attitudes towards and connections with their health care environments and how they made sense of this. I describe my processes of addressing questions in my data below.



**Figure 5.3 Miles and Huberman interactive model: Three concurrent flows to study patient experience.** From © Miles, M. B., & A.M. Huberman (1994). *Qualitative data analysis: an expanded sourcebook*, 2nd ed. Thousand Oaks: Sage Publications. Page 12. Adapted with permission from publisher.

#### 5.6.3.2 Second analytic phase: Analyzing data.

The data analysis phase involved reacting to similarities and differences in the data both within and across cases (hand hygiene interventions) and participants, as well as understanding and absorbing patterns as they formed relationships and revealed the meaning of the whole (Thorne, 2008). Throughout my study I aimed to integrate each individual's unique life context (Cox & McDonald, 2013, p. 226) into my analysis. My ethical analytic framing guided a theoretical interpretation of observed behaviours using interpretive and power lenses. My main interest was in the relational interplay concerning patient and family interactions with self and others, what was said, as well as what was left unsaid.

In my study, constructing meaning took place at two levels. First, I (the researcher) constructed meanings about if, how and why study participants constructed meanings related to specific new QI interventions integrated within their routine health care/their daily work. In doing so, I took

into consideration what I could observe about the context of participants' larger experiences inside and outside the hospital. Second, I constructed meanings about what the whole of these data meant; this context enabled me to describe and interpret patient and family experiences. As Crotty (1998) noted, phenomena are shaped by cultural and social forces and each person constructs the same events in different ways. My analyses included what I perceived to be inconsistencies and gaps in participant reports of their experiences in the context of my evolving understanding of the QI intervention implementation in the organization. For example, some patients perceived the hand wipes intervention to be meant for cleaning their (patients) hands, while other patients perceived that the wipes were for staff. Consistent with constructionism, I considered that all knowledge claims were partial (Given, 2008), perspectives could shift over time, and thus my data would present me with the dilemma of "competing knowledge claims" (Given, 2008, p. 911) as I observed different versions of similar events.

As I began to form interpretations of the context of patient and family experiences, my theoretical framing continued to help me to ask questions of the data and increase my understanding (Given, 2008). Having two patient partners accompany me throughout my research journey was invaluable because they challenged and confirmed my questions and interpretations through the lenses of their own hospital experiences (I describe some of these patient partner contributions in later chapters). I was also mindful of the hazard of relying too much on my pre-study conceptualizations (Thorne, 2008). Proceeding inductively, I captured additional theoretical insights that could not have been identified before the study. I used these insights about how layers of meaning construct the patient and family experience to triangulate

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perspectives and experience (Creswell, 2013; Thorne, 2008, pp. 108–109). In what follows, I elaborate on the role of patient and family stories in my data and in theme construction.

#### 5.6.3.2.1 Role of patient and family stories in reporting data.

Patients' and their family members' views and experiences comprise the majority of the data reported in this dissertation. In my study, participant stories were a starting point to shape my analysis by surfacing the complexity and diversity of contextual, relational and values-based aspects and sensitizing me to "ethically important moments" (Guillemin & Gillam, 2004). I considered Moezzi et al.'s (2017) account of participants describing their representations of what was going on around them "in terms of content, actors, relationships, power, and structure" (p. 1) in the larger context of their health care and larger lives ("what it all meant"). As a methodological choice, I constructed particularly powerful "patient and family stories" (e.g., Olivia's Story) based on experiences and perspectives as voiced by actual study participants. These data were complemented by my own observations and data relayed to me about patients and families by hospital staff, volunteers, and other patients/families.

Stories based on particular participants helped to situate my study findings and began to illustrate my interpretation of the variations and context-nuanced responses that patients and families had to the QI intervention (Thorne, 2016). Participant responses sensitized me to central elements of my thematic analysis that ran through the subsequent narrative (Thorne, 2016). In other words, during data (story) construction, I used key features of these patient responses as starting points to continue my analytic exploration. Similar to the way other researchers have presented data on participant experiences (for example, M. McDonald et al., 2014), I submit that the stories

presented in this dissertation signal the diversity of patient and family experiences in my sample and the contexts in which these experiences occurred, but may not be representative of all patients and families.

#### 5.6.3.2.2 Constructing themes.

Key points of each patient or family story became linked to other participant stories. In other words, stories helped me to construct common themes from the whole of my data. Themes "were selected on the basis of their capacity to convey an appreciation for the context of the phenomenon" (Thorne, 2016, p. 192). Staying close to the data, I used patient words and phrases (such as "we are clean people") to label provisional groupings. Interpretive description methodology guided me to focus on patterns, rather than on quantification or codification (Thorne, 2016). Given that this study was a relational inquiry, the focus always went beyond individual or dyad behaviours and each theme crosses the relational spectrum to consider intrapersonal, interpretsonal and contextual layers of analysis (Doane & Varcoe, 2015).

The emerging analysis involved describing what I was observing about the pilot QI hand hygiene intervention (Case A), the patient/family experience of this QI intervention, and the context of other relational attributes of patienthood such as being ill, relationships with health care providers and the health care environment, and other hand hygiene activities (including Case B). As I have indicated above, I approached this study with a meso level view using theoretical sampling. As my goal was to understand patient and family experience in context (not to evaluate the QI intervention), I placed greater focus on the patient/family experience (Bate & Robert, 2007) rather than on the steps and stages in the QI implementation. For example, I came

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to realize that some patients were unfamiliar with the *pilot hand wipes* QI intervention. I discuss these data in later chapters, using techniques such as metaphoric (Thorne, 2016) and composite representation (Thompson & Kreuter, 2014; Willis, 2018). I then explored the potential implications of these interpretations for patients, families, care providers, volunteers, the Study Hospital, and the health care system. In response to and in addition to the themes constructed in the context of implementation of the *patient hand wipes* QI intervention, I constructed one metatheme from the whole of my data, responding to the overall phenomenon of interest.

#### 5.6.3.3 Third analytic phase: Interpreting data.

Finally, the interpretation phase required 'recontextualization'. This means considering the implications of applying findings that 'ring true' to participants in real-world settings (Thorne, 2014, p. 109). As noted above, interpretation occurred throughout the study process. The intent of my study was to uncover knowledge that is relevant for practice rather than formal theorizing. Indeed, as I have noted earlier in this chapter, interpretive descriptive studies such as mine "do not require the full scale of analytic depth that theoretical sampling contributed in grounded theory methodology" (Thorne, 2008, p. 92). Ultimately my analysis generated an overall description of the meanings that patients and families in my study drew from their experience of care in relation to two case studies of QI interventions involving patients and families in a Canadian acute care hospital. Thorne (2016) states, "interpretive description explicitly acknowledges that your interpretive brain has been in action throughout the process" (p. 215). The reflexivity process, my personal experiences and exposure to media also shaped my analytic insights and interpretation of study data. For this reason, I include some of these insights into my results and discussion chapters.

#### 5.6.4 Enhancing credibility.

Credibility represents the "truth value" of a qualitative study; that is, when the human experience captured resonates with others who experience the same phenomenon (Sandelowski, 1986, p.

30). Sandelowski (2015) has recently stated:

Over the last three decades, the number of texts addressing quality (also referred to as rigor, credibility, trustworthiness, validity and the like) in qualitative research has increased exponentially.... Despite all of this activity, however, no consensus exists on how to define or evaluate the diverse array of studies in the qualitative research domain and even on whether standards are possible or desirable. (p. 88)

My central aim has been that my findings resonate with other patients and families with experience of the same, or a similar, phenomenon. However, an important and unique aspect of this meso level study is that 'patient experience' is situated in the context of a pilot QI intervention on hospital units treating patients with chronic illness. Patient and family stories did not all provide flattering depictions. My findings uncovered some situations where patients and families viewed aspects of the hand hygiene interventions (and other areas of their care) differently than hospital staff. An important secondary aim of mine in this research has been that my findings resonate with health care staff and patient partners who have experience designing and implementing similar types of improvement interventions. These findings do not invalidate one group's perspective, but, rather, provide opportunities for learning across diverse groups.

In summary, a study such as the one I have undertaken here is deemed credible when the human experience captured in the findings resonates with patients and family members with experience of a similar phenomenon. Working within the applied interpretive descriptive approach, I have aimed to make explicit my internal logic to align the purpose, process and context of this research into a coherent and convincing account (Thorne, 2016, p. 239) of hospital patient

experience of pilot QI interventions at the point of care. In what follows, I outline specific strategies and steps to ensure rigour in the various aspects of my research process to produce credible research. In so doing I draw on Thorne's (2016) four guiding credibility principles: epistemological integrity, representative credibility, analytic logic, and interpretive authority (pp. 233–235).

First, epistemological integrity addresses the question, *are the research questions plumb with the epistemological standpoint and interpretive strategies*? (Thorne, 2016, p. 233). I claim this study has epistemological integrity because the theoretical paradigms and perspectives, methodology and methods selected and how they were carried out are consistent with each other and the purpose of the research.<sup>100</sup> Together, these decisions correspond with the study's practical focus and allowed me to study the enactment of values in complex sociopolitical contexts.

Second, representative credibility addresses the question, *are the researcher's findings/ knowledge claims consistent with how the phenomenon was sampled?* (Thorne, 2016, p. 234). Triangulation of primary and secondary data sources (prolonged participant observation [fieldnotes], interviews [audio recordings and transcripts], documentary material, reflexivity [journal entries, analytic memos], and multiple study units) was used to develop my "inherently constructed perception of an event of process" (Thorne, 2016, p. 234). My interpretations reflect a study sample drawn from two acute care units treating patients with chronic conditions. While

<sup>&</sup>lt;sup>100</sup> In this study, I claim that I have constructed an interpretation of personal experience that is *relative to* a specific context (e.g., a particular setting and time). Note that this is not a *relativist* knowledge claim, which would take "the view that there can be no ultimate truth, and that therefore all perspectives are equally valid" (Burr, 2015, p. 238).

my findings may resonate with other patient groups (for example, a different chronic condition), and have relevance to other types of QI initiatives (e.g.,, targeting medication safety rather than hand hygiene), or other health care organizations (e.g., long term care), my knowledge claims are consistent with my study sample.

Third, analytic logic addresses the question, *can a reader – given an appreciation of discipline and context – confirm or reject the credibility of the researcher's decision-making pathway process (from structure through to interpretations and knowledge claims)?* (Thorne, 2016, p. 234). To demonstrate procedural rigour and ensure the logic supporting my interpretations, during my study I saved and dated each fieldnote, interview transcript, reflexive journal entry, analytic memo, mind map, doctoral committee/patient partner discussion, and internal document. These study records documented data collection, analytic decisions, and how patterns developed in my interpretations. For example, patient and family stories about their relationships with health care 'places' prompted me to seek an understanding of the role institutions play as moral agents (Fieldnote #7). To reconstruct scenes and conversations from my data, I provided substantial samples of verbatim accounts of interviews and fieldnotes. In doing so, I aimed to provide rich description (Given, 2008) along with explanatory details about the context of the data sample and why I chose it to represent a specific claim so readers could see similarities and differences of my findings with that of different contexts.

And fourth, interpretive authority addresses the question, *do the researcher's interpretations of the data reveal some truth beyond their own bias and experience (i.e., are they trustworthy)?* (Thorne, 2016, p. 235). As explained above, an important process in my journey as a researcher

was a rigorous practice of reflexivity. As the research instrument in this study, I continually sought clarity on my own values, reactions, attitudes, behaviours, experiences, and motivations or intentions in making specific interpretation or knowledge claim. For example, during my study I had several experiences as a family member in hospital settings and had an opportunity to examine my own willingness to ask care providers if they had cleaned their hands. In addition to reflexivity, strategies to incorporate interpretive rigour included: aiming to stay close to and take a holistic view of the data; sharing samples of verbatim data from my reflexive notes in this thesis; reviewing each transcript while listening to the audio recording to check for accuracy and add contextual notes (Given, 2008, p. 41); researcher triangulations (discussing the original data with my doctoral supervisory committee); and processes to check in with my evolving and emerging interpretations with study participants (such as asking clarifying questions and paraphrasing) and beyond (such as anonymized discussions with my patient partners, and presentations to patient groups, point of care staff, quality leaders, and at conferences).

To reinforce the significance of my strategies to enhance credibility in this study, I return to the study's purpose, which is to understand the patient/family experience of QI implementation in order to influence the efficacy and ethics of QI processes. Thorne (2016) states, "health science disciplines exist because of a social mandate that entails a moral obligation toward benefiting individuals and the societal collective" (p. 233). I discuss the professional obligations and implications of sending research products – even high quality, credible products – out into the field in Chapter 9.

#### 5.7 Managing Data and Confidentiality

As required by the UBC Faculty of Graduate Studies, the study data belong to the doctoral researcher, Brenda Sawatzky-Girling. During the process of completing this study, I engaged in an ongoing dialogue with my doctoral supervisory committee and Amir my research sponsor (as a representative of the Study Hospital) to ensure a clear and mutual understanding about data arrangements.

Thorne (2016, pp. 150–151) describes data management as the process of tracking, organizing, and sorting data collected from the field. Appropriate management ensures the data are protected and can be accessed as needed during and after the study. Furthermore, managing data confidentiality is a central aspect of attending to research ethics (Canadian Institutes of Health Research et al., 2018). Indeed, McDonald (2000) asserts that the research enterprise is predicated on "trust between the research community and society as a whole" (p. 12). In my study, the Study Hospital's trust in my ability to interact with, obtain, and appropriately use information autonomously shared by their patients, families, and staff enabled me to conduct my research. The next section in this Chapter outlines my strategies to protect participant and institutional confidentiality in reporting research findings and in study records: what data are shared; when, with whom, in what format; and how identifying information is obscured.

#### 5.7.1 Confidentiality within institution (Study Hospital).

Thorne (2008) notes, "At the outset of a study, it can be difficult to appreciate just how complicated institutional confidentiality can be" (p. 122). Respecting and protecting institutional and participant confidentiality include several challenges. For example, "anyone closely tied to a

particular research setting will likely be able to recognise participants and places" (Saunders et al., 2014, p. 3). Data that could identify participants and staff therefore were not and will not be shared with the Study Hospital's employees/volunteers.

During the consent process with patient and family participants, I emphasized my role as researcher (not caregiver); and that patients/families should give important information related to their medical care directly to their care providers, not to me. Hospital staff and other patients/family members may have been aware of participants' involvement in my study. Full confidentiality of participation at the study sites was not always possible because (1) staff were facilitating patient and family participation in my study, and (2) I could be seen talking to participants (patients and staff) on study units. As a researcher, I attempted to keep participant involvement confidential by not passing on any identifying information in the context of my data collection. However, there were some exceptions to this, for example, several times I brought what I believed to be incorrect information to the attention of a clinical leader in order to prevent a potential medical error.<sup>101</sup> These are instances of my professional obligation to intervene (Canadian Institutes of Health Research et al., 2014, p. 145; Creswell, 2013, pp. 166–167; Thorne, 2008, p. 80,120; World Health Organization (WHO), 2013a, p. 27). In situations where several family members chose to be shadowed or interviewed at the same time, I encouraged participants not to discuss the content of the shadowing/interview to people outside the group. However, as a researcher I cannot control what participants do with the information discussed.

<sup>&</sup>lt;sup>101</sup> For example, I wrote in my fieldnotes, "I considered this in the medical error realm so passed the information on. [Unit leader] was going to look into it" (Fieldnote #9).

#### 5.7.2 Confidentiality in reports of study findings.

Research findings are meant to end up in the field where the study is conducted, and ethical and political responsibilities go along with that. Calabrese (2013) notes that "there is also a special responsibility that goes along with forming personal relationships with people in the field and collecting their stories, especially those who are suffering from a particular illness or adverse socio-economic situation" (p. 23). Given the significant role of context (relational, environmental, organizational) in this interpretive description inquiry and the pragmatic objective of producing actionable information, this study required knowledge exchange (KT) *during* the study to promote mutual learning and ensure credible, respectful findings that could be disseminated after the study (Canadian Institutes of Health Research, 2014; Thorne, 2008). My patient partners were particularly helpful at helping me to reflect on my emerging findings and prepare me to explain my findings to people outside the research team (Canadian Institutes of Health Research et al., 2018). During-study KT included presentations to Study Hospital staff, patient groups, and a senior-level committee aimed at improving patient/family experience. These opportunities helped keep my analysis on track by giving stakeholders an opportunity to reflect on my emerging analysis. For example, during the study, stakeholder responses to my emerging findings enabled me to validate my results, interpret the context, increase my awareness about disciplinary and epistemological assumptions, mischaracterizations, sensitivities to the way findings are portrayed, privacy considerations, as well as the language in which people understand my findings and recommendations.

Study findings reported in this doctoral dissertation will be available to the public (see below).<sup>102</sup> My commitment to protect the identity of research participants and the study site sensitized me to the importance of *masking*. Thus, I do not provide extensive detail on my sample, yet convey enough to allow the reader to interpret my findings. As is accepted in the qualitative tradition, I used the following strategies to avoid deductive disclosure or contextual clues (Kaiser, 2009, p. 1632; Nisker, 2013, p. 119) and maintain institutional, study unit, and participant confidentiality:

- The Study Hospital is described obliquely (Thorne, 2016, p. 132) as a universityaffiliated acute care teaching hospital in BC's Lower Mainland.
- More than one patient care unit was studied, and some descriptions are general to mask the specific unit;
- Details from organizational reports are masked.
- There is limited reporting in Tables 5.4 and 5.5 of participants' identifying details including age, gender, ethnicity, occupation, place of work, residence, familial relationship, medical history, and/or diagnoses.
- I used pseudonyms<sup>103</sup> and altered details describing people, groups, places, or events (Given, 2008, pp. 339, 692). Pseudonyms enable readers to connect to the participants as persons and relate to their stories.

<sup>&</sup>lt;sup>102</sup> In the future, should the data lead towards unanticipated forms of disseminating these study findings, attempts would be made to re-contact participants to request permission to use their data in these unanticipated ways (Kaiser, 2009, p. 1637).

<sup>&</sup>lt;sup>103</sup> Assigned pseudonyms (see Appendix L) are primarily based on *Baby's Most Chosen Names in British Columbia* (BC Ministry of Health, n.d.-a)

- Narratives that reflect a potentially identifying speech style have been changed in direct quotations (e.g., colloquial English).
- In Chapter 6, 'Susanne's Story' is a composite narrative comprised of situated accounts from multiple patients and families to convey my observational data of (1) the *patient hand wipes* intervention unfolding; and (2) typical aspects of the central patient/family themes in my findings (Thompson & Kreuter, 2014; Willis, 2018).
- I assigned each participant a code number for my research records, and these code numbers are not disclosed.

#### 5.7.3 Disseminating findings.

After the dissertation is published, I will present a summary of main messages and recommended practices to the Study Hospital's senior leadership team, and I will provide a short plain language summary to study participants who indicated they wanted to receive one. While the ultimate potential beneficiaries of this research are patients and families, the study's primary audience is health care leaders; those who design and implement QI interventions, health care providers, ethicists, and health care services researchers. I have presented my early research findings at the BC Patient Safety & Quality Council's Quality Forum in 2016, and a summary of my findings at the 2018 Quality Forum.<sup>104</sup> I also presented my findings at the 2018 Canadian Bioethics Society conference and at the 2019 Qualitative Health Research Conference. My future plans to disseminate my findings from this study include health care leadership, qualitative research, and patient-family centred-care publications and conferences. When completed, this dissertation will

<sup>&</sup>lt;sup>104</sup> The BC Patient Safety & Quality Council has housed the *Patient Voices Network* since 2015.

be publicly available on cIRcle, UBC community's digital repository for research and teaching materials (The University of British Columbia, n.d.).

#### 5.7.4 Confidentiality in study records.

Study records include paper and electronic documents and audio recordings. Only the signed consent forms and the master participant list contained participants' names. All other study documents identify participants only by a code number and provisional role categories such as 'patient' or 'care provider'. During the study, paper documents were kept in my home office in a locked filing cabinet to which only I had access. Electronic documents and audio recordings were password protected and encrypted, and stored on my password protected computer and external hard drive to which only I have access. Audio recordings were stored temporarily on a digital recording device and then transferred to computer. Audio recordings included information that could identify participants or others; these unmasked recordings were shared with one professional transcriptionist who was required to first sign a confidentially agreement (see Appendix M). As noted above, I verified accuracy of and masked each transcript.

Study documents and audio recordings were shared with my supervisory committee (Dr. Patricia Rodney, Dr. Sam Sheps, Dr. Michael McDonald, Dr. Daniel Steel) to guide and verify the integrity of the research. If requested, study records could have been shared with the REB for the purpose of monitoring the study to ensure it was being conducted ethically. Other than my doctoral committee and potentially the REB, information that discloses participant identity (such as signed consent forms) will not be released without participant consent unless required by law. Study documents and audio recordings will be kept in the central office in the UBC School of

Nursing for at least 5 years after the dissertation is published. At the end of the storage period hard documents will be shredded and digital files deleted.

#### 5.8 Chapter Summary

In this chapter I described the qualitative inquiry paradigm, why reflexivity is a central value and process in qualitative research, and the interpretive description and case study methodologies I used to plan and implement my doctoral study. I described the complex process of gaining entry that was essential in defining the study and allowing me to design and launch a feasible study focusing on patient and family experiences in relation to hand hygiene QI projects. Further, I explained the processes involved in constructing data including sampling, recruiting, collecting data, and how I constructed meaning and knowledge from the data and incorporated strategies to enhance credibility. I also summarized the strategies used to manage data, maintain trust and confidentiality, and report findings. In the next chapter I present my study findings.

#### **Chapter 6:** Findings – Patient and Family Experiences in Context

#### 6.1 Chapter Overview

In this chapter, I present the results of my research. My goal is to offer a rich description of patient and family experiences in the context of a pilot hand hygiene intervention. In so doing, I describe the central themes constructed from my data in response to important aspects of patient and family experiences at the point of care. To situate my research process and these findings in a context specific to time and place, I describe four journeys, which are: (1) my own journey as the researcher, and my interactions with (2) the *patient hand wipes* QI intervention (the primary case study) as it unfolded in real time in the Study Hospital; (3) hospital staff and volunteer experiences; together culminating in (4) patient and family participants' experiences of specific and essentially chronological. In this study, time sequence is critical for two reasons. First, relational inquiry and social ecology theory emphasize that time is a significant element in shaping the context of people's experiences. Second, time is uniquely related to the nature of QI interventions, typically designed as changeable pilot projects with starts, stops, and pauses.

In **Part A** of this chapter I present my main study findings about patient and family experiences of QI. Using interpretive description methodology (Thorne, 2016), I have generated a written report of findings that is predominantly descriptive with an interpretative process, and organized around a thematic summary. I constructed one meta-theme emphasizing the importance of relational connections, and three themes more specifically constructed in the context of the QI pilot projects on patient hand hygiene. Each theme crosses the relational spectrum to consider intrapersonal, interpersonal and contextual layers of analysis.

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In **Part B** of this chapter, I describe my observations about QI implementation to provide context in this study. The *patient hand wipes* QI projects did not happen as I had expected on the basis of the project plans (see Table 5.2), and I observed differences between what the QI project teams intended and what staff, volunteers, patients and families did at the point of care. My research did not evaluate the effectiveness (or other measures of success) of the QI interventions studied. Rather, information about project implementation contributed to my interpretation by placing the patient and family-focused themes described in Part A into the context of the particular situation studied.

#### 6.2 Part A: Patient and Family Experiences of QI Interventions

Patients and families are the primary agents of this this dissertation, while the nurses and doctors involved in their care are the supporting cast. It was a privilege to observe and speak with chronically ill patients undergoing treatment in hospital as well as their families. In our conversations, we touched on a variety of topics as we found common ground. Patients and families relayed historical and biographical information, thoughts, and emotional clues to me. As I described in Section 5.6.1.2, the patients and families in my study sample were a diverse group, with a wide range of familiarity with their medical conditions and the hospital unit. For example, some patients and families in my sample were navigating new medical experiences, such as receiving the diagnosis of a new condition. As well, these participants were learning about new care processes, health care settings, transportation routes, care providers, and other patients and families in similar situations. At the same time, they were assessing the impact their condition might have on their lives and the complexity of accompanying social rules and power relations. In contrast, other patients and families were 'experts' on their medical conditions, the care

processes to treat these conditions, hospital routines, and the hospital staff and volunteers. In fact, some participants had interacted with the same care providers and routines for many years.

In the pages that follow, I integrate data about patient and family experiences of the QI projects into a thematic summary. In doing so, I use patient and family stories as a focal point from which to make sense of what was going on around participants, and to illustrate the context of these experiences. The different patient/family experiences represented here are samples of those that intersected with the hand hygiene projects and my study. Participant stories sensitized me to the complexity and the diversity of patients' and families' experiences, patterns in the data, and deeper experiential concepts in a relational way. The variation in patient and family accounts points to how the context of each person's life, their motivations, their current circumstances, and health care setting can affect the values individuals have and the meanings they construct, leading to different responses to health care improvement initiatives such as a hand hygiene intervention.

#### 6.2.1 Relationship between study themes.

I used an inductive process to guide how I constructed themes to represent my ideas about patient and family experiences of QI interventions. An essential part of my analysis focused on relational connections, an area of importance to patients and families as they experienced a new care process designed to 'improve' the quality of their care. In what follows, I briefly summarize the relationship between these study themes (illustrated in Figure 6.1), and then elaborate on my construction of each theme.

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Figure 6.1 Advancing quality improvement through relational safety: Relationship between study themes.<sup>105</sup>

**A-1 Meta-theme.** My analysis indicated that the meanings of the data centred on the metatheme, "patient and family experiences of *moving towards* or *moving away* from relational connections with their care providers and health care settings." This thematic statement connects all themes to the larger whole, responding to the phenomenon at the centre of the inquiry. Relational connections reflect the *common feature* or *connecting element* through the three themes. In Figure 6.1, the arch illustrates the idea of relational connections linking all of the themes to each other.

<sup>&</sup>lt;sup>105</sup> Patient/provider Graphic (©2013 Six Seconds, by permission)

**A-2 Three Themes.** Each theme captures aspects of the way patients and families expressed meanings they made of a QI pilot project on hand hygiene. The themes are: (1) "We are clean people"; (2) "I want to be a good patient"; and (3) "We're all in this together". As illustrated in Figure 6.1, each theme (middle boxes) connects to the meta-theme. In this study, theme names or *thematic statements* hover close to the study data in that they draw on patient and family words taken verbatim or paraphrased, reflecting my construction of the patient/family perspective. Bullet points denote further sub-themes representing the multiplicity of meanings and motivations participants expressed explicitly or implicitly. This suggests that for patients and families, complex sets of reactions, perceptions and behaviours might be going on at the same time.

I portray *theme names* in positive terms for two reasons. First, while my data reflect a complex combination and range of patient and family experiences, the theme names reflect what most participants were telling me in terms of what they aspired to. Second, my use of positive terms reflects aspirational motivations that correspond with the nature of QI initiatives as well as my own commitment to contribute to health care system improvement. *Theme order* reflects the sequence of what patients and families relayed to me upon my entering the field as well as the logic of my iterative analysis.

**B** Contextual Findings. The box at the bottom of Figure 6.1 represents my significant contextual findings about QI project implementation. Importantly, this context situates the patient/family themes to a specific time and place: two pilot *patient hand wipes* projects

implemented on two patient care units in the same hospital. I describe these findings in Part B of this chapter.

### 6.2.2 Meta-theme: Patient and family experiences of relational connection.

In this study, the meta-theme was patient and family experiences of moving towards or moving away from relational connections with care providers and health care settings.



Despite a wide range of age, ethnocultural background and other indicators of social location, every patient and family participant conveyed the importance of relational connections. To set up my analysis, I provide (see Box 6.1), a study definition of *relational connection* that I adapted from several sources (Beach et al., 2006, p. S4; Boissy & Gilligan, 2016, p. 9; Canadian Nurses Association, 2010, p. 3; Cross, 2014, p. 814; Doane & Varcoe, 2013, pp. 150–151, 2015, p. 41; Henriques, 2017, p. 13; Kitson et al., 2014, p. 333; Kuhl et al., 2017, p. S77; Rodney, 2013, p. 314; Rodney, Burgess, Pauly, et al., 2013, p. 85; Sherwin & Feminist Health Care Ethics Research Network, 1998, p. 19). I elaborate on these sources in Chapter 7 (Section 7.3).

### Study Definition of Relational Connection

*Relational connection* refers to a way of connecting with oneself, others, and purpose that allows one to feel known and valued by important others and align one's attitudes and motivations with the other within particular sociopolitical contexts.



# 6.2.2.1 "You can heal a lot better if you feel like you're cared about": Connections with care providers.

In some way, all patient and family participants in my study sample expressed what connections with care providers meant to them. My study focused on patient and family perspectives; thus, patients and families are the ones to identify the 'quality' of their experiences. In this section, I provide examples from my data to show how and why patients and families expressed that maintaining relational connections with care providers was important and valued.

**Noah** and **Hannah**<sup>106</sup> were one of two couples I interviewed. In their early sixties, they expressed that they were accustomed to leading healthy, active lives. Patient Noah operated a home business. For the past six months, he had been in and out of hospitals due to a post-surgical infection. We met on the complex medical unit where Noah had been an inpatient for several weeks. During this period, the *patient hand wipes* intervention was reported to be ongoing on this unit. Hannah and Noah explained that they worked as a team. Hannah, a retired health care professional, spent most days at her husband's side, helping out. Hannah, Noah, and I spoke about their recent experiences in different health care settings. The following is an excerpt from their interview transcript: <sup>107</sup>

Researcher: So right here on [name of unit], if there's one thing that really makes it or breaks it in terms of how your day goes, how would you describe that? What really makes a difference here?

<sup>&</sup>lt;sup>106</sup> In Chapter 5, I described that to maintain participant confidentiality, all study data are reported using pseudonyms and/or composite people, groups, places, or events, and altered details.

<sup>&</sup>lt;sup>107</sup> In the reporting of study data, my observation of non-verbal cues is noted in different ways. For example, many of the patient/family interview excerpts included in this chapter have underlined sections to flag particular words or syllables that the participant emphasized in their speech. At times, my observations or clarifications appear in brackets, for example nuances of the voice such as [soft voice].

Noah (Patient participant): Attitude. The attitude of the nurses. They really care. Now they may not have the time to do all those other things [assisting patients with hand hygiene] but you can feel that they have a caring attitude.

Researcher: And without this seeming like a silly question, why does that make such a difference?

Noah (Patient participant): Uh...the difference is because if you have a caring attitude, you're looking for little things. If you're just walking through the patients...they don't even notice...See they, they're just here for the money. That sounds, I know that sounds rather crass but um I've experienced a couple in here that left me with that idea.

Hannah (Family member participant): Casuals, not, not the regular staff.

Noah (Patient participant): No not the regular staff, just casual staff. Um so it makes a difference to how you feel. Truly.

Hannah (Family member participant): You can heal a lot better if you feel like you're cared about [bold emphasis added].

Noah (Patient participant): Yeah.

Hannah (Family member participant): And you know that when you put the light on, they'll come.

Noah (Patient participant): Yeah.

Hannah (Family member participant): [soft voice] 'Cause he never, never would put the light on, hardly.

Researcher: So, do you feel that caring makes you feel more secure about that you're gonna get better care? I don't really know why I'm asking, I just, I'm interested in more about that.

Noah (Patient participant): It makes you feel secure that you're gonna get good care.

Noah and Hannah acknowledged the staff's professional competence, but they emphasized the

value of caring and connection in the context of their vulnerable circumstances given Noah's

illness. The staff's caring and connection also built on Hannah's knowledge of the health care

system. Moving toward relational connections during interactions with the "regular staff" made

this patient and his spouse feel "cared about" (e.g., knowing the staff would respond to a call bell). Hannah and Noah explained that being "cared about" was the most important aspect of their hospital experience and allowed them to feel secure and heal.

As I inquired about hand hygiene on the unit, I learned that Noah and Hannah valued personal hygiene and understood about infection control, which I elaborate on below. In the above excerpt, Noah told me that his nurses did not help him with hand hygiene. He went on to explain this was acceptable because, for the most part, at this hospital the nurses care about him and are doing their best for him in so many other ways. These comments reflected that Noah perceived positive relational connections with most of his nurses even though he perceived some gaps in his care.

Patient **Chloe** also spoke about what connections with care providers meant to her. I got to know Chloe on the dialysis unit over several weeks. Chloe had a long and complicated health history. A retired historian, she had lived in several countries during her career. At Chloe's bedside on the unit, I had my longest audio recorded interview (2 hours and 6 minutes). Chloe gave me many examples of doctors and nurses who, through their expressions of humanity, reassured and comforted her and her family members during stressful times. In this interview excerpt, Chloe describes important aspects of her experience of dialysis treatment at the Study Hospital (emphasis by participant):

Researcher: What's one thing that makes a difference to your experience as a patient here on the dialysis unit?

Chloe (Patient participant): Humanity. Care. Um that nothing is too impossible for a nurse. The time they take. The um willingness, the good-naturedness of them. Um I never seem to

see anyone in a bad mood. I see them and undoubtedly they have their personal life and but they're <u>here</u> for us...I don't know if it's the role drilled into them or whether it's particularly handpicked nurses here, or what it is.

Chloe extended the positive qualities "humanity" and "care" to each nurse working on the dialysis unit.

I was sensitized to the importance of first impressions and trust when I accompanied my own family member Mei for day surgery in another city. In the pre-operative area, a nurse named Jenny introduced herself to us. Jenny spent several minutes explaining what would happen before, during and after Mei's surgery. She encouraged questions from both of us. After the nurse left the bedside Mei turned to me and remarked, "I like her. She's good. She's smart." Mei's succinct statement matched my own impression of the nurse. I had liked Jenny too, which resonated with what I was hearing from study participants about the importance of first impressions. As Mei and I continued to wait, I asked her what good and smart meant to her in this context. Mei told me that the nurse was "good" because she was nice, and Mei felt that the nurse liked her. Mei also felt comfortable asking questions when things were not clear. Mei said that by "smart," she meant that the nurse knew her job, would not cut corners or make mistakes, and would recognize early if anything was going wrong. Mei stated that her reflection reminded her of Malcolm Gladwell's (2013) book Blink: The Power of Thinking Without Thinking. Gladwell claims whenever we "meet a new person or have to make sense of something quickly or encounter a novel situation....snap judgments are, first of all, enormously quick: they rely on the thinnest slices of experience ....they are also unconscious" (p. 50). Taken together, Mei's perception of Jenny's qualities reassured Mei she could trust the nurse to take excellent care of her. For Mei to anticipate a positive experience of care, it would not be enough for the nurse to be good *or* smart. Both qualities were essential (Fieldnote #8).

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In the context of my study findings, I came to understand that in this situation, both Mei and I *moved towards a relational connection* with nurse Jenny. As a hypothetical example, Mei would feel uneasy if she perceived her nurse did not like her, even if the nurse seemed competent. In such a situation, Mei would *move away from a relational connection* with the nurse, which might not result in a positive experience of care. Like my family member Mei, people in my study sample spoke about what first impressions meant to them as patients. In her early 40s, **Emily** already had a long history of chronic conditions that had resulted in significant disability. In this interview excerpt she explains what it is like for her to navigate interactions with care providers on the dialysis unit:

## *Researcher: Well if there's one thing that, that makes a difference to your experience as a patient coming for dialysis, one thing that's most important or--*

Emily (Patient participant): Probably the personal interaction. Uh...yeah, if the nurses are nice to you and um yeah just show that personal level of uh concern and care, then I mean even just like a small thing that they remember you from last time, right, uh it shows that there is actual concern for you, um and you can't expect them to remember every single detail about you, but even just like one small thing. For example, [nurse's name], she remembers what she did with me last time and my numbers and machine settings and stuff that just from you know just from remembering something....So small details about you, you know, that they know about, you know, that's just as comforting and trusting.

....And then sometimes you get to know the staff so you know what it can be and what you can say to them after a while. And then if it's a first-time nurse, like you know your first interaction with them, you don't know how to deal with that person.

# *Researcher:* So, it's a relationship that you can navigate over time. And with each staff member--

Emily (Patient participant): Oh yeah....Or whether, you know whether that person is ... seems receptive to, to you know some sort of interaction. And of course you know some people just want to come, do their job, and then, and they have multiple patients so they have a lot of stuff to do sometimes. And some will be here in a bad mood. Yeah, we're
all gauging a person, how receptive they seem to suggestions or criticisms, stuff like that.

Emily unpacked her ways of connecting with care providers and determining who she is comfortable with; those who seem "receptive to some sort of interaction." She was less comfortable with those who seem "in a bad mood" or "just want to come, do their job" or talk to patients rudely. I came to understand Emily was conveying that this assessment was a relational process, one that *added work* to her role as a patient. Importantly, the above excerpt also suggests that Emily connected with nurses who remembered details about her medical treatment and those with whom she felt safe to pass on her suggestions. Furthermore, how each patient/family perceives providers showing "concern and care" varies, depending on the context.

Emily's description of her comfort level with different nurses has a second dimension. Emily described to me her process of assessing to what extent she trusted care providers. For example, Emily stated, "I'm making sure that they're [the nurses monitoring her dialysis] doing things properly." Emily said that her assessment went on to shape her experience as a patient, "So I just want to be hooked up [to dialysis] and then I can just go [to sleep]. And if I can trust a nurse during that time, then I have no problem taking my nap or whatever."

Another patient, **Evelyn**, told me she had been on the complex medical unit for several weeks recovering from an assault. Evelyn talked about her interactions with care providers and other hospital staff such as cleaners. Evelyn was in her late 30s and self-identified as a First Nations woman living with problems that included substance use and unstable housing. Evelyn told me she was very sick and stressed, and was fearful that her ex-boyfriend would come into the

hospital and hurt her again. Evelyn attributed some of her current depression and anxiety to tension with her family in another city and not knowing what was wrong with her. Specifically, Evelyn voiced her frustration with the "groups of doctors" who quickly came in and out of her room, and "don't listen to me or tell me anything"; "Like I can't tell him how sick I'm feeling inside, of the depression I'm going through. Like it's off to my nurse or someone, nurses will listen, but not him, not one of the doctors stands to listen."

However, Evelyn spoke differently about the nurses. In the following interview excerpt, Evelyn describes her favourite nurses (emphasis by participant):

Evelyn (Patient participant): ....The nurse I got [Jenny] today is really good. And the other nurses, they're okay. My favourite nurse is Kamala and Matt...'cause they're right here...Jenny's good too but.

### Researcher: So, the ones that you like, your favourite ones, how are they different?

Evelyn (Patient participant): Oh, oh they're [voice goes up] way different. Kamala calls me 'baby.' 'What do you want, love? What do you need?' I said I want a popsicle; she gets me one.

Evelyn, along with many other patients and families, told me it was important to her that care providers be physically present, willing and able to help, and to listen. A particular area of importance to Evelyn was a respectful socio-emotional<sup>108</sup> presence; a relational connection. Evelyn appeared to feel most connected to nurses who hovered near her and used endearments.

<sup>&</sup>lt;sup>108</sup> Socio-emotional refers to the relational ways people initiate, cultivate and respond during interactions to foster a sense of emotional security with others (Henriques, 2011; Mentor, 2019). Henriques (2011) notes that such behaviours can include eye contact, and the expression of positive emotion (p. 87). Mentor (2019) further notes that socio-emotional aspects can be transient or ongoing, and typically, but not always, occur with familiar people (p. 1007).

Other patients told me they felt patronized when nurses and doctors called them 'dear' or 'cute'. While there is a cultural element to this interpretation (for example, 'luv' is a colloquial form of address in Britain, even with strangers), one participant in my study described these types of interactions as, "matronly but a little bit condescending at the same time". Yet Evelyn, who lives in circumstances that could contribute to her vulnerability and marginalization, described endearments as making her feel safe, comforted, and connected to her nurse. In my observations of interactions between Evelyn and Nurse Kamala on a different day, I interpreted that Kamala understood Evelyn's need for this expression of caring and connection.

**Oliver**, a different nurse I shadowed on the same unit (complex medical), told me, "I spoil patients while they are here." Actions such as bringing juice to a patient who could walk to the nursing station were his way of showing that "I'm on their side." Oliver explained that he shows extra care to patients who experience social exclusion through racism and discrimination outside the hospital. Oliver (respectfully) alluded to professional tension between his colleagues because his approach conflicted with other nurses who were more likely to apply "100% behaviour modification". Oliver's example suggests that care providers on the same hospital unit use different relational approaches to respond to the sociopolitical context of their patients' lives, and that patients respond differently to these approaches.

In summary, patients and families in my study described their experiences with care providers at the Study Hospital, on the whole, in positive terms. Many participants spoke about positive connections with specific providers they knew by name. For example, "My favourite nurse is Kamala 'cause she's right here" or "Dr. Khan really listens to me" or "Eunice is excellent, she knows what my mother needs and sure gets things done". Some participants seemed to refer to positive connections with all care providers on a particular unit. For example, "The nurses understand me here." These data allowed me to appreciate what participants told me about their connections with care providers in a larger context. The range of examples of connection, even within the same patient/family story, shows the complexity and nuance of these experiences and how people explained their experiences to themselves and to me.

*6.2.2.2 "There's a wonderful ethos in this hospital": Connections with health care settings.* Some patient and family participants in my study expressed that their health care connections extended beyond interpersonal connections with care providers. The positive statement "there's a wonderful ethos" describing the meta-theme reflects my findings that many participants spoke favourably about connections with the *places* where they received care. As the data I review below indicates, patients and families across both study units used words, metaphors and stories to convey the feeling of being known and valued – or not – in particular health care settings. As I will explain, my data showed that, at times, participants' feelings and connections extended beyond the ecological layers of their direct experience. For example, a good experience in one part of a hospital could prompt positive expectations regarding the hospital as a whole.

Many patients and families talked about their connections with a *specific patient care unit*. Both study units (dialysis and complex medical) are set up to treat people with chronic conditions. Many patients and their families had been coming to the same unit for many years. Likewise, many care providers had worked on the same unit for years. My data collection included several examples of patients, families and staff describing the dialysis unit as "it's *home*". Furthermore,

several staff, patients, and families alike referred to the camaraderie they experience on their unit being like their "*family*". One such patient was **Logan**, who had received dialysis on and off, in between kidney transplants, since he was a child. As an adult, Logan has a choice of places to come for dialysis treatment. He prefers to come to the Study Hospital's dialysis unit even though it is further from his home. I elaborate on the idea of a health care setting as home in Chapter 7.

During my fieldwork, some patients were 'regulars' on both units where the *patient hand wipes* intervention was piloted. Patients such as **Mia** required complex medical, mental health, as well as dialysis care; a challenging array of conditions for her to deal with all at once. I shadowed Mia for a few hours during her dialysis treatment. Mia described herself to me as often homeless and someone who frequently clashed with others. At the end of our conversation, Mia told me she had liked having me there to talk to and asked me if I could be her "advocate".<sup>109</sup> She described what she liked and disliked about the two units where she received care on a regular basis. Mia explained that she felt comfortable with the patients and staff on the complex medical unit (a population of patients who tend to be sicker and more disadvantaged socioeconomically): "They like me, I like them, they respect me." She clarified why she did not belong on the dialysis unit, "The patients here are friends with each other, but none of them like me, they don't talk to me." Mia also mentioned the "kidney doctors won't even look at me." In other words, Mia perceived a sense of otherness; she was not part of the dialysis "family". In the same hospital, in the context of her life and current circumstances, Mia described a positive relational connection (feeling that

<sup>&</sup>lt;sup>109</sup> In response to Mia's request to act as her advocate, I explained that this was not possible because my role was limited to that of an external researcher. I directed Mia to the organization's patient care representative, whose name and contact information was provided in my study consent form (see Appendix H). Mia responded that other people had directed her there but she had not followed up.

she belonged and "at home") with one unit and a negative connection (feeling excluded) with a second unit. Mia's experience might reflect differences between patient populations and care approaches on the different hospital units in my study (see Chapter 5, Section 5.5.6.4), as well as different life experiences for her regarding whom to trust.

My data suggest that the ways in which patients/families perceive their experiences with *specific health care settings* shape their larger institutional relationships. These in turn inform patients'/families' experiences of interactions and processes with different health care situations. These experiences are important considerations regarding how staff, patient and families relate to each other and experience changes in unit processes, including when health care improvements are being tested. In the following interview excerpt, patient **Chloe** describes the impact a hospital waiting room had on her (emphasis by participant):

I was waiting for my appointment [not at the Study Hospital] and of course in a lot of pain, um a lot of anxiety or whatever. It was just all of those things, and probably going through the mourning process. I mean they're all things in my head. And I, had HandyDART<sup>110</sup> take me there and I was able to walk into the waiting room. And what struck me was the greyness of the waiting room. It was grey. Uh and every person I saw seemed to be wearing black. And it was, it was a dour day and the waiting room was, is, is not particularly filled with rainbows and light. And I thought this is so, um, unfortunate. And I would never have been aware of it had I not had a disability...But this was a different situation. This was me, now, in a disabled um situation. And I thought the sadness is what is it, why is it that disabled people are always subject to the worst conditions, to greyness, um to that institutionalization who are already institutionalized. And it seems to me they're institutionalized even more...particularly when you are <u>unable</u> to move around as anybody else, um <u>live</u> in a world that is discriminatory anyway just by nature of the whole setup, and the, and subject to these grey rooms of illness....And I would have loved to have said to [hospital name], the workers there should wear bright colours, get rid of the

<sup>&</sup>lt;sup>110</sup> HandyDART is British Columbia's door-to-door shared public transit service for passengers with physical, sensory, or cognitive disabilities who are unable to use conventional public transit without assistance. HandyDART is operated by Translink, under the BC Ministry of Transportation. Customers receive reminder telephone calls the day before and shortly before pick up. Drivers come to customers' homes, help them board the vehicle, and assist customers to the outside door of their destination (Translink, n.d.).

black.....Think about how can we, how can we change our environment to suit the individual more humanely and respectful as an individual.

Chloe's story illustrates experience in the context of her recent disability. She articulately describes how a health care setting's design itself has the power to diminish her agency and her value. For example, Chloe feels trapped with those who wear black within society's "grey rooms of illness."<sup>111</sup> In so doing, Chloe illuminates not only her intrapersonal meanings about mourning the loss of capacity and power, but also how social structures and arrangements shaped her experiences. This story reflects a patient moving away from a relational connection with a health care setting. Based on accounts such as Chloe's, I further explore the meaning of patient and family experience in the context of chronic illness and disability in Chapter 7 (Section 7.3.2).

In my data, some patients/families described connections to *hospitals as a whole*. Patients described positive connections to a hospital in specific ways. For example, **Emily** stated, "I think a lot of it can come down to the hospital itself too, 'cause um here at [Study Hospital], they're very accommodating. You know, they care for you. If you need something, they'll do it for you." Some patients/families spoke about feeling cared for and respected by care providers/other staff at a particular hospital, or how *observing staff treating other patients* impacted them. Several participants told me specifically about 'othered'<sup>112</sup> others. For example, several patients and

<sup>&</sup>lt;sup>111</sup> In Chapter 5, I noted that my patient partners suggested I wear cheerful clothing while conducting my fieldwork on patient units rather than blending into the "bland and depressing hospital environment". On the day of my interview with Chloe, through her description of disabled people subjected to greyness in institutions, I became aware that I was wearing a black dress that day. I acknowledged to Chloe that my clothing was dark and she asked me to include in my study her ideas about adding colour to health care settings.

<sup>&</sup>lt;sup>112</sup> In Chapter 2 (Section 2.4.1.1) I described othering as a sociological concept whereby individuals and/or groups are considered to be different and inferior from the mainstream social group (Griffin, 2017; J. L. Johnson et al., 2004).

family members linked their hygiene concerns stemming from sharing emergency waiting rooms with a diverse group of patients, for example: "you get all kinds of people coming in who aren't, aren't the cleanest of people" or "the clientele the hospital deals with." **Chloe** described her impressions at the Study Hospital (emphasis by participant):

Chloe (Patient participant): Well and go to the emergency. What's impressed me really because I've been a number of times, I mean you wait around and you're sitting in the triage place, and how kind and gentle the doctors are to these [referring to marginalized] patients. There was one fellow that came in obviously mental health and very agitated, couldn't, he had to get up and go outside and have a cigarette and come back. He, I don't know what was wrong, he was cut or something. And he would continually go up to the doctor and sort of you know 'my turn, my turn'. And I remember the doctor was so nice to him, he was so nice. He un-, obviously understood this guy was [inaudible]. But he wasn't condescending. He just was really, like that, that takes a lot.

# Researcher: So how does that make you feel as a patient when you're coming for care? Does that have an impact on you?

Chloe (Patient participant): I was impressed because it made me, it made me change my thinking again about my prejudices. And you know so many people have been brought to the emergency ward, [makes noises imitating someone vomiting]. And I know how to say that I'm very aware of my, my, my hygiene level then and I choose where I sit carefully. But I have to remember that these guys are, are human and that for the grace of God there go, go us. I mean you know we're only that close away from maybe ending up like that. And, and so the humanity of it all. Only once have I heard a nurse yell at someone to shut up or something. But generally speaking, and the way the security guards deal with them, that's impressive too.

Chloe's story shows how watching health care staff treat others with respect can help patients

empathize and appreciate the complexity and challenges other people faced. Another patient,

Noah, describes his thoughts:

Noah (Patient participant): I mean we're, we're supposed to be adults. We're all supposed to be in control of ourselves, but there are some people who think that they can do whatever they want to do. Well I have learned a lot. Um I've learned a lot about compassion. I'm exposed to addiction, um just how [Study Hospital] treats the addicts. Yeah it's, which I never knew before. I always assumed that a hospital was taking care of sick people. But addiction is a sickness. So is mental illness, which is something I never really thought about before....

Conversely, previous experiences of trauma in health settings shaped patient experiences as well. One patient, whom I will talk more about later in this chapter, was **Liam**, an accountant in his 50s and new to dialysis. Over the hour that I shadowed Liam, I learned about his childhood in a different province, during which he was hospitalized for long periods. In particular, Liam described his vivid, horrific experiences watching staff treating other patients cruelly. These traumatic experiences, he said, made him wary of hospitals to this day. Liam implied that by avoiding hospitals whenever he could, he was protecting himself from harm, highlighting an aspect of context that includes a person's history over their life course and raising questions about the impacts of different types of harm on patients.

Some patients/families situated their relational connections with *one hospital in relation to that of another hospital*. **Chloe** extended her experience of positive relational connection beyond care providers and the dialysis unit to the Study Hospital as a whole. She describes her connection with the Study Hospital: "Particularly in [Study Hospital], **there's a wonderful ethos** [bold emphasis added]. And there's a care here. It's something, it separates it from some of the other hospitals I've been to." Chloe went on to explain that when she needs a referral, she asks for a specialist at the Study Hospital, "I'm pretty adamant that I go to [Study Hospital]." Here Chloe explains why (emphasis by participant):

I remember saying that to uh my [specialist] doctor about how <u>safe</u> I felt at [Study Hospita], and she said that's, she said that's what she's heard from other doctors who have gone away and they come back to [Study Hospital]. They like the atmosphere. And then my, my [specialist] doctor....he's been here since the 1970s and he told me, so he's been there and done that and seen it. Anyway, he said that um people ask to come to [Study Hospital] emergency. They <u>seek</u> it out. They <u>feel safe</u>, um as I say.

Chloe suggests that she shares this common feeling of safety at the Study Hospital with other patients and care providers. At times, patients/families told me about their experiences at other hospitals. Noah's wife **Hannah** says (emphasis by participant):

However. [Different hospital] has the most beautiful body and not a heart to be seen. And [Study Hospital] doesn't seem, you know you'd come back here in a, in a heartbeat. All the rest of the things don't really matter 'cause everybody cares... And things look cleaner and it looks much more beautiful at [different hospital] but we were treated <u>terribly</u> by, especially like discharge and stuff, like 'you just gotta get outta here, gotta go', and basically bullied out. Very, very unhappy. Nurses themselves were, were very proficient but obviously not terribly happy either. And I think everything starts at the top right? Here [Study Hospital] you can just feel that people <u>care</u>.

In the interview excerpt above, Hannah described a recent bad experience at a different hospital, showing why she and her husband felt better, more cared for, and safer in the Study Hospital. This was not an uncommon finding in my study data. Many patients/families echoed this idea of a unique ethos or culture of care at the Study Hospital that reflects a common set of values, beliefs, attitudes/perceptions that are demonstrated through behaviours. Patients and families described, in various ways, moving towards or moving away from 'the way things are at this hospital'. For example, in the above excerpts, participants referred to aspects of hospital appearance, staff satisfaction, and leadership. It was not uncommon in my data for patients/families to experience care on one or perhaps two patient care units in the same hospital, and then apply their care experiences to the hospital as a whole.

Unlike the previous examples, at least one patient in my study sample did not appear to form or convey relational connections within health care beyond those with select care providers. During our interview, **Evelyn** (introduced above) grew annoyed with my questions about her experience as a patient (emphasis by participant):

Researcher: When you say safe, what does safe mean to you when you feel safe?

Evelyn (Participant): I don't do...street drugs and all that. I'm happier here.[pause] I think that's enough question. I'm getting bored with them I'd say.

Researcher: Okay.

Evelyn (Participant): You're not asking about me, you're just asking about the hospital.

Researcher: Pardon?

Evelyn (Participant): I said you're just asking about the hospital. The hospital's fine.

Researcher: Yeah hospital's fine. What should I, what should I be asking you about?

Evelyn (Participant): I don't know.

Researcher: Right. Okay I understand. Yeah.

Evelyn (Participant): You guys kinda, certain people like you guys come in, just want to nose about the hospital, about certain things, and it's got nothing to do with us.

Researcher: Uh-huh, okay.

Evelyn (Participant): We're just patients.

Researcher: Yeah. So, I guess I, I'm trying to figure out what's important to <u>you</u>, to learn what they do at the hospital, how that makes you feel and how it changes your experience as a patient.

Evelyn (Participant): Nothing changes <u>my</u> experience. I mean I know it's a hospital. I'm here for a reason.

Unlike Chloe's experience of an ethos of care throughout the Study Hospital, Evelyn could not (or chose not to) articulate a connection in relation to "the hospital". Furthermore, as a moral agent, she might have perceived that she had little power in relation to "the hospital", an institution. Furthermore, it seemed that Evelyn perceived me as working on behalf of the hospital. My questions grew to irritate Evelyn because, as I described above, she wanted someone to listen to her and comfort her, and became angry and defensive when she perceived this was not the case. Perhaps this was the reason she wanted to stop the interview, or perhaps my questions confused her, or her pain was too much. Evelyn's story emphasizes the importance of trying different methodological approaches to listen to diverse patient voices. At the end of Chapter 9, I reflect on the ethical and methodological implications of my research approach.

In summary, these examples in my data show that patients and families observe what happens around them, and these observations shape how people make sense of their own experience. This sense-making affects the relational connections patients and families form with *health care settings* such as a patient care unit or a hospital. Experiences that leave patients and families feeling known and valued can form the basis for moving towards relational connections with places of care. The diversity of the patient and family data I collected pointed to the complexity of institutional relationships, showing that patients and families value positive relational connections with care providers and health care settings. The next sections of this chapter more specifically describe the three themes in the context of the hand hygiene QI, "*We are clean people*," "*I want to be a good patient*," and "*We're all in this together*." I then link these themes by returning to data showing how patients and their families value positive relational connections with their care providers and health care settings.

#### 6.2.3 Theme 1: "We are clean people": Personal hygiene an important aspect of identity.

In the context of a QI pilot project on patient hand hygiene, the first theme constructed is the role of personal hygiene as an important aspect of identity.



- Personal hygiene important
- aspect of identity

  Family identity
- Let hygiene slide when
- unwell

As discussed in Chapter 3, our society shows evidence of increased awareness of hand hygiene's role in infection control (see Section 3.2.4). In this section, I discuss constructions of personal hygiene as an important aspect of identity. Many patient/family participants talked about how they wanted to be seen as clean people. As the data presented below will show, cleanliness appeared to have a multiplicity of meanings for participants. Sub-themes include links between a person's values, family/group identity, and current circumstances (see Figure 6.2).



Figure 6.2 Constructions of personal hygiene as an aspect of personal identity.

# 6.2.3.1 "I'm not going to ask patients offensive questions about their bathroom hygiene": Early signal of values complexity.

The first signal to me of the values complexity with implementing an improvement project related to a person's hygiene arose early in my data collection. As I was gaining entry to the hospital, I shadowed team meetings for the *patient hand wipes* project. Both study units used surveys with patients and staff before and after the four-week pilot period. Questions focused on hand hygiene practices and perceptions. For one project I saw the patient survey results, and for the second, I observed the results being discussed. During my observations, I learned that most patients did not currently have ways to clean their hands before meals. Most patients liked the idea of hand wipes to fill this void. The hand wipes also made sense to me in the context of my

own life experiences, including my preferences, observations about hand hygiene norms in hospitals, and my knowledge of the patient safety literature. Given my observations and my personal reflections, I expected patients and families on the study units to be positive about hand wipes.

As noted earlier, patients on the complex medical unit often struggle with challenges, including infection, mental health, substance use, and social exclusion. While observing QI project planning meetings on this unit, I learned that **Ethan** was a long-time volunteer on the unit who had a good rapport with many patients. For this reason, the QI project team thought he would be a good person to conduct pre-surveys with patients about their hand hygiene attitudes and practices.<sup>113</sup> I learned that Ethan had readily agreed to do these surveys. However, as the surveys got going Ethan found that some patients were highly offended by his questions about hand washing after using the bathroom. Ethan became uncomfortable and he refused to do more surveys, although he remained engaged in his usual volunteer role (Fieldnote #9). Several months later when I shadowed Ethan, I asked him about the survey (excerpt from fieldnotes):

Volunteer said he was happy to do surveys with patients. Patients don't even know that it's a survey or a study, he just asks questions and then discretely writes down patient responses. Survey had "offensive" questions such as asking patient if they wash their hands after going to the bathroom. To deal with this, the volunteer contacted [his supervisor off the unit] and said he wasn't comfortable asking that question. (Fieldnote #10)

<sup>&</sup>lt;sup>113</sup> The use of volunteers is a common strategy to gather feedback from patients and families in health care settings (e.g., patient experience surveys, QI surveys). Graham et al. (2018) reported pros and cons of using volunteers. Pros include patients/families feeling comfortable talking with volunteers, patients valuing talking with volunteers, and volunteers alerting staff to patient concerns if necessary. Downsides include the tentative and unreliable nature of volunteer recruitment and retention (p. 111).

While these data point to the potential moral ambiguity of the volunteer role, it is important to note that as a participant observer I have incomplete information. In Ethan's story, I do not know the exact wording of the survey questions he was asking.<sup>114</sup> In addition, as I did not observe the patient interactions that Ethan described to me, I do not have a full account of how the interactions between volunteer and patient unfolded. For example, how did Ethan orient patients to the topic area? What I did learn in the context of my data, however, was significant: the message received by several patients on the unit was that they were 'dirty' and 'less than'.

In addition, I learned that "the bathroom question" had implications for how the *patient hand wipes* project unfolded in the hospital. On the complex medical unit, the project team removed the bathroom question from the post-pilot patient survey; team members had not realized these questions would insult patients and they did not wish to cause offence. Later, on the dialysis unit, the QI project lead also excluded the bathroom question from all patient surveys. This is an example of a PDSA cycle approach to QI that arose in the *patient hand wipes* intervention, whereby patient, staff, and volunteer feedback shaped how and why changes were incorporated into QI interventions. I elaborate on the values tension between patient/family feedback and preferences and legitimate medical goals in Chapter 9.

In summary, as I began my data collection, I had early signals that hygiene was a sensitive topic area. Ethan's experience surveying patients about hygiene alerted me to the fact that at least

<sup>&</sup>lt;sup>114</sup> The patient survey questions for the *patient hand wipes* project on this unit were not part of the data collected. I was told the bathroom-related questions were similar to: "how often do you wash your hands after using the bathroom." The results of the patient surveys were not included in the QI project report. This is discussed further in Section 6.3.2.2.5.

some people are sensitive to how these conversations happen. Sensitivity might be particularly acute when people perceive themselves to be interacting with a person of power who they deem might not be working to promote their best interests. For example, in Ethan's story, perhaps some patients did not perceive that a volunteer was helping them by asking potentially offensive questions about their hygiene. I also learned from Ethan's experience to take extra caution when asking about hand hygiene to avoid causing patients, families and staff I interacted with to feel 'less than'.

#### 6.2.3.2 "You think I'm dirty": Personal identity and sense of value and worth.

Ethan's story at first may appear surprising, given the focus on infection control and hand hygiene in hospital settings. But, unpacking the situation revealed information about the needs, preferences, and insights of the people involved. During my data collection and analysis, I grew to understand hand hygiene as part of a broader concept of personal hygiene, which I came to appreciate is a sensitive area because it is closely tied to a person's sense of value and personal worth. My conversations with patient and family participants (whether through informal shadowing or formal interviewing) usually began in the context of how the *patient hand wipes* intervention fit into their understanding of health and other hand hygiene initiatives. An early question typically included some version of a general question: "What do patients notice about what the hospital is doing to promote cleanliness?" (see Appendix K). This led to conversations about meanings of cleanliness, cleanliness of a person or group, cleanliness of the surrounding environment, and what clean means and feels like. For example, when I met patient **Noah** and his wife Hannah, Noah had been an inpatient on the study unit for several weeks. As Noah explained, **"We've always been . . . clean people."** 

These conversations typically expanded to how ideas about cleanliness and interventions to promote cleanliness shaped patient/family experiences of specific care episodes, as well as experiences of health care generally and of their lives outside of the hospital. For example, the word *clean* in the ordinary sense refers to *free from* dirt, unsoiled or unstained (OED Online, 2017b).<sup>115</sup> My data contained many examples that suggested patients and families interpreted hygiene questions as going beyond their bodies to their sense of self-worth. Patient **Chloe** told me about a book she had recently read – *The Dirt on Clean* by Canadian author Katherine Ashenburg (2007). Ashenburg describes connections in Western culture between cleanliness and virtue. Maxims such as "cleanliness is next to godliness"<sup>116</sup> relate being clean to virtuousness and moral purity. These constructions of clean and dirty resonated with what I was learning from patients and families in my research. The constructions were related to participants' experiences with hand hygiene interventions and other practices in the Study Hospital, as well as connections with their personal identity, family identity and current circumstances. These experiences shaped how participants viewed themselves and others.

A person is not intrinsically 'clean' or 'dirty'. Rather, a person comes to understand how these ideas apply to them. Complex power dynamics and existing social rules situating a person shape this understanding. The words and cues of most of the patients/families I interacted with clearly

<sup>&</sup>lt;sup>115</sup> A comment on the use of the Oxford English Dictionary (OED) in this dissertation. This study used interpretive description methodology to understand meanings of patient and family experiences in context. I used a number of strategies to interpret the *words people used* in my data (comprised of interview transcripts, fieldnotes documenting my conversations with and observations of others, and reports). During analysis, when I was drawn to particular words, such as *ethos, clean,* or *dirty* at times I found it helpful to anchor (or begin) my interpretation of meanings of a word as used in the context of the word's common usage. For this reason, in addition to theoretical interpretations in the literature, I cite the OED in several areas.

<sup>&</sup>lt;sup>116</sup> Attributed to English cleric and theologian John Wesley during a sermon given in 1778 (Wilkinson, 1879).

suggested they considered themselves to be "clean people". Their construction of being a "clean person" was linked in a positive way to a sense of personal identity, and a feeling of value as a person. Building on Noah's comment, I thought about other patient/family participants who, in describing how important hand hygiene was to them, labelled themselves in the extreme as a "germ freak" or "germaphobe" or "clean freak" or "anal" or "paranoid" or "I don't have OCD, I can tell you that." They seemed comfortable with admitting this; a combination of pride and embarrassment.

My data also showed that in a health care context where the patient identified as a "clean person", an offer of a hand wipe could make a patient feel better because it allowed them to clean themselves of germs, and to feel clean. This action helped align their current situation (being in a confined space with other sick people and dangerous germs) with their self-perception as a clean person. In addition, interpersonally, an offer of a hand wipe conveyed a measure of respect to the patient, who then felt seen as a person not patient, and valued as a clean person. This interpretation can work to lessen the power imbalance between patients and their care providers, strengthening relational connections. Conversely, some patients suggested that an absence of the ability to keep themselves clean while in hospital could make them feel worse. Sometimes this hygiene–personal identity theme played out differently in my data; the opposite of clean is *dirty*. My data also included examples of staff and volunteers (such as Ethan) who were aware they had unintentionally offended patients when talking about hand hygiene. In what follows, I share a story about Ben.

While I was shadowing a nurse on the complex medical unit, the nurse relayed to me the story of her patient, **Ben**. Ben was a street-involved man in his 20s with several previous admissions to this unit over the past five years. He was currently receiving treatment for a leg ulcer. During the pilot project, when the nurse offered Ben a hand wipe before his meal for the first time, Ben responded in an accusatory tone, "what, you think I'm dirty?" The nurse explained to me that some patients are *offended* (emphasis by participant) when she offers them a wipe because they feel judged. In other words, "You think my hands are not clean" meant "you think I'm a dirty person" (Fieldnote #11). This example suggests that the hand wipe interaction challenged Ben's sense of worth. He was angry with his nurse, who was complying with the new QI intervention on the unit. The nurse explained to me that her aim was to try to prevent Ben from getting another infection and spreading germs around the unit, but Ben did not see it that way. The nurse told me how badly she felt about this interaction. She also expressed some reservation about the hand wipes process because not all patients "take it the right way."

The story about Ben resonates with Ethan's uncomfortable experience on the same unit asking patients about bathroom hygiene. While this tendency could apply across patient groups, it may in particular impact those who feel overlooked. In a stigmatized context where a patient might feel perceived as a 'dirty person', an offer of a hand wipe from a care provider in a hospital (seen as a person in power) could be interpreted as a values assessment. Lacking control over their lives, those offended might lash out verbally at the care providers trying to 'help them', weakening relational connections and in turn resulting in damaged relationships and suboptimal health outcomes. In my data, Ben's story (as told to me by Ben's nurse) is one example of a patient–care provider interaction that might reinforce stigma, previous trauma and power

imbalances for patients marginalized by society. While most patients and families I interacted with conveyed there was "no harm" in hospital staff or volunteers offering patients a hand wipe, an important finding in my study is the offer of a hand wipe is not automatically seen as a benign behaviour by all patients.

Furthermore, my data also show how staff/volunteer perceptions of their patients' hygieneidentity might exist in ways that reinforce stigma. A small number of staff/volunteers on the complex medical unit said (or implied) that some patients "didn't care" about hand hygiene. For example, one participant told me about their visit to a patient's home in a transitional housing unit, describing the home as unhygienic chaos (Fieldnote #12). The implications of this participant's statement were that patients marginalized by society, such as those who are unstably housed with mental health and substance use challenges, do not care about hygiene inside or outside the hospital given their other challenges. This interpretation contrasted with what I learned from (and about) the perspectives of some unstably housed patients, with responses such as, "people who work at this hospital think I am worthless." Meanings of these examples in my data point to differences in sense-making by staff and patients; where staff appeared to focus on the *functional* aspect of hygiene, patients appeared to focus more on relational aspects of the value of hygiene.<sup>117</sup> This interpretation illustrates the importance of understanding both functional and relational aspects of care improvements from staff/volunteers and patients/families, an area I discuss more in Chapters 8 and 9.

<sup>&</sup>lt;sup>117</sup> I described functional, transactional and relational aspects of care in Chapter 2 (Section 2.4.3).

Ben's and Ethan's stories were not typical of my data about the *patient hand wipes* intervention. Most of the patients/families in my sample who indicated an awareness of the *patient hand wipes* project appeared to respond positively to the hand wipes they were offered. In fact, they expressed that they wanted more hand wipes rather than fewer. Likewise, most of the patients and families who appeared to be unfamiliar with patient hand wipes on the unit expressed support of the idea. However, the stories I have recounted above are an important illustration of the range of responses possible, depending on the context of the patient's life and current circumstances. More specifically, given the characteristic marginalization of the patient population on the medical unit, Ethan's and Ben's examples illustrate the role assumed values and context can play in the design and implementation of QI interventions involving patients/

Overall, the theme "we are clean people" reflects what many study participants conveyed to me about personal hygiene as an important aspect of personal identity; one connected with worth or value. Clean people were seen to have higher value, and unclean people were seen to have lower value. In the context of this QI project, such values-laden connotations of "being clean" meant that some patients interpreted 'routine' questions about their hygiene practices as personal insults. This finding demonstrates the significance of understanding local institutional contexts, the importance of relational connections, and the need to consider diverse patient/family experiences when gathering information and changing care processes to improve health care quality.

#### 6.2.3.3 "Who I am as part of a family": Personal hygiene part of group identity.

In their stories, many patient/family participants situated themselves in the context of a group. For example, patient **Chloe**, introduced above, described herself as "a thinker, from a thinking family". Several patients relayed specific stories about handwashing in relation to their connections with their families, and explained how these connections shaped their current habits and ideas about hygiene. For these patients, hand hygiene was significant; it was something that was taught and valued. I illustrate this sub-theme with four examples.

Patient **Charlotte** was an older widow who described close relationships with her children and grandchildren. Charlotte "looks forward to coming for dialysis" several afternoons each week, something she has done for many years. She seemed happy to have someone to chat to while she had her dialysis, and one day I shadowed (sat beside) her for three and a half hours. When I asked Charlotte about hygiene at the hospital, she explained that each time she comes, she brings and uses her own hand sanitizer, cloth, and blanket. She never eats at the hospital and waits until she gets home via HandyDART to have dinner. Charlotte explained she washes her hands in a sink upon arrival at the hospital. At home, she uses paper towel in her bathrooms instead of shared towels. When I asked about the paper towels, she said her father was a doctor, and this is what he taught her. Charlotte, a woman born in the 1920s, attributed her daily hand hygiene routine to her upbringing.

During my interview with **Noah** and **Hannah**, they talked between themselves about why the bottle of hand sanitizer Hannah brought to Noah's hospital bedside table is consistent with their family culture of washing before eating (interview excerpt):

Hannah (Family member participant): None of that is as good as washing your hands I don't think.

Noah (Patient participant): Yeah...But then because Hannah's a [health care professional], we've always, you know, I'd say, promoted....

Hannah (Family member participant): Anal.

Noah (Patient participant): We've always, you know, made it a point to wash your hands, everything like that. But like not so much in here. I mean they bring your food tray in. 'Do you want to wash your hands before you eat?' They never ask you that.

Patients Sophia and Olivia told me about how they taught their children and grandchildren about

hand hygiene. Sophia – now living on the street – spoke with pride about how her teenage

children were mocked by their peers for their regular hand washing routines (interview excerpt):

But they were going and washing their hands before a group, like a picnic or something, or not a picnic, a barbecue at their house. And their friends are going "oh there go [name] and [name] again." And I go "yeah, good for you" [claps]."

The following is an excerpt of my fieldnote while shadowing Olivia:

Olivia's granddaughter doesn't want to wash her hands before eating. Olivia tells her granddaughter that she's already washed her hands when she comes to the table. Granddaughter doesn't believe her, so they go together and wash again – this is a behaviour technique she says her son-in-law suggested "give her 2 choices, do you want to wash your hands now or in 5 minutes." (Fieldnote #13)

These examples illustrate that hand washing before eating, like other food-related and social customs, can be a value that is part of family identity (Visser, 1991). As several participants indicated, hand hygiene behaviour is known to be established at a young age (Ashenburg, 2007; World Health Organization (WHO), 2009a). Cole (2014) states that such habitual actions are taught as a means of self-protection from germs (p. 78). Furthermore, as the data I have cited above indicates, hand hygiene can become part of a family's legacy across generations.

The diverse group of participants in my study did, at times, talk to me about aspects of their religious and cultural backgrounds. Yet no participants explicitly referenced religious or other culturally-based hand hygiene practices that I interpreted as being connected to food or family. My research framed hand hygiene in the context of infection control. It is possible that this orientation shaped participants' responses to me, or what they chose to talk about with me. There might be additional factors – religious and/or culturally-based – to consider when constructing meanings of hand hygiene generally and hygiene before eating specifically (Al-Tawfiq & Memish, 2017; Ashenburg, 2007; Reilly et al., 2016; Vermeil et al., 2019; World Health Organization (WHO), 2009a), and I elaborate on this point in relation to cultural safety in Chapter 7. In summary, in my study I found personal hygiene to be an important aspect of a person's identity, and one that connected individuals relationally, as part of a family.

#### 6.2.3.4 "When you're in hospital, you'll let some things slide": Burden and capacity.

Most patient and family participants described feeling less clean during hospital stays than in their usual circumstances. When patients are in hospital, largely immobile, and generally not feeling well, they are not able to do what they normally do in terms of personal hygiene. One of my patient partners explained to me what it feels like to be in the hospital: "on top of being sick and scared when you're not at your best, you feel like a pig" (Fieldnote #14). Many patients in my sample had limited mobility, related to challenges such as weakness, dizziness, confusion, paralysis, or being encumbered by medical equipment. Sometimes this limited mobility was on a temporary basis as a consequence of their illness or treatment; sometimes it was permanent. I also observed other patients whose severe illness or dementia meant that at times during their hospitalization, they were unable to physically get to a sink or even reach items on a bedside table.

As I have noted previously, in my study sample patients on the complex medical unit were generally more physically compromised compared to the patients on the dialysis unit. For this and other reasons, while in hospital, patients described suspending the expectations they would normally have of themselves when they are feeling well. **Noah** explained the dilemma of not being able to keep up his usual hygiene standards as an inpatient: "...when you're in hospital, you'll let some things slide, just because you're not feeling well." Patient **Liam** provided an example from the outpatient dialysis unit. Liam showed me the packaged hand wipe his wife sent along with his lunch. In so doing, Liam was disappointed to realize he had forgotten to use his hand wipe. Liam was fairly new to dialysis and told me there were so many new things going on that he forgot all about cleaning his hands, even though he had intended on doing so.

In my conversations with patients and families, including the examples noted above, many participants described their usual practice of handwashing before meals outside the hospital (at home, in restaurants, and so on). I was surprised to learn through the QI project planning, patient/family comments, and my own observations (at the Study Hospital and with my own family members in other hospitals), that in the absence of an initiative such as the QI project I was studying, patients do not generally have the means to clean their hands before eating while in hospital. Reachable hand hygiene supplies or assistance from staff for bed-bound patients in acute care hospitals is not the norm. In other words, the QI intervention to provide patients with hand wipes before meals was not replacing another form of hand cleaning. A small number of

patients had regular assistance from family members. **Hannah** said, "Nobody gets washed unless their loved one comes and helps them, or unless they're with it enough to go wash themselves....Noah always asks for a basin now but he wasn't always able to. I mean for the first three months, I came in and did all his care." In my analysis, that patients were unable to maintain their usual standard of personal hygiene was not an unexpected finding, given theories about the burden that illness and treatment have on patients and their related limited capacity to perform their usual tasks (May et al., 2014; Shippee et al., 2012).

In addition, in a health care system that is often organized around tasks (Nagle, 2019), cuts that result in eroding staffing levels influence what tasks are prioritized (Ball et al., 2014; Canadian Nurses Association, 2015; Canadian Nurses Association & Canadian Federation of Nurses Union, 2019; Francis, 2013; Registered Nurses' Association of Ontario, 2004). My observations seemed to be a contradiction in the context of an 'infection obsessed' organization such as the Study Hospital. Indeed, Cao et al. (2016) state, "Despite concerns raised by some recent studies, patient handwashing is not a routine practice in hospitals to date" (p. 706). A lack of systematic approaches to patient hand hygiene also seems to conflict with stated patient safety priorities in the health care system (Canadian Patient Safety Institute, n.d.-e).

At times, I felt that patients and families interpreted a care provider's offer of a hand wipe as a neutral gesture, one that was more value-neutral than the 'clean person' and 'dirty person' interpretations described above. For example, several patients commented that it felt "nice" to be offered a hand wipe by a nurse or volunteer and be able to clean off their hands before their snacks because it showed "they care". Some patients and families described the meaning of

having their personal hygiene attended to by a nurse or volunteer as not primarily related to infection control. Rather, they saw it as a demonstration that patients were being cared for, attended to, seen, comforted, and valued made patients feel more like "themselves". In a related personal hygiene example, my patient partner Marie-Thérèse described a hospital experience (at a different hospital) of how one nurse who was "different from all the others" made a lasting impression by washing Marie-Thérèse's hair when she was "so sick". The meaning Marie-Thérèse brought to the hair washing was that the nurse made her feel cared for "as an individual, that this was just for me, like a person" (Fieldnote #15). The hair washing example also conveys how the journeys of the health care staff can be linked to those of patients and families. I thought of these as intersecting or parallel journeys as I observed the ways nurses and volunteers connected, or did not connect, with patients and families.

I was particularly interested in burden and capacity in relation to the ways that hospitals encourage patients and families to ask care providers to wash their hands before touching them. As I explained in Chapter 5, two hand hygiene initiatives were selected as cases in my study. The data in this chapter is primarily related to the *patient hand wipes* QI intervention. My secondary case study included hand hygiene signage and supplies around the Study Hospital. During my analysis, when I inquired about "it's ok to ask" (or pointed to the posters) patients/families generally agreed that it seemed like a good idea. One of my patient partners was unfamiliar with "it's ok to ask" when we first met. She expressed that having someone tell her this kind of behaviour was encouraged may have given her "permission" to ask about handwashing, as she thinks of herself as proactive and assertive to protect her safety while in hospital. Yet, during an Emergency Department (ED) visit sometime later, this same patient partner had a chance to

reconsider her thinking. She said she was so overwhelmed with her health problem that it did not occur to her to notice whether the staff were washing their hands properly. She told me that she recognized that while in the ED, she had to hand that job over to the professionals. This is a different example of how the burden of illness and treatment can shape the contrast between what patients told me they would do or wished they could do, and what they realized they were able or willing to do when they were "sick, scared, and not at your best."

## 6.2.4 Theme 2: "I want to be a good patient": Maintaining relational connections.

In the context of a QI pilot project on patient hand hygiene, the second theme constructed is that typically, patients want to be "good patients" and families want to be "good family members".

I learned that for the most part, patients and families want to do what their care providers ask them to do and expect of them, without causing a fuss or being too demanding. This is consistent with Gerteis's (1993) *Through the Patient's Eyes*, in which the author states, "Patients who comply submissively with "the system" are deemed "good" patients; those who challenge wellestablished hospital routines are seen as deviant, uncooperative, 'problem' patients" (p. 33). For patients, being "good" sometimes results in tension from balancing competing needs: the need to get what they want or require; and the need to avoid alienating their care providers in the process. It was my observation that few patients set out to be a "problem patient".

My research centred on hand hygiene interventions in a local context. The "good patient" theme provides examples where the patient voice might apply to attitudes, behaviours and interactions

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"I want to be a good patient"

Don't bother busy care providers
Fear care providers will get mad
Relational connectors.

workarounds

Filling in gaps to get well

beyond QI to health care contexts more generally. In other words, while my data centered on a patient hand wipes intervention, it situated patients and families in the larger context of their care experience and their lives. This aspect of my study sample is discussed further in Chapter 7, where I explain my *Relational Safety Framework*. During my time observing on patient care units, patients, family members and care providers showed me how, at times, they as moral agents made a conscious choice and "took action" to enact their agency. Patients and families told me and showed me a range of motivations for this, including not bothering care providers whom they perceived as 'busy', fear of consequences, active strategies such as being 'nice', giving gifts and using humour, following instructions, and filling in perceived gaps in their hospital care. These motivations, explored below, are not necessarily unifocal because at times it appeared that a complex set of reactions, perceptions and behaviours may be going on all at once. I considered patient and family motivations in terms of who can speak, who can be heard, and the perceived consequences of speaking up.

#### 6.2.4.1 "They are busy and I don't want to bother them".

Most of the patients and families I interacted with spoke favourably about their care providers. They typically expressed that they believed their caregivers to be responsible professionals who were as kind as possible within a busy hospital unit. **Emily**, introduced above, seemed comfortable describing what worked well and not so well for her on the dialysis unit. Dialysis patients are generally well during dialysis treatments, and many participants I interacted with had been coming to the same dialysis clinic several times per week for many years. Typically, many patients and family members have a lot of "down time" during dialysis (which takes approximately four hours) to be observant of what is going on around them. Some patients are

willing and able to participate in their own care. Being observant and being able to participate in their own care are important aspects of patient agency that distinguish some patients from others. In the following interview excerpt, Emily described herself as wanting to be a "convenient patient" (emphasis by participant):

Emily (Patient Participant): Uh I want to be like, I don't know, I'm pretty sure a lot of patients are this way, I just want to be a convenient patient. I don't wanna ask for more than what's necessary, right. If I can do something on my own, I don't mind, I'm gonna do it on my own.

*Researcher:* So, can you tell me a bit more about like why you think you would like to be a convenient patient and do as much as you can?

Emily (Patient Participant): Lots of reasons. Number one, they have a lot of stuff to do already. You know, I'd rather have them concentrate on doing <u>this</u> [referring to dialysis machine] properly than covering me up with a blanket.

As a patient, Emily conveys that she strives to do manageable tasks on her own and not bother or interrupt staff unnecessarily. This suggests she is trying to be a model, cooperative patient. In doing so, she may be acting in her own best interests. While several other patients told me how much they appreciated the nurses covering them with a warm blanket or doting on them, Emily might prefer that care providers focus on performing the medical processes correctly. So, she might feel hesitant about distracting her nurse with small talk.

This example illustrates how patients sometimes enacted agency by not engaging. In other words, at times, patients act in their own best interests by *not* acting. They do not want staff to think of them as a 'complainer'. In describing her feelings, motives and behaviour (requesting assistance only with those tasks she cannot do herself) in relation to the social circumstances, Emily demonstrates an awareness of relational autonomy. For example, Emily enacts relational autonomy by acknowledging her care providers have competing responsibilities and other

patients, indicating consideration for others. In my study, Emily and many other patients and families expressed how busy or rushed the nurses and doctors were. This sense of 'busy-ness' is also reflected in the literature. For example, in a study with older patients, Mitchell and McCance (2012) found that when patients perceived that the nurses were busy they felt neglected. As noted above, other researchers have written that patient–provider interactions in acute-care settings are largely dominated by a task-centred or a task-orientated approach to care (Kornhaber et al., 2016; Mitchell & McCance, 2012; D. C. Taylor, 2015). My data showed that some patients and families moved away from relational connections with care providers whom they perceived to be rushed or focused on clinical tasks. I elaborate on this finding in Chapters 8 and 9.

As I talked about hand washing and hospitals with patients and their families, most participants told me that washing their hands before eating in a hospital was "common sense". However, these same patients did not seem to expect to wash their hands before eating in hospital, and I did not observe a lot of patient hand hygiene before meals. As I have noted above, there is also the issue that hand washing facilities or supplies may not be readily available or accessible to patients. Many patients/families conveyed that they would have liked help with hand washing during their hospital stay. Yet, typically, patients and families told me they decided not to ask for this help. They seemed to have a number of different motivations. At times, by not "bothering" their care providers, patients silently communicate that they see how busy the staff are. For example, perhaps Emily was reluctant to add on more work for her nurses, as she wanted to help the staff out. In particular, I noticed this response when patients and families seemed to have a good rapport with their nurses. Some patients and family members (usually on the complex medical unit) used terms such as "casual", "workload", "short-staffed", "staff shortages" and

"cutbacks." Use of these terms conveyed participant familiarity with human resource challenges on hospital units. My interpretation was that many people (patients/families and health care staff alike) have come to accept situations such as lack of assistance with hand hygiene and resource constraints as the standard in a BC hospital.

It was my observation that patients may be hesitant to ask staff for something they "don't need". I interpreted these data as meaning that patients may be embarrassed, or may avoid doing something to emphasize their vulnerability not only to others, but to themselves. For example, not asking for a blanket might allow **Emily** to maintain her independence and pride, and manage her vulnerability. This finding might also represent subjective versus objective perceptions of discomfort. For example, family member **Hannah** said that her husband **Noah** rarely rang the call bell when he needed help. I interpreted Hannah's comment as a not-so-subtle hint to Noah that he ought to ring the bell more often. This finding is consistent with other studies that show differences between staff and patient perceptions: staff perceive that patients ring the call bell on a whim, while some patients perceive that they need to (and many do) put off ringing for as long as possible (Maher, 2017; Mitchell & McCance, 2012).

One day I shadowed **William**, a middle-aged patient who was new to dialysis and had recently moved to Canada. It seemed to me that William was comfortable sharing his story with me. Several care providers came by to talk to him about a new diagnosis and treatment unrelated to his kidney failure. During these interactions William nodded in agreement, looked worried, but asked few questions. After the staff left the bedside William asked me medical questions about his new diagnosis and if his traditional diet or previous antibiotic use caused his kidney failure.<sup>118</sup> This patient seemed quite familiar with medical terminology. When I asked William where he gets his medical information, he said, "the internet". As we said our goodbyes, William said, "thank you for taking the time to talk with me." My feeling with William and many other patients/families I interacted with was that we had developed rapport. Participants perceived they were not interrupting me from other 'more important' tasks. I was there to listen, a role that contrasted with health care providers and staff who had "jobs to do". Several participants expressed that they valued an opportunity to share their experiences and, at times, ask me questions.

#### 6.2.4.2 "You don't know how good the care's gonna be after that": Fear

A different motivation for patients and families not wanting to "bother" staff was fear their care providers (doctors, nurses, and so on) might be offended and might even retaliate. Several patients and family members expressed apprehension about consequences, often smiling as they expressed their fears, for example "I'm afraid the nurses will get mad at me [embarrassed giggle]".<sup>119</sup> Such responses suggest that this fear was somewhat uncomfortable even to put into words. While apprehension about alienating doctors, nurses and other care providers arose in my data, the fear of alienating volunteers was uncommon.

<sup>&</sup>lt;sup>118</sup> In response to William's request to provide medical information, I reiterated that this was not possible because my role was limited to that of an external researcher. I explained to William that he would need to follow up with his care team for answers to these kinds of medical questions.

<sup>&</sup>lt;sup>119</sup> Several of the patient/family interview excerpts included in this chapter include non-verbal cues noting what I interpreted to be awkward reactions. For example, in Emily's quote below she says, "they'll be nicer to me [laughs]." I interpreted this laugh as accompanying a statement that the patient felt uncomfortable conveying to me.

In the excerpt above, **Emily** relayed her rationale for not wanting to bother care providers unnecessarily with her wants, needs, concerns and complaints. Emily illuminated how patients navigate different motivations to 'be a good patient', suggesting that it depended on the situation and the people involved. Emily had positive things to say about her health care experiences in general and specifically on the dialysis unit. However, her description of her patient experience also revealed elements of fear; such as when it would be risky to speak up:

Um...and also you know if I'm nicer to them, they'll be nicer to me [laughs]. You know if I'm an easy patient, then they'll have no problem with me. But if I'm you know a difficult patient, then you know might put them in a bad mood and you know I don't know frustrate them, you know. I want to be as, as l-, as, as...least demanding as possible. Because it's like you know I can put a blanket on myself, I can adjust my stuff on my own, you know. I don't, you know they're here to care for me, not to be my servant, you know.

Emily worried about the downside of putting her care providers in a bad mood. Later in our conversation, Emily relayed a negative one-off experience with a new nurse. This nurse usually worked at a different hospital and Emily observed that she was "less caring" than the usual dialysis nurses. On this day, Emily told me she felt particularly weak after her dialysis, and asked the new nurse for a wheelchair. The regular nurses would have recognized her weakness and automatically brought a wheelchair. However, not only did this new nurse fail to anticipate her medical need, she took more agency away from Emily by being rude to her. Emily explained what happened next:

And then after all that, um she just abandoned me. I was sitting in my wheelchair waiting to get pushed out and she didn't come back. So I had to ask another nurse to push me out. It kinda, it was a bad day for me, you know.

In this scenario, Emily felt punished for being unable to manage her own care. She described the importance of keeping on the good side of her care providers (emphasis by participant):

You know you don't want to get them <u>mad</u> at you because you know, especially when you're admitted or something, you have 'em for 12 hours. You know, you want to be able to get the care that you need for that 12 hours right. You know, if you get them mad at you, you don't know how often, you know, how good that care's gonna be after that.

The power imbalance between patients and care providers can make patients fear the consequences of speaking up. Importantly, these consequences might apply beyond the immediate care encounter, and as Emily describes, to future hospital visits (emphasis by participant):

I can just brush it off as just a one-off situation. So but then if, if it was, if it was like more like a 50/50 situation where half the nurses are good here, treating me well, and half the nurses are, are <u>not</u>, then I'd be more concerned about coming here.

Another patient who spoke to me about the downside of speaking up in a therapeutic relationship was Liam (introduced above as someone who was traumatized from health care experiences as a child), who was experiencing a transition from an active life to one with kidney failure. I was interested in including patients new to dialysis in my study sample. While Liam did not convey particular enthusiasm, he agreed to talk with me while he was hooked up to the dialysis machine. Liam expressed that he was unhappy and frustrated with the need to fit dialysis into his busy schedule. He told me his goal was to transfer to a community dialysis clinic closer to home, and then get a kidney transplant. While most patients on the unit seemed to have easy interactions with staff and other patients/families, Liam appeared to be uneasy around the staff. For example, he told me there had been some mix-up and the doctor had forgotten to write something in his

chart. When I asked Liam about the mix-up, he said there was no use in trying to correct the error because no one was interested in listening to him.<sup>120</sup>

Near the end of our conversation, I asked Liam how he would go about asking the nurses and doctors for things that he wanted – for information, a hand wipe, or the table moved to the side where he could reach it. Liam came across to me as bold and confident; it was hard for me to imagine him being shy with requests. Liam told me, "I don't ask for anything. You know they all talk about the patients in the lunchroom." He told me that he did not want the nurses to say, "that Liam's a real prick." He described avoiding any action that would cause the staff to think he was a difficult patient (Frosch et al., 2012; Gerteis et al., 1993; Hor et al., 2013; Towle et al., 2003; Wyer et al., 2015). Ultimately, Liam feared the staff would give him inferior care. Liam told me he attributed his knowledge of what goes on behind the scenes in hospitals to his traumatic experiences as a child (described in Section 6.2.2.2). Stories such as Emily's and Liam's conveyed a sense of powerlessness consistent with related literature. For example, in the context of primary medical care Rhodes et al. (2016) reported:

Participants [adult patients with multiple long-term conditions] sometimes indicated that they downplayed or forgave mistakes because acknowledging the possibility of unsafe care might have troublesome consequences ... This suggests that for some patients there may be a threshold for action, although this is likely to vary between patients and contexts. (p. 279)

I learned that for some patients, previous experience in the health care system in general, or in specific contexts, created fear – for example, a fear of being mistreated, abandoned, or ignored.

<sup>&</sup>lt;sup>120</sup> After my encounter with Liam, I followed up with a clinical unit leader because I believed Liam may have experienced a medical error that he was reluctant to report. This action was in accordance with my ethical obligations as a professional and a researcher on a patient care unit (see Section 5.7.1).
This fear, whether real or perceived, keeps tendencies to ask, suggest, or complain in check.

Ben's and Ethan's stories were an exception, because more typically in my data, patients and

families told me they self-censored (chose not to act). At times, patients tried to be a "good

patient" not by getting the staff to like them, but by ensuring that staff do not *dislike* them.

In the context of hand hygiene, I thought specifically about fear of consequences with "it's ok to

ask"-type QI interventions. Several patients noticed these kinds of posters on the walls in the

Study Hospital. For example, John describes (emphasis by participant):

## *Researcher: --what do patients notice about what [the Study Hospital] is doing to promote cleanliness?*

John (Patient Participant): Um one of the things that I noticed first of all was signs, like posters, you know getting out the elevator. Um there were posters, which before I never saw things like this I say years ago in hospitals, um about hand washing and even pictures of like the doctors themselves, because some of those posters have doctors, which I'm not quite sure. I just can't um remember, but something to the effect like um before the, if, if say you're being treated by a doctor and you notice that, that he's seeing that patient over there and now he's come towards you without washing his hands, that you're at liberty to challenge him. That part of it, there's a poster that depicts that. I'm not quite, I, I can't remember exactly the wording, but basically that's the meaning behind it. And I thought, I thought that was great because I didn't think before that I could say to a doctor you know you need to wash your hands, you know, because. And, and I noticed that there was that poster. And I also in my own experience with doctors that I've seen them doing it, yeah, either that they put gloves on, and if they're seeing me with just their bare hands that they wash before they get to me. I've noticed that, yeah.

My patient partner Carol described "it's ok to ask" in two different contexts. First, she had a role as a patient partner in an "it's ok to ask"-type hand hygiene project (not at the Study Hospital). Carol was supportive of the idea even though the project was not successful because the point of care staff "were not eager to participate". She subsequently found herself hospitalized (not at the Study Hospital). During her hospital stay Carol never once asked her care providers if they had washed their hands, even if she may have wished to. As she eloquently described: Patients know what you're up against is the power imbalance between patients and caregivers. You ask the nurse "did you wash your hands?" you fear they will take offence, and care will not be as enthusiastically provided. You would alienate the staff you're depending on for your life. These are psychological barriers to asking. (Fieldnote #16)

During observations over several months, I did not witness any patient or family member asking a care provider if they had washed their hands. I asked patients and families about the "it's ok to ask" posters on the walls, curious about circumstances where they might ask, want to ask, or avoid asking about this. My findings confirmed what is well known in the literature; health care settings worldwide encourage "it's ok to ask", but patients/families worry about alienating their care providers (R. E. Davis et al., 2015; Flannigan, 2015; Kim et al., 2015; Longtin et al., 2009; McGuckin & Govednik, 2013; Treise et al., 2016). In the previous section, I discussed my finding that personal hygiene is an important aspect of one's identity. Participants described fear of offending their care providers in two ways. A patient asking, "Excuse me nurse, have you washed your hands?" might offend the care provider personally. More importantly, it might challenge that person's *professional* identity. Patients/families do not want to be on the wrong side of causing offence to a caregiver.

Patients and families bring with them a wide range of experiences and also encounter a range of experiences while in hospital. Given this complexity, some patients/families might perceive issues or areas as 'sensitive' compared to different patients, or to patients who have experience working in the health care system. The samples from my data discussed here reflect that patients/families are, for the most part, conscious of the risks of speaking up. At the same time, many patients and families seemed unconscious of the risks of *not* speaking up. For instance, a few patients on the dialysis unit told me that during the time they were new on dialysis, a nurse

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called Mandy taught them to ask care providers about hand washing. First-hand teaching by a respected nurse seemed to be a powerful message that this was the 'right' thing to do in a dialysis context. Yet, I did not see it happen during my data collection (which does not mean it did not occur during my study period). These patient stories link my findings with the power and context elements of relational ethics theory. I learned that patients and families navigate interactions with care providers carefully because they believe their lives depend on it.

While my data show the complexity of patients' and families' descriptions of their experiences and their concerns about asking care providers for clarity or for something they need or want, my data also supports a large body of previous research supporting patients/families fearing negative consequences from asking, such as was cited above by my research participants. Patients and their family members do not want to get inferior care in hospital either physically or psychologically, or have other needs ignored. As Ronald Epstein (2017) notes, "Even wellinformed, highly educated patients fear that by questioning their physician, they will get lowerquality care" (p. 88). Volunteers had more time, less responsibility, and wielded less retribution. In other words, in patient-volunteer relationships there was a more equal balance of power. I observed that this power asymmetry came through in my data with differences in patients' expressed willingness to ask for things they wanted or needed, such as information or a hand wipe.

#### 6.2.4.3 "I'm a nice person": Relational connectors and workarounds.

A third way I observed patients and families trying to be "good patients" was through active relational strategies such as gifts and workarounds. These strategies focused on ways

patients/families connected to care providers relationally. For example, staff told me about, and I observed patients bringing token gifts to hand around to everyone on the unit. One patient said that it was important for others to see him as a "nice person". When I asked more about this, this patient said his elders taught him that it was important to be nice. And one way to be nice was to give people small gifts. During my observations, it became clear to me that several patients who stood out for sharing gifts and stories appeared to be popular with staff and volunteers on the unit. For example, staff and volunteers spoke fondly about these patients to me, and my observations of interactions between these patients and staff conveyed that knew about each other's personal lives. I came to understand these behaviours as "relational connectors." I noticed that a small number of patients tended to chat a lot with nurses and volunteers. Other patients, families and some staff also pointed this behaviour out to me, some of whom complained that these patients were trying to be the 'favourite' and, importantly, monopolized the staff or volunteer's time and attention. I wondered: What motivations were behind this patient behaviour? Is this expressing gratitude? Leveraging charm to curry favour? An investment to try and get better care or more attention? Seeking reassurance? Passing the time? Or a genuine nurturing of long-term relationships? These observations in my data prompted me to explore motivations for patients and families to connect with care providers.

In contrast to relational connectors, some patients/families described getting what they wanted or needed from care providers by using what I came to think of as "relational workarounds".<sup>121</sup> For

<sup>&</sup>lt;sup>121</sup> Workaround: "A (usually temporary or makeshift) means of bypassing or resolving a technical difficulty when a system, procedure, or mechanism fails to work; a means of avoiding or resolving a problem when the usual or most obvious solution is not feasible, possible, or available" (OED Online, 2018f).

example, when I asked a patient how she felt about asking care providers about hand washing, she told me staff hygiene was important to her, and she would ask the care provider *after* seeing them hand wash. Another patient described asking a nurse in a "joking way". Patients and families described these kinds of workarounds with care providers such as nurses and doctors, but not with volunteers. One family member, a nurse, described how she "teased" nursing staff while reminding them to pay close attention to infection control for her loved one's safety:

Like I mean when I trained, you know hygiene and an absolutely spotless bed and on and on was very important...I tease the girls because they're wonderful. The girls here are just fabulous. And I know they've got different concerns but I mean I did work in [a different hospital] not that, that long ago.

These examples reflect both patients and families using humour with people they perceive to be in positions of power, in a similar way to what is described in other studies (for example, see (Duhn & Medves, 2018). In patient/family–care provider relationships, the patient/family member can try to maintain the "good patient" role and also communicate their values or preferences, such as "hand hygiene is important to me". Moreover, I observed that patients/families seemed likely to enact agency using relational strategies with care providers in a relationship-based way. For example, the family member above said, "I tease the girls because they're wonderful." In other words, meanings of the data centre on patients and families being more likely to use strategies such as humour if they felt they had a good rapport with care providers. A different participant (a patient who was also a health care professional) described that if a patient asked him about handwashing in his clinic, he would put them at ease by responding, "Actually I did wash my hands before I came into the room. Uh I was putting on a new pair of gloves because the first pair I ripped on my ring. You go oh [laughs] sorry." Again, the notion of humour, or keeping an interaction lighthearted, is a strategy I observed both patients and providers use to negotiate power imbalances.

Lucas, a family member, told me about a situation where he was successful using a different type of relational workaround to communicate with a care provider. Several years ago, his wife Olivia was in hospital (not the Study Hospital). Lucas asked to be present when the doctor visited his wife to explain a bad reaction to medication. The doctor told him, "well you're allowed in as long as you are quiet." Lucas told me how he, as a family member, felt "dismissed as a person" and "excluded" from his wife's care, and how stressful this was for him. Lucas told me, "Oh I was really annoyed and put out". But, at the same time he felt grateful to be allowed to attend the consultation. Lucas told me how *hard* he had to work to navigate a relational connection with the doctor to prevent foreseeable harm to his wife. In this stressful situation, Lucas signaled he was *moving away* from a relational connection. Lucas then described what happened when he saw the same doctor later on (emphasis by participant):

Lucas (Family member participant): I'll tell you <u>exactly</u> how it happened because I came down the stairs in that hospital and <u>saw</u> the doctor walking along. So when I called his name, he stopped and turned. But I'm up on the stairs looking down on him. And I explained what was happening with the medication making Olivia really sick. And he said he would correct it. And I went away feeling childish, like I was like "oh good." I'm glad I was standing looking down on him because he's such a…you know...I just appreciate when doctors have [laughs] good manners with people. And when they don't, I'm like ugh. So I was glad. That balanced it all out [laughs].

In this situation, Lucas wanted to be a "good family member" and not get on the wrong side of his wife's doctor. His wife was very ill, and her care was his primary concern. Being a "good family member" *also* meant he needed to get his wife's doctor to listen to his concern. Lucas described using the stairs to his advantage to "balance" – work around – the power difference

between him and his wife's doctor. Lucas' story emphasizes the importance of relational connections between care providers and family members from the family perspective.

In summary, my data showed how some patients/families engage with care providers using relational connectors and workarounds. Patients and families described a sense of losing control and gaining control. These findings show how patients and family members can negotiate power when someone has something they need, and they have little control over how they get it.

#### 6.2.4.4 "I want to get well": Filling in gaps as a potential fast track to health.

A fourth way in which I observed patients and families being "good patients" was in taking action that would help them heal. Two strategies that arose in my data were patients and families following their care provider's instructions, and patients and families filling in perceived safety gaps. Patient **Isabella** described the role of a patient as: "the patients should do those things what they are <u>supposed</u> to do and they're <u>advised</u> to do to get well" (emphasis by participant). Isabella's words also convey, in the context of the *patient hand wipes* intervention, that if a nurse gave Isabella a hand wipe and instructed her to clean her hands before eating, Isabella would take the wipe and clean her hands. Isabella would understand the meaning of this situation as the nurse was giving her a hand wipe because it would help her get well.

Isabella's ideas echo Noah's story at the beginning of this chapter. **Noah's** main health goal was to gain enough strength to survive another surgery, and he described wanting to be "available" when staff came to attend to him. This suggests a specific rationale for patients to pursue an opportunity to improve the quality of their own care. Furthermore, if the staff advised Noah to do

something to move towards wellness, Noah's wife Hannah had the motivation and capacity to act on the advice, even if Noah was not well enough. This is an example of aligned interests (and abilities) between the patient, family, and care provider. In this instance, the motivation for patients to be "good" and do what care providers ask of them is not out of fear of neglect. Nor is it from wanting to be liked or reassured while lonely and vulnerable. Meanings of the data centre on patients wanting to be "good patients" as a potential fast track to their own health. In many situations, patients seemed keen to try to do what the staff asked of them because their goal was to get healthy. Patients/families told me, "well, why *wouldn't* I do what they ask me to do?" Furthermore, these patients and families trust that their care providers' expertise and interests align with their own interests. Following instructions can be a win-win if the instructions are seen as in line with patient's values and intentions rather than in response to a perceived power imbalance.

In what follows, I summarize other ways in which patients and families went about being "good patients" to meet their value and safety goals. Some participants described filling in perceived gaps in the hand hygiene options offered to them by the hospital – literally by 'taking hand hygiene into their own hands'. A few patients on the dialysis unit told me they were hesitant to use anti-microbial products such as hand wipes because they had heard that it was a bad thing to wash away their "good bacteria".<sup>122</sup> So, when a nurse/volunteer offered these patients a hand

<sup>&</sup>lt;sup>122</sup> See, for example, patient-targeted materials such as the U.S. Food and Drug Administration's (2016) Consumer Report that describes downsides of antibacterial products and encourages consumers to wash their hands with plain soap and water.

wipe,<sup>123</sup> some of them said, "no thanks". By refusing a hand wipe, I learned that in some cases patients were not indicating that they did not value hand hygiene, but rather that they perceived hand sanitizer to be contrary to their goals. This example shows that when patients/families receive conflicting or incomplete information, they make sense of it in different ways.

More often in my data, I observed the ways in which patients and families provided their own hand hygiene solutions over and above what the hospital offered. This action responded to the limited (or complete lack of) assistance with hand hygiene before meals at the hospital (except when the *hand wipes* initiative was being piloted on two units). Examples of patients' hand hygiene practices included: **Chloe** wore gloves in hospital settings to protect her sensitive hands, thus eliminating the need to clean her hands with soap, hand sanitizer, or hand wipes; **Charlotte** and **John** brought their own hand sanitizer and washcloth; **John** refrained from eating in areas of the hospital with no hand hygiene supplies (such as the waiting area for the HandyDART, where he was alarmed that he routinely observed patients touching the garbage can with their hands and then eating); **Olivia** (sometimes) asked her nurse for a towel to protect the table before she put food down on it; **Sophia** offered to help sicker patients with hand hygiene as meal trays were delivered, explaining, "I come across as this sorta weird sage to some people or an overly rulebased old-timer" to indicate that other patients did not always welcome her assistance; and **Jin** asked for his own canister of hand wipes because "the nurses kept forgetting to give me one".

<sup>&</sup>lt;sup>123</sup> The hand wipes used in the *patient hand wipes* intervention were alcohol based and did not contain other antimicrobial products such as triclosan.

Patients also told me about related hygiene practices such as wearing designated shoes and clothes to and from the hospital.

Family members also relayed strategies to supplement hand hygiene for themselves and their loved ones. For example, **Hannah** had a health care background and had spent much of the last several months at her husband Noah's bedside. As Hannah stated (emphasis by participant), "I'm not really just a family member". During our interview, Hannah pointed out the bottle of hand sanitizer she had brought for Noah's bedside table. Hannah told me that she performed hygiene duties for Noah that used to be, and ought to be, routinely provided by staff for patients in hospitals (I elaborate on this point below). Although Hannah and Noah were on the complex medical unit for several weeks when the patient hand wipes intervention was reported by unit leadership and point of care staff as ongoing, neither Hannah nor Noah were aware of such a care process when I asked about it. Hannah also mentioned that she occasionally assisted other patients or alerted staff others needed help, a tricky boundary for her to navigate. Hannah suggested that Noah was receiving superior care compared to the other patients because she supplemented his care. Hannah's opinion reflects Pittet's (2017) caution that "adequate safeguards have to exist to guarantee care of similar quality for those who are not able or decline to be involved in a hand hygiene initiative" (p. 198). Some patients have family members to assist and others do not. Regardless, family members are not usually at the hospital 24 hours per day. One exception in my data was **Isabella**, who was accompanied by a paid caregiver (a trained nurse) during our interview. Isabella told me that her family insists on having a caregiver present to oversee her dialysis treatments.

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Scarlett, the daughter of a patient who was fairly new to dialysis, was learning the ropes of the unit. From my theoretical sampling perspective, this participant was interesting on two levels: she was new to (her parent's) dialysis; and she represented an ethnocultural background with which I had not had much interaction. I could not talk with her parent due to my language barrier. Scarlett was keen to talk about my study and described herself, with an embarrassed giggle, as "paranoid" about handwashing because she did not want to get her parent or children sick. She described washing her hands at the sink at the nurses' station. She said, "I'm not sure if I'm supposed to use that sink, I just do it anyway. No one has said anything." In health care settings, part of the uncertainty for patients/ families is navigating hierarchical structures, knowledge gaps and power gaps at a time when they are often unwell and in vulnerable circumstances. Scarlett was also industrious about using CaviWipes<sup>124</sup> to wipe off surfaces that her parent might touch, such as television and chair remotes (Fieldnote #17). Family members who were not physically present at the hospital also played a role in facilitating their loved one's hand hygiene. For example, as I described above, Liam's wife sent a packaged hand wipe in his lunch pack that he forgot to use.

In this section linking my findings about the desire to be "good patients" with the need for relational connections, I have relayed examples of how family members filled in gaps for their loved ones. Hannah told me that when Noah was feeling a bit better, after several weeks as an inpatient, "I stopped coming in and doing all his care....because I was burning out." Several of

<sup>&</sup>lt;sup>124</sup> CaviWipes are towelettes used across Canadian health care settings to clean and disinfect non-porous surfaces and fixtures. The active ingredients are Isopropanol and Ammonium Chloride. CaviWipes (or equivalent) are not for use on skin and these were not the wipes used in the QI intervention.

the family members to whom I spoke – all supporting loved ones with chronic illness – relayed how stressful the job of being an unpaid caregiver was. Some also spoke about how difficult it was to give up control and rely on the staff to take care of their loved ones, and to navigate unfamiliar rules. I close this section with a related personal experience of hospital hand hygiene with my own family. During my data analysis, **Aaron** (pseudonym), one of my older family members, underwent major surgery. The surgery required a one-week hospital stay (not at the Study Hospital). Aaron's goal was a full recovery, and preventing a post-surgical infection was crucial. During my doctoral research, I had learned a great deal about hand hygiene from the QI project teams, and staff and patient/family participants. I purchased hand sanitizer and hand wipes for Aaron's room post-surgery, and coached Aaron and other family members on why and how to clean their hands at the hospital. Reflecting on my experiences with Aaron's surgery from an "outside–inside position" (Dwyer & Buckle, 2009, p. 61) in the methodological sense enabled me to better understand the incredibly nuanced perceptions of many participants in my sample.

As I visited Aaron in the hospital, I noticed that when the meal trays arrived, the menu sheet said, "wash your hands before eating". Nevertheless, this hospital's processes were consistent with my data at the Study Hospital: there were no hand hygiene supplies or staff support to assist Aaron with hand hygiene at mealtime. Between post-surgical medication and weakness, any 'extra' trips to the bathroom sink were either impossible or hazardous. I quickly realized that hand hygiene was important, but not as important as preventing a fall. So, we family members helped Aaron with hand hygiene before eating when we were present. Family members also began to notice other threats, and wiped off surfaces before Aaron touched them (for example, walkers that were shared between patients). At a time when my family felt overwhelmed,

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providing hand hygiene gave us a way to 'take safety into our own hands'. In so doing, we could simultaneously meet our value goals (empowered, clean), safety goals (infection free, reduced potential for falls) and health goals (recovery, discharge) in a way that did not require us to bother busy nursing staff. In other words, while we did not build relational connections with the nurses, we also did not run the risk of alienating Aaron's care providers.

In summary, patients and families implied that being a "good patient" requires balancing competing needs, values, and motivations, as described in the sub-themes above. In the context of hand hygiene, patients/families conveyed the desire to feel clean while in hospital, maintain a sense of autonomy, and attend to relational connections with care providers. In particular, patients/families were sensitive about alienating care providers, either by interrupting or annoying them, and usually erred on the side of caution in terms of not wanting to do the 'wrong thing'.<sup>125</sup> In my study, I also recognized that competing values are not entirely incompatible. The complexity is such that being a "good patient" is not strictly based on one motivation or one value; instead it can be a combination of several motivations and values at once.

<sup>&</sup>lt;sup>125</sup> A situation involving a set of circumstances where one requirement is dependent upon another, which is in turn dependent upon the first is known as a "Catch-22" (OED Online, 2018c). One Catch-22 situation in health care settings is that, patients and family members are not always sure what that right thing is, what their role is, and what is appropriate for them to do.

## 6.2.5 Theme 3: "We're all in this together": Relational constructions of hygiene in hospital settings.

In the context of a QI pilot project on patient hand hygiene, the third theme constructed is that, typically, patients and families understood the value of hygiene in health care settings in a larger context.

#### "We're all in this together"

- Mutual vulnerability
- Hygiene a shared concern and a shared responsibility
- Perceptions of hospital
  - cleanliness

My relational ecological theorizing led me to construct a derivative theme about how patients and families understood the value of hygiene in health care settings in a larger context. This larger context focused on interpersonal and contextual levels of analysis. While the relational analytic lens runs through all the themes in my study, I identified "we're all in this together" as an independent theme about the shared nature of hygiene based on three sub-themes. First, study participants acknowledged the mutual vulnerability of people sharing confined spaces, especially in hospital settings. Second, participants described their experiences of hand hygiene as a shared concern and shared responsibility, where they need to rely on other people and systems. Third, participants situated meanings of a 'clean' or 'dirty' hospital in relation to hand hygiene.

#### 6.2.5.1 Mutual vulnerability.

Most patients and families conveyed an understanding of the unique challenge of infections in hospitals: they are confined spaces with sick patients together, and many people coming and going. Patients/families described how the threat of infection related to them personally and in relation to others. Examples included the spread of germs from person to person (patients, family members, hospital staff, other people) and via surfaces such as chair handles. **Noah** described:

Noah (Patient participant): Well it'd be important for me [clears throat] because I'm one person in a group of other people who, who I do not know who, who have different

diseases and whatever the case may be. And we're not in an isolation area. We're just lumped all together. Now maybe they can't do anything about that.

Hannah (Family member participant): No.

Noah (Patient participant): Just that'd be my concern.

Researcher: Right. You'd be worried about getting more sick.

Noah (Patient participant): Yeah....That's why doctors want to send you home these days rather than stay in the hospital 'cause all you're doing in here is collecting bugs.

People sharing confined spaces share a mutual vulnerability of infection, particularly those who are immunocompromised. **Hannah** also spoke about her concern about Noah's low resistance to germs while in the Study Hospital's Emergency Department (ED) waiting room. Hannah described negotiating with ED staff to move Noah to a more private space where he would be less inclined to contract an infection. Another example involved Hannah arranging Noah's use of a private commode on an inpatient ward to avoid a shared washroom. In what follows, John, who identified as a clean person, illustrates the meaning of the *patient hand wipes* intervention for someone who was highly motivated to prevent infection due to his unique medical situation.

#### 6.2.5.1.1 "Nothing can get in the way of my transplant".

When I met **John**, he had received dialysis for many years and was preparing for a kidney transplant. One of John's family members, who lived in another province, was flying in to donate a kidney. Before John's surgery I shadowed him a couple of times on the dialysis unit. We met at his home several months after the surgery for an interview. John, who was in his early 60s, shared a lot with me about his life and family. He stated that he was vigilant about hygiene in general and had learned the importance of hand hygiene at a young age. John expressed delight

about the new *patient hand wipes* on the dialysis unit because cleaning his hands before eating complemented his values and habits inside and outside the hospital. Most importantly, any opportunity for hand hygiene aligned with his interests to stay healthy to receive a new kidney. What follows is an excerpt from my interview with John after his transplant surgery:

### *Researcher: Can you tell me your reflections about how [the patient hand wipes] worked for you while you were going for dialysis?*

John (Patient Participant): It worked well for me. Once it came into being, um I used it. And there were times when the volunteers didn't offer it. And I would ask for it and they've gone back to the cart to get it. Whereas there were, some of them, not all the time, would actually have it in their little pocket, they already had it. Uh so I would say about 50% of them, of the ones that I dealt with that would come around would have it. But there were others that I actually had to ask for it before I touched anything, yeah.

John expressed that he did not hesitate to ask nurses or volunteers for a hand wipe if one was not offered to him. In fact, he insisted on a wipe every time he ate something on the unit. John told me he was particularly vulnerable to infection because he was on anti-rejection medications. Furthermore, an outpatient dialysis unit is not like a single, double or even a four-bed patient room. Many patients are close together in a shared space, all receiving dialysis treatment with different machines but sharing bathrooms, scales, and so on. It perplexed and distressed John when he saw other patients declining hand wipes (emphasis by participant):

John (Patient Participant): I've watched, you see. I used to watch as, as the volunteer moved from one patient to the other. And I think to myself 'good grief', you know. But there was this one patient that was next door to me more or less, and, and she refused [the hand wipe]. He [the volunteer] did like this [motions offering a hand wipe] to her [the patient] and she said no. And then he put [the canister of hand wipes] back on, on, on the, on the cart. This is just, i-, i-, i, it's unbelievable. I mean it's I cannot understand why you would, I'm very glad, if I'm walking on the street to have somebody hand that to me, you know.... Why a patient would refuse them, when it's something, I mean it's for your own health, it's for your own sanitation...Why?.... Don't people realize that...your hands carry germs? I, I don't know. I, I don't understand why, why this isn't something that resonate with you that this is my body, this is my health, you know. It's cleanliness. Not only that, you with your own dirty hands, you could be touching somebody else. For John, the stakes related to hygiene could not be higher because an infection would make him ineligible for his kidney transplant. This would impact not only John but also a close relative, who was his donor. John expressed that he had to do what he could to make the transplant happen. John's story suggests a specific rationale for patients to pursue an opportunity to improve the quality of their own care. Overall, the context of John's health and illness journey reinforced the importance of and desire to prevent infection. This sense of connectedness was consistent with the two other themes "We are clean people" and "I want to be a good patient", each drawing different inferences from the data.

#### 6.2.5.2 Shared concern and shared responsibility.

My conversations with patients and families reflected the perception that most people in the hospital paid attention to the importance of hand hygiene. Patients/families cited 'evidence' – such as watching staff clean their hands and use gloves, the availability of hand hygiene information and supplies, and the many signs posted around the hospital – that helped build their confidence in the cleanliness of the physical environment. Furthermore, my data showed that most patients and families conveyed an attitude that reflected a shared concern for hand hygiene in hospital settings. In the sub-theme described above, **Noah** situates himself as being vulnerable to catching infections *from others*. In addition, Noah told me, "As far as hand-washing, I mean I wash my hands no matter where I go. And try not to deliver my bugs to anyone else." Here, he conveys his concern to avoid infecting others, as best as he can in or out of hospital. In my study, I recognized that most patients and families saw good hand sanitation as a civic as well as a personal responsibility: "we all have to do it". My findings point to what I came to think of as a

'herd immunity'<sup>126</sup> understanding of hygiene in hospital settings: protection from germs was only possible if everyone participated in hand hygiene. This attitude reflected a broader theme of connectedness, interdependence, and concern for self and others.

Patients and families frequently talked about problems such as infections, "superbugs", and antibiotic resistance. Participants accepted that hand hygiene and other strategies to address these concerns were based on science. For example, **Emily** said, "I'm aware of germs. So there isn't much extra education I need about hand washing." My findings about the *patient hand wipes* pilot project suggested the intervention was believed to be a good idea that was not controversial. Yet, in the larger context of my findings, patient/family concerns about hand hygiene were overridden by worries about alienating care providers. In other words, an important finding in my study was that hand hygiene was a concern but not necessarily the most dominant one.

In order to fulfill individual and collective values and accomplish infection control goals, patients and families expressed to me that they needed to rely on other people and systems. As discussed previously, hospital patients are in a unique situation. First, patients often experience fluctuating agency and capacity to clean their hands (for example, when Hannah referred to the earlier part of Noah's hospitalization when she was very ill, or when Emily described being afraid of frustrating her nurse). Second, various drivers of lower capacity mean that patients (and possibly families as well) may not be able to follow through on what hospital staff has asked

<sup>&</sup>lt;sup>126</sup> Herd immunity is an epidemiologic concept whereby community resistance to infection becomes stronger by the presence of immune individuals and provides a protective barrier for more susceptible individuals (Fine et al., 2011).

them to do, or to act according to their wishes and values.<sup>127</sup> Patients described to me that they were/are not always able to be fully responsible for their own hand hygiene (for example, Noah's, Liam's, Sophia's, or Evelyn's stories). As the data I have reviewed above and review below indicate, some patients/families describe ways they perceive hand hygiene in hospital settings as a "partnership". This partnership could be between a patient/family and the staff, or between a patient and their family members.

As noted above, patients and families spoke about watching what the staff were doing. In my study, patients and families regularly relayed observing that staff cleaned their hands "all the time". For example, **Scarlett** spoke about "feeling safe because everything was so clean." Furthermore, my data showed that most patients/families members assume that "care providers are professionals"; this meant that they do what they are "trained to do" and "supposed to do". Participants also referred to institutional roles, such as having hand hygiene supplies available for everyone to use, policies and procedures about infection, proper cleaning, monitoring compliance, and professional training programs. These data examples also suggest that patients and families rely on institutions and systems in a relational way in a hand hygiene partnership. A patient memoir I read while writing this dissertation echoes this belief. Mary Elizabeth Williams (2016) stated, "You can tell he's a doctor because he instinctively opens doors with his elbows" (p. 143). Part of the power on the side of the care providers is that patients/families assume training and competence results in consistency. So, believing that hospital staff practice good

<sup>&</sup>lt;sup>127</sup> As noted in Chapter 2, Naik et al. (2009) describe the capacity to execute agreed-upon aspects of one's own care as *executive autonomy*.

hand hygiene makes patients feel that they are safe when in situations beyond their control – literally, they are in good hands.<sup>128</sup>

While most patients/families seemed to assume that their care providers practiced good hygiene, some participants raised questions that suggested they did not have full confidence in the hospital staff's infection control practices. For example, John raised the idea of interconnectedness when wondering about volunteer hand hygiene, saying "Because these are the same people that you know um they're coming from outside too. You know, are they washing their hands before they start? I don't know how that part of it is handled" (emphasis by participant). Hannah told me in a hushed voice: "But they [doctors] might not, they might not change their gown between superbug patients. They might not." Yet, as described above, I found that patients/families are essentially unwilling to ask/confront providers about hand hygiene. More typically, patients and families in my sample described examples of poor staff hygiene practices from their experiences in other hospitals. For example, Patient Sophia (also a health professional) explained that, according to her assessment, "this hospital as a *community* [referring to all of the people in the hospital], is aware and pays attention to the importance of hand hygiene." Based on her expert knowledge, Sophia went on to say that hospital leaders are required to implemented mandated national infection control programs; the staff follow some of these and ignore others.

<sup>&</sup>lt;sup>128</sup> Figuratively, the phrase *in good hands* means "in the charge or care of a reliable and trustworthy person or persons; securely protected by a dependable party" (OED Online, 2018d).

Some patients and family members complained to me that patients/families were not doing their part to practice good hand hygiene, such as John's example above about patients refusing hand wipes. Other examples included not cleaning their hands properly, and going around "touching stuff that they weren't supposed to be touching". On the dialysis unit, once patients were hooked up to the dialysis machine, they were immobile for several hours. Patient **Emily** described her concern (emphasis by participant):

Emily (Patient participant): the one thing I, sorta concerns me sometimes is, especially in the beginning was ... just the access of all the, of the equipment and all the common touching between the patients. And I can trust that the nurses and staff know that there's supposed to be washing their hands and different things like this, and uh just kind of unsure about how clean other patients are, you know, and whether or not they are considering the other patients when they're doing their own thing, you know grabbing the equipment or supplies or whatever. And I remember one time um...one nurse got upset at not the patient but the person that was with the patient, I think it was a family member, because they were touching stuff that they ... weren't supposed to be touching. So it kinda sits in the back of your mind how often does that happen and how often does it actually get caught or if it you know, if someone can contaminate something and no one notices then what happens from that point, right? 'Cause it's just everything is freely accessible right? You know, carts. And people do their own things. So that sits in the back of your mind sometimes. It's not necessarily the staff but ... the other patients more that are a concern sometimes.

On the complex medical unit, patients could be more mobile, causing concerns from patients/families as well as staff on this unit. For example, patients feared that other patients did not wash their hands after using the toilet and that the shared bathrooms were not cleaned often enough. The high number of street-involved patients and family members on this unit resulted in some patients eating food from leftover meal trays. In the context of confined health care settings, many patients and families interpreted these types of behaviours as being "bad patients" that put others at risk of infection. These examples point to the important roles that context and values play in shaping the attitudes, behaviours, and organizational practices of the patients, families and staff in a particular health care setting.

Meanings of the data centred on most patients assuming (and expecting) that others would follow infection control practices, and assuming that 'the system' will work, despite a general knowledge of issues with infection in hospitals. To bring the complexity and variation in patient/family perspective into this theme about values and shared concern for hand hygiene, I return to Ben's and John's stories about the *patient hand wipes* intervention. The fragment of **Ben's** story ("you think I'm dirty") relayed to me by Ben's nurse suggested that the relational affront Ben experienced overrode any relevance hygiene might have had for him in that moment. In contrast, **John's** ("nothing can get in the way of my transplant") hypervigilance to protect himself also relied on others. I now describe Emma's story, which was a unique response to the patient hand hygiene intervention in the data I collected.

### 6.2.5.2.1 "I'm going palliative soon".

**Emma's** story illustrates a dramatic contrast concerning the threat of infection. As I shadowed Emma one afternoon on the dialysis unit, I learned that she was in her 90s. She had chronic medical challenges including kidney failure, impaired mobility, and debilitating pain. Emma told me that she felt like a burden on her family, all of whom were "experts on what she should do". Emma explained to me that she was "going through the motions" and would soon "go palliative" by stopping dialysis. Emma used words in relation to this decision such as acceptance, time, control, hope, euthanasia, and peace. My interpretation of Emma's story is that she hoped for an imminent death – a peaceful death over which she had control.<sup>129</sup>

<sup>&</sup>lt;sup>129</sup> Afterward, as I reflected on my conversation with Emma, I wondered if Emma had shared her feelings and plans with her family and health care team. Emma had not appeared to be distressed, yet I was unsure if I had any professional obligations as a researcher. I discussed the situation with my co-supervisor and we decided I would follow up with Emma and probe if it would be appropriate for me to arrange support for her. Shortly after, when I

Emma told me that as a retired nurse, she understood the relationship between hand hygiene and infection. But she saw the situation differently now. She assured me "the care here is very good," suggesting she had good relational connections with the care providers and health care setting. Yet, she said she no longer cleaned her hands and shrugged her shoulders. She declined hand wipes when they were offered to her. Like John, Emma's response to the *patient hand wipes* was based on scientific evidence about infection control. In the current context of Emma's health and illness journey, however, preventing infections no longer had value to her. It no longer aligned with her interests. Hand hygiene could have been perceived by her as irrelevant. Or, I wondered if Emma avoided hand hygiene because it played a role in keeping her alive. In Emma's case, an infection would be an opportunity to hasten her death, along the lines of Sir William Osler's (1904) suggestion that "pneumonia may well be called the friend of the aged" (p. 109). Emma's story suggests a rationale for patients not pursuing an opportunity to improve an aspect of the quality of their own care. Given Emma's waning interest in preventing infection, it is also possible that Emma did not reflect on how her own lack of hand hygiene could impact other dialysis patients around her who would be harmed if they contracted an infection.

Most of the patients and family members I interacted with fell somewhere in between John and Emma in the different ways they expressed 'valuing' the hand wipes as a care process, and where it fit with their sense of safety (infection-wise or relationally) or as part of their larger

asked Rupi (one of the clinical leaders on the dialysis unit) about Emma, Rupi gently told me that Emma had transferred to a hospice where she died surrounded by her family (Fieldnote #18). My interaction with Rupi also sensitized me to the sadness and loss care providers can experience, especially when they say goodbye to patients and families with whom they have had long-term relationships. This is one example of my experiences as a researcher that helped me to understand that being open to "ethically important moments" requires an obligation and ability to, as Doane and Varcoe (2013) state, open relational space for difficulty (p. 153).

hospital experience. Some patients explained they were already clean in their hospital beds while waiting for a meal or snack to be served. As **Emily** said, "I used the alcohol rub earlier, and I haven't touched anything." These patients conveyed that the *patient hand wipes* intervention was not necessary for them; they perceived themselves to be clean at that moment, and were already doing their part for themselves and others. In addition, some patients referred to the specific circumstances in which they were eating. For example, cleaning their hands would be unnecessary before eating a salad with a fork but appreciated before picking up a sandwich.

In summary, the patient/family data I have reviewed above describes four layers of connectedness hand hygiene as a shared concern in hospital settings: 'I need to protect myself', 'I need to rely on other people to protect themselves to protect me', 'I need to rely on institutions and systems,' and 'I also need to protect others' (see Figure 6.3).



Figure 6.3 Relational construction of hand hygiene as a shared concern in hospital settings: Layers of connectedness.

This sub-theme is another example in my study that illustrates my analysis of patients' and families' descriptions of their experiences in a relational ecological way, with intrapersonal, interpersonal and contextual levels. This further suggests that for patients and families, a complex set of relational concerns regarding hand hygiene may be going on at the same time.

#### 6.2.5.2.2 "Hey everyone, remember".

As described above, for many patients and families, preventing infection while in hospital usually aligned with a desire to restore or maintain their health. I considered this finding in the context of the *patient hand wipes* intervention. As the *patient hand wipes* pilot project began, the QI project teams put posters around the two study units. The posters showed a care provider offering a canister to a patient sitting in bed with a meal tray, and the patient pulling a hand wipe out of the canister and wiping their hands. I asked **Jin**, a patient on the complex medical unit, if he had seen signs about washing before eating in the hospital. Jin replied, "there's no harm in reminding people." From this response I was unsure if he had noticed the posters or not. Nothing arose in my data to suggest patients and families were aware of these posters on either of the study units. Three months after the pilot period ended on the dialysis unit, I noticed most of the QI project posters had been removed from the hallways of the unit. The regular hand hygiene posters were still visible, most often in proximity to a sink, hand rub dispenser, or doorway.

A few patients expressed to me that, at times, they wished staff would remind them about hand washing. For example, as described above, several dialysis patients told me about being taught how to wash their own hands in the clinic, and to ask staff to be sure to wash their hands too. Upon arrival, dialysis patients who are mobile are expected to clean their hands with soap at a sink or with hand rub, weigh themselves, then clean their hands again before getting settled at their dialysis station. Then they are hooked up to the dialysis machine for several hours. Patients conveyed that watching other patients go about this hygiene routine made them feel like they were in a clean place. It reassured them. Several patients told me that they liked managing their own hand hygiene to the extent that they were able.

**Olivia** provided an example of how shared concern for hand hygiene comes into this. Olivia told me she occasionally feels dizzy when coming for dialysis. She said she would like the nurses to double check if she washed her hands as she arrives on the unit because she thinks she forgets sometimes. She does not quite feel she can trust herself to remember. This suggests some patients value hand hygiene enough that they do not want to be fully responsible for executing what they would want to do when they were feeling their best. In other words, meanings of the data centre on patients' and families' challenges with keeping clean in the context of feeling situationally vulnerable. Furthermore, they know that collective protection is only possible if everyone in the unit was doing their part by cleaning their hands.

As highlighted by patient/family participants who were bothered by watching other patients or visitors not performing appropriate hand hygiene (e.g., Hannah, John, Sophia, Emily, Noah), patients/families noticed "some people don't care about my safety". Such concerns reflect a different type of tension in values. Some participants talked about wishing the nursing staff would remind other patients and family members to stop "spreading their germs around". In this way, patients and families depicted staff as allies. Yet patients/families were largely unwilling to 'cross the line' by reporting the transgressions of other patients/families who did not follow what they believed to be (or ought to be) a shared set of hand hygiene rules. This was another area of values tension highlighting how patients and families safeguarded their relational connections with staff and other patients. In other words, this is an example of "we're all in it together" having both infection control and relational aspects.

As described above, most patients/families in my sample conveyed the sense that "it's not enough for one person to do hand hygiene – we all have to do it." Yet, patients/families highlighted the need to take complexities such as power and authority into account when talking to people about hand hygiene. This applied to interactions between care provider and patient/family, and, to a lesser extent, between patient/family and patient/family. For example, patient **Sophia** described herself as recently homeless and told me about her strategies to avoid "smelling bad" on the street. She told me that her attention to personal hygiene fluctuates according to her substance use. Sophia anticipated that hospital patients whose usual circumstances involved street life would take offence when asked to clean their hands. This was consistent with earlier data I collected emphasizing the need for careful attention to relational connections and cleanliness as an assessment of worth. Sophia thought patients would say to the nurse, "Why are you asking me if I washed my hands? It's none of your fucking business." In relation to the *patient hand wipes* intervention, she proposed a theoretical scenario of how nurses could remind patients about hand hygiene without being patronizing:

Sophia (Patient Participant): ...well it's not up to the people who deliver the food, but nobody's coming nurse-wise on any individual basis that I've seen and said 'oh hey, lunch is here, mmm that looks good, did you wash your hands?' That would be a simple thing to communicate to patients um at every mealtime, you know. And if, there'll be, there'll be jokes made about it initially. 'Did you wash your hands?' You know, 'yes Martha Stewart, we all did. We lined up in the hand-washing column with holding the rope and we all got an Oreo when we were finished'.

#### Researcher: So, it would feel kind of like you were being treated like a kid?

Sophia (Patient Participant): Uh I think if it were treated like that around the actual meal delivery itself. Supper's here, who hasn't washed their hands? 'Oh John, do you need a hand uh sanitizer squirt 'cause you're bedridden and like now's not a great time and your food's just been delivered, to expect you to get up and get to the washroom and wash your hands'. But something that says, **'hey everyone, remember'**.

Sophia alluded to the increased complexity in power dynamics between care providers (reflecting people in authority) and patients marginalized by society. Her story reveals that people who are homeless have varying awareness of what it means to be clean and why this is important for everyone. In Sophia's opinion, a "hey everyone, remember to clean your hands" – done *consistently*, at the *right time*, and in the *right way* – was needed and could grow to be accepted by the patient population on the complex medical unit. This finding points to a way patients and families might *move towards* relational connections with care providers and health care settings while increasing collective protection against infection.

#### 6.2.5.3 Perceptions of hospital cleanliness.

I identified hospital cleanliness as a third relational feature of patient and family experiences of hand hygiene in a larger context. As described above, while most (but not all) patients and family members expressed appreciation for the care received, time spent in hospitals was not usually perceived as ideal. For example, **Noah** told me, "I'd much rather be at home." In this section, I explain how hospital cleanliness arose in my data, and how participants related hospital cleanliness to hand hygiene interventions and their broader experience of care. As noted above, when I spoke with patients and families I included a version of the question "What do patients notice about what the hospital is doing to promote cleanliness?" (see Appendix K). Since my study focused on infection control, it is not surprising that participants talked about germs, objects, and surfaces. Often, patient/family responses related to the hospital facility being clean or dirty rather than to personal hygiene. Responses described the immediate area (e.g., patient room, dialysis unit), other units (e.g., the emergency department), common spaces of the Study

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Hospital (e.g., hospital entrances, hallways), and other health care facilities. In what follows, I describe these data in terms of patient and family meanings of a 'clean' and a 'dirty' hospital.

Only a few patients/families spoke about the Study Hospital (or hospitals in general), as a clean place. More often, patients said that the areas where they received care were adequately clean. Participants gave examples of how seeing or imagining cleanliness in the hospital affected them in positive ways. For example, I asked **Scarlett**, "what's one thing that's important to your experience as a family member here?" At first she said, "the nurses are so good and kind." Then she looked around and added, "the cleanliness of this unit." Scarlett described that she watches the housekeepers clean the floor, and said, "I like that the medical supplies are packaged because I can see the staff open everything". When I asked Scarlett what all of this meant to her, she said, "it feels like we won't get sick here" (Fieldnote #19). Scarlett's story reinforced that 'seeing is believing'.

Typically, however, patients/families in my sample conveyed an awareness that the hospital environment (as distinct from the people within) was dirty. Many expressed concerns about this, compounded by the fact that some people perceive hospitals to be dangerously germ-laden, as epitomized by the phrase "pest houses" (Ambrose, 2005; OED Online, 2018e), a historical phrase used to describe hospitals or any institutions where infectious disease is prevalent. In what follows, I describe my data about hospital cleanliness in terms of unseen germs (e.g., on elevator buttons) and a visible lack of cleanliness (e.g., spills on floor, garbage). In relation to infection control, what concerned patients and families most was the cleanliness of "shared surfaces" they touched with their hands, such as elevator buttons, bedrails, and television/bed

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controls. Many participants perceived germs lurking on surfaces to pose a direct threat to their health. Several family members described using CaviWipes to disinfect surfaces. Some participants attributed the increased hospital infection risk as the primary reason patients are "sent home quickly these days." These data highlighted patient/family awareness of the importance of infection control, and most directly situated many participants' stated support of new opportunities to keep their hands clean.

The second troublesome aspect of hospital cleanliness that arose in my study sample was a visible lack of cleanliness of the physical environment. Patients and families shared their observations about grimy floors and sinks, overflowing garbage cans, and bedside tables cluttered with old food and bedside urinals. Participants' perception of hospital cleanliness might have been shaped by characteristics of the specific unit where they were receiving care, including the age of the unit, patient population, or type of care provided. Participants also provided examples of how seeing – or even suspecting – a lack of cleanliness in the hospital might harm them. For example, **Lorenzo** (a patient being treated for cancer as well as kidney failure) commented that if the stairwells were dirty and garbage cans were overflowing (dirt he could see), then he wondered whether his bed remote control was clean (dirt he could not see). Therefore, 'seeing is believing' worked both ways.

In the following interview excerpt, **Chloe** described how a dirty physical environment detracted from her patient experience, consistent with data from other patients and families who conveyed that cleanliness is a key feature of quality (emphasis by participant): Chloe (Patient Participant): Um I'm put off when I see dirty bathrooms, I think any of us are, because bathrooms to us are uh you might be dirty at home but that's our dirt, you know. In public um it's just the thought, it's um the sensitivity of going and <u>standing in something you know has got urine on the floor, just um that, that's um disgusts me uh personally.</u>

As my patient partner Carol remarked, "Personal cleanliness and cleanliness of the environment is connected to the quality of care. It's almost insulting to call it 'improvement'" (Field Note #23). This comment connects meanings about hospital cleanliness with the themes ("We are clean people", "I want to be a good patient" and "We're all in this together"). Specifically, how a person identifies as 'clean' can shape how they engage with the people and places in health care settings. For patients such as **Ben** who felt he was considered dirty, there may be a disconnect between perceptions of "we are clean people" and patients being made to feel like they are unclean – when in fact looking around, the hospital facility itself is not clean. Therefore, hospital cleanliness is a significant contextual feature to consider when designing a QI intervention to promote patient hand hygiene.

During several conversations, patient/family participants, the majority of whom were older adults in my sample, explained to me *why* hospitals are dirtier now than in the past. Generally, explanations pointed to broader perceptions about how social structures were shaping people and situations. For example, **Noah** referred to nurses' "changing priorities" whereby in the past nurses used to assist patients with hygiene, "everybody got a facecloth to wash their hands and face before their meals." In the following interview excerpt, **Chloe** pointed out a troubling contradiction and offered her opinion about why attention to "bugs" has increased while general "cleaning standards" have decreased (emphasis by participant):

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So I think there's certain, there's certainly, uh it <u>all</u> happened with um HIV. Things changed from that. And then with all these other <u>bugs</u> and whatever, Legionnaire's Disease, you know they've upped the ante. Um so um I'm not sure about the cleaning, I think the cleaning, it having um privatized, and I think that probably has suffered a little bit. So I think the cleaning standards, for the workers, are tough. They are not as good as they used to be. Um but that, I mean that's a political thing. I, I ended up in um uh [different hospital] at one time 'cause I had an [injury]. And it became infected. And I remember I was put into a geriatric ward. And I don't believe that ward was cleaned very much. I, I've noticed a difference in cleanliness regarding um hospitals themselves over the years, that I think that's deteriorated. Um as I say, that's political so....so I mean that's the, that's the downside of privatizing. So I mean there's new people who come around but who knows how thoroughly they are cleaning. And then you'll see papers on the floor. They do their best but it's, it is what it is.

A different participant described how the cleaning staff cleaned patient rooms compared to that

of a different hospital (interview excerpt):

Family Member Participant: [at a different hospital] the cleaners would come and they'd wipe all the tables off and they'd wipe the side tables off. And they just went around washing and then they'd do the floors.

### Researcher: And how does it work here?

Family Member Participant: Somebody comes and does the floors occasionally but this stuff [referring to side table, overbed table, windowsill] never gets cleaned. I, I do it.

In my own family experience with **Aaron** at a different hospital, another of my family members was concerned that "the cleaners rarely mopped the floors and when they did they just sloshed the dirt all around." For my family member, the biggest hygiene issue was the lack of concern about dirty floors because Aaron was walking around in non-slip socks and getting back into bed. These accounts situated health care organizations as neglecting to prioritize cleaning in the same way as in the past, and/or health care staff (especially cleaning staff and nursing staff) seemingly not to care how clean or dirty the facility was, or being too overburdened. Again, in the larger context of my findings, patient and family concerns about hand hygiene were often overridden by worries about the cleanliness of hospital areas, or other personal or medical issues. This is another example of hand hygiene being a concern but not necessarily a dominant one.

As noted above, several patients and families attributed lower cleaning standards to cost cutting and privatization, revealing some participants' awareness of the complexity of the multiple people, processes, and systems operating together in health care delivery. Accepting the state of hospital cleanliness also suggests values tension. For example, some patients/families expressed worries that not everyone shared the same level of concern about hygiene, or were able to act according to their values. Furthermore, while many patients/families pointed out observed 'deficiencies' in hospital cleanliness, they typically followed up these comments by rationalizing why these deficiencies were acceptable. For example, "no one was concerned, because the nurses haven't got time to be dealing with that stuff" or "it's a political thing ". In addition, many patient/family stories implied that they could not be paralyzed with worry about things they could not control, such as when **Lorenzo** said, "Oh well, I haven't gotten an infection so it's probably ok" (Fieldnote #20).

In summary, in the context of a QI pilot project on patient hand hygiene, meanings of the data centred on a sense of mutual vulnerability and shared concern in relation to infection control. These data reinforce that the "we're all in this together" theme includes "not just on me" but "all of us". While most patients/families conveyed that the staff (including care providers and cleaning staff) were doing their best, my data also showed that a perception of a dirty hospital can conflict with patients' and families' sense of being cared for. Patients and families described these aspects of their hospital experience in a larger context and in relation to the meta-theme of

patients *moving towards* or *moving away from relational connections* in the context of their situatedness. In other words, in my study sample what seemed more important to most patients and families than dirty floors – or being assisted with personal hygiene before eating – was being treated in a *caring manner* by care providers. Meanings of the data centred on the point that if patients and families felt connected with their care providers and care settings, then the wider issue of hospital cleanliness could be less threatening to them. Attention to relational connections is particularly important because it applied to infection control overall as well as specific QI pilot projects to improve patient hand hygiene.

# 6.2.6 Revisiting the Meta-Theme: "It's like each time they are saying to me, 'why bother, we may never see her again'."

Collectively, patients and families expressed concerns about hand hygiene and more general observations about health care across all levels with considerable variance amongst individuals and across care settings. My

findings have also shown that patients and families continually navigate their interactions with care providers in a relational way. The significance of the meta-theme centres on the *value* patients and families place on moving towards *positive* relational connections with their care providers, as well as health care settings. Here I revisit this meta-theme with a patient story that shows ways in which patient Oliva moved towards and away from relational connections, and how she describes the impact these experiences have had on her.

**Olivia** was a retired physics teacher who came for dialysis three times per week. Over a period of five months, twice I shadowed Olivia on the dialysis unit and once interviewed her together with her husband **Lucas** at their home. Olivia shared an element of her patient journey that was emotionally painful for her. She said that on all of the dialysis units she has attended, the kidney doctors do not speak to the patients unless there is a medical issue. Each day, the nurse asks her, "do you have any questions for the doctor?" If there are no concerns, there is no reason for the doctors to check her, and the doctors just walk by. According to Olivia, the doctors do not acknowledge her, or even look at her. She said her family members tell her, "make up questions to get the doctor to come and examine you" because they think she will get better care if the doctor checks her each time. But Olivia does not want to bother the doctors with concocted complaints. She wants to be a good patient.

What really disturbs Olivia about all this was not getting better care, rather the *feeling of being ignored*. She understands she would die if she did not receive dialysis. But, being ignored makes her feel hopeless. It gives her the feeling that "I'm only temporarily here, occupying a bed in the dialysis unit." Olivia told me, "it's like each time they are saying, 'why bother, we may never see her again'." As a researcher and witness to another's pain, this was a difficult story for me to listen to. It points to Olivia's yearning for relational connections with care providers who have the power to make her feel valued, and the power to take her value away. Olivia's experience with the *patient hand wipes* had a similar impact on her, albeit on a smaller scale. In addition to a personal relationship with her care providers, hand hygiene and especially washing before eating were important to Olivia, both in and out of the hospital. Thus, when the *hand wipes* project was piloted on the dialysis unit, Olivia understood and responded to it in a positive way, in the

context of her life experience. When Olivia and I talked about hand wipes, she told me she liked being offered a hand wipe before eating. Despite this preference, Olivia told me that she was reluctant to ask for towels and hand wipes, gestures she felt provided patients with dignity and sanitary conditions. She would sit quietly and hope the staff would meet her needs, both physical (a towel or hand wipe) and relational (that she would feel valued). *Not* being offered hand wipes made Olivia feel like she was less worthy, as if the nurse or volunteer did not want to bother taking the time for her despite knowing that hygiene was important to her. On those days Olivia was not offered a hand wipe, she felt neglected, overlooked.

Olivia's story also illustrates how the lack of consistency in the offering of hand wipes shaped the themes in this study that I have conceptualized collectively as aspects of relational connection. Olivia's husband **Lucas** shed insight on Olivia's need for relational connections, saying "[laughs] I don't know how this fits in, but Olivia is a kind of person that she needs a personal relationship with her doctors." For example, Olivia's description of her care experience shows how she perceived an interaction as harmful; feeling ignored and neglected compounded her feelings of being disabled and diminished. Other patients with very different life circumstances also expressed a sense of not being cared about when "the kidney doctors won't even look at me" (Mia) or "not one of the doctors, nurses, other care providers, and volunteers were caring and validating, and how these connecting behaviours made them feel safe. Together, these patient stories show the complexity of human experience and that we cannot make sense of experience unless we understand a person's situatedness.
In summary, QI interventions, as with other care processes, can have neutral or profound impacts on a patient's or a family member's experience. Olivia and the other patient and family participants in my study expressed their care experiences in a multitude of ways. Although not all aspects have been captured in my data, their stories do point to the subtleness of what patients and families 'notice' about health care processes, both new and routine. These stories shed light on how a patient/family might feel when care processes are, or are not, carried out. And, they reveal that *how* different aspects of care are carried out can make patients/families feel more, or less, safe and valued. Thus, findings of this research emphasize that we cannot make sense of impacts of QI on patients and families unless we look at the context of the larger systems, given that neither human experience nor implementation of QI interventions occurs in a vacuum. In what follows, I provide an important organizational dimension to the findings derived from my interactions with patients, families and individual staff.

# 6.3 Part B: Contextual Findings About QI Implementation

As described above, the relational themes I constructed from my data responded to

Contextual Findings – how QI projects were implemented Gap between Work-as-Imagined & Work-as-Done

important aspects of patient/family experiences *in the context of* specific QI interventions. In the pages that follow, I describe a set of significant contextual findings that reflect my observations and analyses about how the two *patient hand wipes* QI projects were implemented on two study units. From an applied ethics perspective, my data about project implementation are a critical part of my analysis that provide an important organizational dimension to the findings that I derived from my interactions with patients, families, hospital staff, and volunteers. Consistent

with the relational ecological theoretical lens and interpretive description methodology scaffolding this study, Thorne (2016) explains the importance of context:

The trick is to maintain a healthy respect for context, since you may not realize until much further along your analytic path that a particular contextual bit is in fact quite relevant in a way you might not have imagined at the outset. At the same time, it is important not to confuse context with data. (p. 141)

As I describe below, my study captures the middle phase of an ongoing QI intervention. The most salient feature in these findings is the *disconnect* or *gap* between how quality leaders thought about the patient hand wipes intervention before, during and after the projects took place, and how I observed the intervention carried out where and when it happened. I describe this disconnect in a chronological way to parallel the journey of my data collection and to situate the relevance of this clinical context: my initial expectations about what I would observe, patient/family perspectives, and organizational perspectives about the same QI intervention.

# 6.3.1 My initial expectations about what I would observe.

In the *first stage* of my data collection, I observed QI project team meetings (2 different project teams) and thus primarily gathered perspectives of quality leaders and unit leaders. During some of these meetings, I observed the process of team members planning to roll out the *patient hand wipes* at the point of care and addressing challenges (e.g., Ethan's story, timing hand wipes offered by nurses to coincide with meals). I also shadowed QI team members as they surveyed a dozen patients (suggested by unit leaders or randomly chosen) about their hand hygiene needs.

No patients, families, or patient partners participated in any project planning meetings I attended on either study unit.<sup>130</sup>

During the *second stage* of my data collection I began observing on the two hospital units where the *patient hand wipes* intervention was active. Study posters (see Appendix E) and unit leaders introduced me to staff and patients on the units as a "researcher studying hand hygiene". The following excerpt from my fieldnotes, "at end of rounds, there was an explanation of who I was and my study, and then questions/joking about 'remember to wash your hands'" (Fieldnote #21) prompted me to consider the potential bias of the Hawthorne effect (knowing one is being observed) (Given, 2008). In other words, I anticipated that care providers, volunteers, patients and families might go out of their way to use hand wipes or other forms of hand hygiene because my presence might serve as a reminder.

On one study unit, the four-week *patient hand wipes* pilot period ended a couple of months before my observations began. Unit leaders told me, "the hand wipes are now a regular routine on the unit, and the key challenge seems to be getting the staff to remember because it is new" (Fieldnote #22). On the other study unit, my observations began at the beginning of the fourweek pilot period. Although the implementation science literature reviewed in Chapter 3 is clear

<sup>&</sup>lt;sup>130</sup> Both study units piloting the *patient hand wipes* intervention surveyed patients in advance of the four-week pilot phase to assess whether patients perceived a need for hand hygiene. One study unit also reported results of a post-pilot patient survey with positive results; this unit also had a patient-led and unit-supported patient/family committee that met periodically. My data overall indicated that while patients were the target of the *patient hand wipes* on two study units, the planning and design of the intervention via two different project teams did not involve patients and family members in a meaningful way.

about the difficulty of sustaining QI interventions, my expectations (of which I was not yet aware) were that I would observe what people were telling me was happening with the *patient hand wipes* intervention at the point of care. In other words, I expected to see nurses and volunteers offering hand wipes to their patients before meals/snacks with a high degree of regularity. I also expected to see patients cleaning their hands with these wipes.

## 6.3.2 Disconnect between Work-As-Imagined and Work-As-Done: *Patient hand wipes*.

In this section, I describe my data about what I learned from study participants - patients,

families, and a range of hospital staff and volunteers - about how the patient hand wipes

intervention was implemented at the study hospital during my data collection period. As Box 6.2

summarizes, quality leaders assumed the intervention would be rolled out in a particular way, but

these assumptions were not consistently fulfilled at point of care.

## Disconnect between how QI intervention was imagined versus how it was done

The most salient contextual feature in my findings is the disconnect between how quality leaders thought about the patient hand wipes intervention before, during and after it took place (work-as-imagined) and how the intervention was actually carried out where and when it happened (work-as-done).<sup>131</sup>

Box 6.2 Disconnect between how QI intervention was imagined versus how it was done

<sup>&</sup>lt;sup>131</sup> Erik Hollnagel's (2015) concept is that what happens at the point of care (work-as-done [WAD]) is always different from what is imagined by those who plan the work (work-as-imagined [WAI]). I elaborate on Hollnagel's concept in Chapter 8 (Section 8.2).

# 6.3.2.1 Patient/family perspectives on patient hand wipes intervention implementation.

Viewing the *patient hand wipes* implementation over eight months through patients' and families' gazes and in the context of their lives enabled me to form a more nuanced understanding about how the QI intervention unfolded over time. In what follows, I describe patient/family perspectives about project implementation.

# 6.3.2.1.1 As the patient hand wipes intervention started.

My participant observation on the dialysis unit coincided with the beginning of the four-week *patient hand wipes* intervention pilot study. Initially, I observed several patients asking the volunteers what was going on, and that volunteers often chatted with patients about the reason for the hand wipes. Nothing in my data suggested that patients understood that the new hand wipes was a process being 'tested out'. Some patients/families were particularly helpful in helping me understand the trajectory of the *patient hand wipes* by describing the pilot project in relation to other aspects of their care experience. For example, in the following excerpt from my fieldnotes, **Olivia** narrated how the *patient hand wipes* intervention came to be:

I asked about hand wipes. Patient gave me quite an accurate account of the initiative:

- She said the initiative was that the volunteers gave patients hand wipes before the coffee and cookies
- It wasn't always like that, the hand wipes started 1-2 months ago
- The first time the volunteer handed her one, said she was surprised [face: eyebrows raised]. Said "what's this?"
- She thought she should be offered an explanation about why they were doing this, even if it seems obvious
- She isn't always offered one, not consistently
- She likes when she is offered one
- Thinks she should be offered one each time
- She thinks that probably the volunteers aren't trained properly about the wipes, and the importance of them. (Fieldnote #23)

Olivia's comments then helped me direct my observations to certain aspects of the project implementation. For example, what words, if any, did volunteers use when offering hand wipes? How often were wipes offered, and to which patients? How were the volunteers trained about the wipes process, and what were their expectations? The patient stories in my data provided dramatic contrasts in 'first impressions' of these hand wipes on the hospital units. This is an example of patient/family feedback that shows while patients do not expect to know all that goes on, they can be very aware when their care routine changes and they form opinions about (in other words, construct meanings or make sense out of) these changes.

## 6.3.2.1.2 Two to three months post-pilot period: 50/50 frequency on both units.

I first met **John** a couple of months after the four-week pilot ended on the dialysis unit. In the following interview excerpt, John describes reduced frequency after the pilot period:

John (Patient participant): But if, to me, if only in my estimation, from my experience, only 50% does it [volunteer offers patients hand wipes], why, something is wrong somewhere, you know, that I have to ask for it when it should be automatic, you know. You're, you're offering patients food and really these are patients that are not mobile um and, and they're dialysis patients, you know. And, and you're in a hospital setting. Um this should be, everyone should be carrying around, you should be offering this to the patients.

On the complex medical unit, I had the opportunity to talk with patient **Jin** about 3 months postpilot, and he described a similar trend. Jin had been on the complex medical unit for many months, the span of which covered before, during, and after the *patient hand wipes* pilot. For this reason, Jin was unique in my study sample.<sup>132</sup> Jin looked to be in his 50s and struggled with mobility. He expressed that he was very keen for hand hygiene opportunities. When I asked Jin

<sup>&</sup>lt;sup>132</sup> I had hoped to come back and interview Jin further, however he had been discharged when I returned to the unit. 278

about hand hygiene, he told me that the nurses started to bring hand wipes to him because he was not mobile, but the problem was that they only brought hand wipes to patients before meals "half the time". He said the plan was not very efficient because he had to keep asking nurses for wipes (Fieldnote #24). Olivia's, John's and Jin's stories signify the value of understanding patient and family experiences of the context of QI project implementation. These patient stories reflect the frustration for some patients who were thinking, "I'm supposed to keep myself clean; they're supposed to be giving me a hand wipe before I eat – so where is it?"

#### 6.3.2.1.3 Four to nine months post-pilot: drop-off in recall.

As the months went on, patient and family data suggested that the frequency of hand wipes available to them continued to diminish. These data correlated with my own observations on the two study units, where I noticed a reduction in frequency dwindling to rarely. Working from my initial expectations, I reasoned that patients/families who had been on the study units for lengthy periods should be able to recall at least some exposure to the *patient hand wipes* intervention. How would they describe their experiences of this care process several months post-pilot?

My interview with **Emily** occurred about four months after the four-week pilot period ended on the dialysis unit, meaning Emily had come for dialysis about 60 times since the *patient hand wipes* pilot started. Emily, who conveyed an understanding and appreciation for hand hygiene, stated that she had accepted a hand wipe "one out of a dozen times" she was offered one. My data are incomplete and do not indicate whether volunteers only offered Emily a wipe one in five times (e.g., the process was unreliable), or if she was sleeping during most snack times (e.g., the patient missed the process), or a combination of the two. This example shows the complexity of understanding patients' and families' experiences of a QI intervention. It also reflects that each person had a unique experience of what the QI intervention was, and how the intervention related to them as well as others around them. In Emily's case, the hand wipes process was not a regular feature of her dialysis care, and my interpretation was that the process had little meaning to her. Several patients and families told stories that conveyed they had never been offered a hand wipe before eating while in the Study Hospital. Some patient/family participants in my sample, including Noah, Sophia, Isabella and Emma, were retired health care professionals. Due to their knowledge of hand hygiene protocols in clinical settings I considered these participants to be especially reliable narrators. For example, during my interview with patient Isabella (about five months post-hand wipes pilot), she detailed her own hand hygiene practices both as a health professional and as a patient. When I asked Isabella if the volunteers offer her a hand wipe along with the coffee and cookies, she replied, "No, I've never noticed that." Non-health care professionals provided valuable insight as well. I asked **Scarlett**, a dialysis patient's daughter, to tell me about the snack time. Scarlett described herself as "paranoid" about hygiene. She was familiar with the coffee and snacks but had never seen a hand wipe or been offered one. She said emphatically, "Oh, I would remember."

On the complex medical unit, I interviewed three patients and one family member nine months post-pilot. When I asked about hand wipes, participants told me no one had offered them a hand wipe on the unit over the past several weeks: patient **Noah** replied "nope", family member **Hannah** "not once", and patient **Sophia** "I don't see anyone helping anyone to clean their hands before eating". When I asked patient **Evelyn** about opportunities to clean her hands before the meal tray arrives, she responded (interview excerpt):

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We don't have uh hand sanitizer near our table. And I can't get up to the, to walk over there [refers to windowsill, where there is a canister of hand wipes]. But if I ask for a facecloth, maybe they'd bring it. You have to find our own way of doing it.

Therefore, during the latter stage of my data collection and on both study units, talking with patients/families about the patient hand wipes intervention suggested that most patients and families were never (or rarely) offered a hand wipe. The further away from the pilot period, the fewer patient/family participants were able to recount seeing hand wipes at all, and therefore I was unable to distinguish the QI intervention from accounts of their larger patient/family journey. These data contrasted with the diversity I observed in initial patient/family reactions to hand wipes in Part A (e.g., an insult [Ben], a surprise [Olivia], key to survival [John], or irrelevant [Emma]). Furthermore, by the end of my study most patient/family participants on both study units no longer conveyed an expectation of being assisted with hand hygiene before eating. So, Hannah, Noah, Sophia, Evelyn, and Scarlett did not express disappointment when a hand wipe did not arrive. In fact, for these participants, being offered a hand wipe before eating was a new, hypothetical idea they were in favour of. Yet these observations conflicted with my data from hospital staff who generally conveyed that the intervention was still "active" on the study units several months post-pilot. I will elaborate on organizational perspectives in Section 6.3.2.2.

#### 6.3.2.1.4 Composite Story: 'Susanne' describes hand wipes at her hospital.

To close this section on patient/family perspectives of the *patient hand wipes* intervention's journey during my data collection, 'Susanne's Story' (see Box 6.3) is a composite

representation<sup>133</sup> showing that for most patients and families in my sample, the hand wipes came and went without making too much of an impact. My study data are inclusive of a wide range of participant reactions, attitudes and perceptions, knowledge, and behaviours about the QI interventions I studied. 'Susanne's Story' portrays the disconnect between how patients and families experienced this QI intervention and how it was "imagined" by quality leaders. 'Susanne's Story' also represents typical aspects of the study themes described in Part A.

<sup>&</sup>lt;sup>133</sup> Using interpretive description methodology to describe a phenomenon does not aim to construct a meta-narrative of all participants in my sample (Thorne, 2016). In Box 6.3, I use composite representation as a technique to explain the general trajectory of the *patient hand wipes* intervention (Thompson & Kreuter, 2014; Willis, 2018) based on situated and narrative (Nisker, 2013) accounts from patients and families.

# Susanne's Story (Composite)

I've been coming to this hospital for the past six years for my health condition. My problem started when [long patient history]. Now I need to come to the clinic three afternoons a week. I use HandyDART so it's a *really* long day for me. The first few times Mandy – she's one of the nurses, so sweet – taught me all about my condition and the treatment. Now I'm familiar with how things work and what I'm supposed to do here.

The nurses rotate so I don't always have the same nurse, but I've gotten to know many of them over the years. Most of them are really good. They know what they're doing, and they're so nice. Sometimes a doctor comes over to check on me. I started with Dr. Jones but the doctors work as a group.

Also, volunteers offer us a snack most of the time. It breaks up the day. You know they're coming when you hear the snack cart rolling down the hall. Like on an airplane. If I'm dozing, this wakes me up. For a snack I usually get tea with milk and two cookies. Once in a while a volunteer will ask me if I want a handi-wipe with my snack. Mark comes on Wednesdays unless he has an exam or band practice, and he offers me a wipe right away [smiles]. Mark always says to me, "Susanne I know you like to keep as clean as you can". The volunteers change quite a bit, and I know some of them too.

For a while there most of the volunteers gave me a hand wipe each time I was here. I saw them giving wipes to other patients too. That was a while back though... last summer? I wasn't sure why, just one day they started giving these wipes out. Then it was only sometimes. I guess I could ask for a hand wipe, it's just that I wouldn't want to bother anyone. There are lots of patients, it's not only the nurses that are busy you know. But I'm not sure if they even have those hand wipes anymore. Maybe they stopped them because they weren't useful [shrugs] or people are too busy. I could ask Mark next week.

When I was new here, Mandy explained about hand washing. They all really stress the importance of it, especially with my health condition. Before I get settled in my bed, I wash my hands at that sink [points]. Or at least I try to. Honestly sometimes I'm too tired by the time I get in here. The nurses and doctors are constantly cleaning their hands. They say, "we want everything to be super clean around here, and we all need to do our part." Cleaners disinfect the equipment before I arrive, but I may touch things that other people have touched. And what about the TV remote. I wonder, how clean is it, really? [laughs]

My mother taught me to wash my hands before sitting down at the table and I taught my kids the same thing. It's what we do. I think using these wipes is a good idea. Look at all the people in this one room together! It's common sense to do what I can to be clean, same as I would at home. Some patients say "no thanks" to the hand wipes. I don't get it, especially with all the germs around this place! On the news you hear about people getting sick just from walking into a hospital.

#### Box 6.3 Susanne's Story (Composite)

# 6.3.2.2 Organizational perspectives on patient hand wipes intervention implementation.

Health care staff, including quality and unit leaders, care providers and volunteers were important participants in this study. They too came with their own histories and backgrounds. As my analyses thus far have shown, the *patient hand wipes* QI pilot project started off with excitement and good intent, but faded away over time. In what follows, I use data representing organizational perspectives to further explain the disconnect between how the QI intervention was imagined and how it actually played out (Box 6.2). I elaborate on these contextual findings in my ethical analysis in Chapter 8 and recommendations in Chapter 9.

# 6.3.2.2.1 Positive intentions.

In my study, quality leaders and leaders on the patient care units voiced a sincere commitment to support staff, patients and families, and to make a difference in patient hand hygiene. As noted above, the *patient hand wipes* intervention was driven by quality/safety leaders in the organization. As I began data collection, two multidisciplinary (primarily nursing) QI project teams realized that they were in the process of planning similar *patient hand wipes* pilot interventions on different acute care units. In health care organizations with so many ongoing efforts to improve the quality of care, overlapping initiatives are not uncommon (Gould et al., 2017). From data gathered during conversations I had and observations I made, I noted concerns of senior quality leaders about leadership coordination between these two projects simultaneously pursuing what looked to be common objectives. In particular, one department perceived another as not freely sharing information and insights. I interpreted this tension as an example of the complexity in organizations with different areas of responsibility, lines of

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accountability, incentive structures, and differing ideas about what the 'right' thing to do was and how to go about doing it.

While I was shadowing on patient care units, care providers talked about many aspects of their jobs, including medication management, prioritizing tasks, patient assignments, and their strategies for dealing with patients, family members and colleagues. On both study units, I observed a general sense of support for the *patient hand wipes* project, especially during the four-week pilot period. I observed that, for the most part, care providers and volunteers at the point of care were open with me about their experiences of the *patient hand wipes* intervention. For example, care providers and volunteers provided estimates of how the project was going and how frequently they were able to offer hand wipes to patients. My findings also suggest that while quality leaders and point of care staff assumed that patients and families would experience the *patient hand wipes* intervention in a positive way, this was not necessarily the case. Indeed, my data showed diversity in experiences, and many patients and families had not seen the intervention at all.

# 6.3.2.2.2 Inconsistent, declining implementation over time.

On my first day observing a patient unit, I shadowed volunteers Nancy and Pardeep. They told me they had received the volunteer supervisor's email about the *patient hand wipes* pilot intervention the week before and they knew what to do. I observed:

Seemed to offer all patients handwipes – hand wipes container remained on top shelf of cart. For each patient, the volunteer took hand wipe out of container, walked over to patient and handed it to them or asked if they needed help cleaning their hands. Volunteers seemed to be comfortable with the hand wipes portion of the coffee service, and used to the routine. While I was not following each and every patient, most patients

I observed seemed to accept the hand wipe. One or two [patients] seemed a bit uncomfortable. (Fieldnote #25)

As I shadowed volunteer Lisa the next day, I noticed she did not offer hand wipes. I asked Lisa about hand wipes, and she conveyed no knowledge of them. However, because I pointed to the canister she said "oh, I'd better do it." Without opening the wipes canister, Lisa asked some patients "do you want a hand napkin?" (Fieldnote #26). From what I observed on this day, most patients said no. Overall, though, during my observations of the four-week pilot period on this unit, most volunteers seemed to know why the canister of hand wipes was on the snack cart.

As one of the nurses I shadowed explained to me, "I'm bad about remembering to offer my patients hand wipes. It's just not part of my routine. I want to improve. Patients like it" (Fieldnote #27). This general description resonated with what I was hearing from many staff/volunteers (as well as patients/families) about the *patient wipes* intervention. In general, it seemed like a good idea, it was just hard to remember to do. Canisters of hand wipes were stored in hallways, outside patient rooms. Staff relayed that they did not routinely leave wipes canisters at the bedside because the canisters would go missing. Nurses described difficulties such as timing each patient's hand wipe just as their meal tray was delivered; having concurrent situations to deal with; or patients being off the unit at mealtime. Nurses also described ways of dealing with these challenges, such as putting a wipe on top of a patient's meal tray if the patient was absent or asleep. Some nurses told me that if they were going to be on break during meal service, they asked the nurse covering to give wipes to their patients. This suggested to me that a nurse covering another nurse's patients might not automatically offer hand wipes to all patients under their care. Especially on the complex medical unit, I noticed how frequently the point of

care staff were interrupted. A busy clinical setting is a significant contextual feature of a QI intervention that is also reflected in my patient/family data above; specifically, in that many patients and families said they were reluctant to bother staff/volunteers, especially those who appeared to be 'busy' or 'frustrated'.

I wondered if staff/volunteers were cautious about making changes in their routine, which was hard to do, for a QI process being piloted, and was therefore viewed as temporary. As I shadowed care providers (mostly nurses) while they went about their day-to-day work, it was not uncommon for staff to tell me about the wipes process – and then forget to offer patients a hand wipe at a meal or snack time. When staff realized this disconnect (or I pointed it out to them), they explained that they had gotten distracted, either because I was shadowing them or the hand wipe was not part of their usual routine. I learned from staff of only one patient who developed a physical adverse reaction (red hands) from the hand wipes.

In summary, during my data collection covering two *patient hand wipes* projects on two hospital units, my data (first-hand observations and conversations with patients/families and staff/ volunteers) revealed that staff/volunteers regularly offered patients hand wipes before meals/snacks during the four-week pilot period and then for the immediate period post-pilot. However, my data did not support that patients were routinely offered hand wipes in the latter months of my data collection, suggesting an apparent failure of the QI intervention at the microsystem level. As John asked me, "is it just a one-shot deal?" It is unsurprising but significant to realize that post-pilot, staff/volunteers offered patients hand wipes on an

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increasingly infrequent basis, dwindling to rare or never over the duration of my observational fieldwork.

# 6.3.2.2.3 Lack of clarity in project communication and expectations.

Many of my interactions with point of care staff/volunteers and unit leaders on both study units were unplanned and informal. These data gave me some valuable insight into the context of some of the 'pauses' that were part of the *patient hand wipes* intervention. My data about the context of the QI project implementation indicated some lack of clarity in communication and expectations from the perspective of point of care staff and volunteers. One area of confusion was the project status: were the hand wipes were "on" or "off"? For example, I learned by talking with a unit leader that "we're not doing the wipes right now. They ran out and are on order." A few minutes later, the person checked the supply room and saw the hand wipes canisters had arrived, and then restocked them in the appointed spots around the unit (Fieldnote #28).<sup>134</sup> However, I do not know if some (or all) staff were alerted (and how, such as at rounds or via email) that "the wipes are back on". Or, perhaps some staff noticed the new canisters and began offering wipes again, while other staff were unaware and/or uninterested. At times, some staff/volunteers would ask me, "are we still doing it?" or they would tell me, "we're not doing that any longer." Other staff/volunteers appeared not to know about the *patient hand wipes* intervention at all.

<sup>&</sup>lt;sup>134</sup> This is one of a few examples where my presence as a participant observer may have impacted the *patient hand wipes* intervention.

For the *patient hand wipes* intervention, another complicating organizational factor was that different groups of staff/volunteers (staff mix<sup>135</sup>) had different reporting structures. For example, registered nurses, licensed practical nurses, other care providers (e.g., dietitians, social workers), and volunteers all reported to different people. These groups were also integrated into unit processes in different ways within the two units. Many individuals and groups were involved in consulting, decision making and communicating updates about the *hand wipes* process. Overall, the context of project implementation varied by unit, and also reflected the complexity of communication and accountability in health care settings.

# 6.3.2.2.4 Focus on functional details of implementation.

Overall, care providers and volunteers in my study sample talked a lot about *functional* details of how the *patient hand wipes* process unfolded at the point of care. These details included aspects that worked well for the staff/volunteers (e.g., it was a simple task, or "the patients like it") and challenges (e.g., the timing, or uncertainty if "we're still doing it"). Yet, I observed little about *relational* aspects of the hand wipes process. That is, I learned little about how staff/volunteers perceived socio-emotional aspects of the hand wipes process, or about how they perceived their patients made sense of the new process. Based on my observational data (with the exception of the participants in Ben's and Ethan's stories), I wondered if staff/volunteers experienced tension when engaging with patients/families about hand wipes. This raised questions about the degree

<sup>&</sup>lt;sup>135</sup> Staff mix is defined by the Canadian Nurses Association (2012) as, "the combination of different categories of health-care personnel employed for the provision of direct client care in the context of a nursing care delivery model" (p. 3).

to which staff/volunteers were aware of relational aspects of their own, or their patients' and their family members' experiences, in regard to the QI intervention.

Several relational examples became apparent during my observations. Nurse **Ella** emphasized the importance of developing trust with her patients, and described situational trade-offs to balance clinical and other goals. For example, Ella told me her priority was to ensure Harry took his medication. In order to accomplish this, she had minimal contact with Harry, who she described as a quarrelsome person. Ella explained to me that she did not want a "small win" (such as Harry agreeing to having his vital signs taken, or to clean his hands before dinner) at the expense of "losing a significant battle" (such as Harry refusing to take his medication). In addition, Ella expressed that because she had been on vacation she needed time to develop trust with all of her patients – and Harry in particular (Fieldnote #29). Ella's story illustrates how care providers adjust relational interactions and clinical priorities in caring for individual patients. Such diverse details about the context of implementation show that staff 'compliance' with QI interventions can only be understood within the context of patient circumstance and larger systems. I explore this implication for QI further in my analyses in Chapters 7 to 9.

# 6.3.2.2.5 *Post-pilot QI project evaluation reports.*

Both project leads of the *patient hand wipes* intervention prepared and submitted internal reports about their respective QI project. The purpose of each report<sup>136</sup> was to summarize the team's

<sup>&</sup>lt;sup>136</sup> Project reports summarized the QI intervention's background, methods, qualitative and quantitative results, and recommendations. The nature of the project report is one of the features traditionally understood to distinguish QI from research; for example, research reports describe a systematic investigation to develop generalizable knowledge (Kass et al., 2013, p. S5).

experience implementing the *patient hand wipes* intervention on the patient care unit. Both reports included self-reported<sup>137</sup> staff/volunteer survey results pre- and post the four-week pilot studies. These data were not linked to staff compliance, infection rates, or reported reasons patients liked/valued or disliked/did not value being offered a hand wipe before eating. Project reports focused on *functional* details of the patient hand wipes care process. For example, one project's report delved into practical barriers that prevented staff/volunteers from integrating the new hand wipes process into their routine (e.g., workload, timing), and conducted a second follow-up evaluation several months after the initial pilot study. The second project's report did not identify any barriers to staff/volunteers integrating the new hand wipes process into their routine a picture of staff/volunteers willing and usually able to comply with the hand wipes process (how the QI intervention was imagined), which was clearly at odds with what I observed (Box 6.2).

In the context of my study findings, it is noteworthy that no *relational* aspects of the hand wipes process were mentioned in these project reports, and neither report referred to the role of family members in patient hand hygiene. Although patients were surveyed on both units, only one project report included results of patient surveys. These pre- and post- survey results indicated that most patients liked being offered hand wipes, and that patients who did not want a hand wipe were not bothered or offended when they were offered one. These self-reported patient

<sup>&</sup>lt;sup>137</sup> Self-reports from patients/families and staff are commonly used forms of evaluation in QI. Limitations of selfreporting include that: point of care staff/volunteers typically have busy workloads. Staff self-reports may not relay an accurate picture of a QI intervention because staff are too busy, they do not value the activity, or they want the project to be successful (The Health Foundation, 2010, p. 120). QI patient surveys are typically satisfaction measures (e.g., did you like it?) that have limited meaning for understanding patient experience (P Bate & Robert, 2007).

findings, submitted shortly after the four-week pilot period, were consistent with the early data I collected on this unit. Overall, the two post-pilot project reports described the *patient hand wipes* intervention as successful pilots that were sustained and should be spread because staff were able to comply with the task and patients liked being offered a hand wipe before eating. In other words, the pilot process was seen as successful and benign. Notwithstanding the progress made, this message was more promising than the results I observed. On the whole, my data collected during my study period did not show lasting action at the unit level once the pilot period ended.

## 6.3.3 Journey of a QI intervention: A stone dropped in a pond.

In summary, my patient/family and organizational data showed that the *patient hand wipes* intervention was not fully implemented by staff nor consistently experienced by patients and families as planned or reported. My findings suggest that the journey of the *patient hand wipes* QI pilot intervention was somewhat like a stone being dropped in a pond. At first there was a splash. The ripples appeared to dissipate and then disappear in the absence of consistent monitoring and reinforcement.

Overall, my findings about the disconnect between how the *patient hand wipes* intervention was imagined by quality leaders and how it was implemented in practice suggest that staff/volunteer intentions and effort were, on the whole, overly optimistic. The QI intervention I studied in this research had widespread acceptance – it was not controversial; it was supported by scientific data and it was envisioned as simple to implement. Quality leaders appear to have assumed that because the pilot project had been launched, it was happening as intended. However, my observations indicated that the hospital had trouble navigating the practical and relational

complexities in order to operationalize (design, implement, evaluate) this intervention effectively.

My qualitative methodology provided me with significant views into power and interaction at several levels of the organization pertaining to this QI intervention. However, there were also many related details that were not within my study focus, and study participants raised topics and questions beyond the scope of my research questions. For example, participants' queries included: did the intervention ensure patients had clean hands before eating? Were patient hand wipes effective in preventing the spread of problem bacteria to patients? These data led me to recognize that more clarity was needed regarding the balance between competing goals, including patient/family preferences, staff compliance, and infection prevention and control.

#### 6.4 Chapter Summary

In Part A of this chapter, I described my main study findings focusing on patient and family experiences of a QI intervention. I organized these findings as a thematic analysis along one meta-theme showing that patients and families move towards and away from relational connections with care providers and health care settings. I described links and tensions between this meta-theme and the three themes "We are clean people", "I want to be a good patient", and "We're all in this together". In the context of patient hand hygiene, patients/families expressed moving towards connections within health care structures when they felt their sense of personal hygiene was acknowledged by others, when they could be good patients without giving up something they wanted or needed, and when they perceived that others around them were on the 'same page' about personal hygiene and other aspects of hospital cleanliness. My data showed

many attempts at positive relational building, and also revealed defensive actions to avoid negative impacts from care providers perceived as indifferent and even hostile. Yet, the data revealed considerable variance amongst individuals. Overall, themes constructed in the context of two QI pilot projects on patient hand hygiene showed that patients and families seek to preserve relational connections with care providers and health care settings. Thus, how human connection and caring fit into quality and safety interventions will drive this dissertation's forthcoming discussion chapters.

In Part B of this chapter, I described the context of QI implementation, the main feature of which was the disconnect between how quality leaders imagined the hand hygiene intervention and how it was done at the point of care. These findings are important in my study because they situate the context in which I constructed the themes about patient and family experiences in Part A, and how the themes played out in my research. These contextual findings also suggest that staff assumptions that patients experienced the intervention in a positive way were, at times, inaccurate and simplified. Overall, my findings about the nature of QI project implementation provide a new perspective on the way QI interventions are implemented, and highlight the need for longer-term follow up to understand what goes on at the point of care.

# **Chapter 7: Discussion – Implications about Relational Safety from the Findings**

# 7.1 Introduction to the *Relational Safety Framework*

In this chapter I present a deeper interpretation of the findings centring on the value patients and families placed on positive relational connections with their care providers and health care settings (as described in Chapter 6). Here, I turn to unpack the meaning of patients' and families' relational needs in the context of the real-time implementation of QI interventions at the point of care. I explain key implications of this research in terms of how I constructed the *Relational Safety Framework* in this study. As has been evident in my research findings, and as I further discuss throughout this chapter, I found that *relational safety* is of utmost importance to patients and families in their health care relationships.

# **Relational Safety Framework**

Implications of the research centred on the value patients and families placed on positive relational connections with their care providers and health care settings. Relational connections occur through interactions with others that potentially ground relational safety. It was my observation that when people have a sense of relational safety, they move towards connections with others, fostering trust.

## Box 7.1 Brief summary of the Relational Safety Framework developed in this study

In my *Relational Safety Framework*, the initialism ICST stands for four components of relational safety I have identified: Interaction, Connection, Safety and Trust. In Figure 7.1, I use bidirectional lines to illustrate the dynamic relationship between these constructs without specifying causal relationships.



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## Figure 7.1 The Relational Safety Framework.<sup>138</sup>

My methodological and theoretical approaches<sup>139</sup> enabled me to probe the layers (self/others/ context) that moral agents navigate in novel ways. My analyses led me to explore a diverse array of relevant ethical concepts. For example, of prominence in my findings was the complex relational space between concepts I interpreted as "relationship" and "trust". Beach et al. (2006) articulate a description of health care relationships that reflects the full range of intrapersonal, interpresonal, and contextual relations:

Relationships provide the context for many important functions and activities in health care. Within relationships, we exchange information, allocate resources, arrive at diagnoses, choose treatments, and assess the outcomes of care. None of these is carried out solely by 1 party; all are mediated by the qualities of the manifold relationships that link patient, clinician, team, organizations, and community. (S4)

<sup>&</sup>lt;sup>138</sup> Patient/provider Graphic (©2013 Six Seconds, by permission)

<sup>&</sup>lt;sup>139</sup> My interpretation reflects my relational ecological theoretical framing; my interpretive description methodology; my own researcher biography; and the study methods described in previous chapters. Thorne (2016) maintains that interpretive description methodology focuses on the "real world" where findings are destined to be applied (p. 224). This practical focus required ongoing "theorizing and developing 'best guesses' about explanations" (p. 185) without making a full commitment to final theoretical framing.

Further, patterns in my observational data prompted me methodologically to explore new literature to inform my interpretation (Thorne, 2008, pp. 196–197, 225). As I described in Chapter 4, given that human experiences are products of numerous relational interactions, processes, and social contexts (Bronfenbrenner, 1993; Doane & Varcoe, 2013, 2015; Sherwin & Feminist Health Care Ethics Research Network, 1998), I was primed to notice how power came through social structure and arrangements such as gender and culture, and how these elements may have been shaping people, situations, interpersonal relationships, as well as my own research processes (Doane & Varcoe, 2015; Thorne, 2016). In my findings, patients' and family members' accounts of their life histories and current circumstances shaped the diversity in responses to the QI intervention I studied. For example, some patients and family members at the hospital appeared well informed about hand hygiene and open to opportunities to keep themselves and their immediate surroundings clean, while other patients/families seemed unwilling or unable to engage. Moreover, the health care organization priorities (e.g., concern about nosocomial infection) and larger societal values (e.g., an expressed desire to engage patients/families) shaping my study data pushed me to evolve my analysis of the role that trust plays in patient and family experiences of QI, and to unpack its role in relational safety.

In what follows, I explain (1) why I locate three components (connection, safety, trust) of the *Relational Safety Framework* on a continuum, and (2) why I situate the names of the components on the positive end of these continuums. First, consistent with other literature, my interpretations of study data in Chapter 6 reflected complexity and diversity in the care experiences that patients and families navigated (the pilot QI intervention, as well as health care more generally), and these experiences were not fully positive or fully negative. These interpretations are consistent

with other related literature (Bate & Robert, 2007; Entwistle et al., 2012; J. A. Wolf, 2017). In other words, these complex social concepts are not unqualified goods. Furthermore, patient and family experiences were highly context-dependent and fluctuated depending on situational factors such as the people involved, patients' health status, and the nature of care processes as well as care settings. I address the complexity in my data by describing three *Relational Safety Framework* components along three continua: (1) relational connection as moving *towards* a relational connection, *moving away* from a connection, and *disconnecting*; (2) relational safety from *safety* to *unsafety* or *danger*; and (3) trust in terms of *trust, trust wary*, and *mistrust*. For example, in Chapter 6, I portrayed some patients (e.g., Evelyn) moving towards connections with nurses who used endearments such as "dear", while other patients (e.g., Sophia) described feeling patronized from similar endearments and moved away from connections with these care providers.

Second, I use positive terms to name continuums (connection, safety, trust) to reflect what most participants shared that they wanted and needed in a health care encounter. My interpretation of these findings is that patients and families were, for the most part, conceptualizing and *seeking* relational connection, relational safety and trust as positive attributes of their health care experiences. I came to understand these data as reflecting how patients and families wished things could be, or what Bate and Robert (2007) term "ideal or aspired experience" (p. 105). My use of positive terms also reflects the aspirational motivations that correspond with the nature of QI initiatives, and my own commitment to contribute to health care system improvement. Over the remainder of this chapter, I elaborate on and draw distinctions between each of the four components of my *Relational Safety Framework* as a way of analyzing patients' and families'

relational needs in the context of the real-time implementation of QI interventions at the point of care.

# 7.2 Relational Interaction (Component 1)

Relational connections occur through relational interactions with others.

"Everyone's existence is tied to that of others: life is not time merely passing by, life is about interactions." (Pope Francis [Pontifex], 2017).



My relational ecological perspective led me to focus on the space at the point of care when and where a social *interaction* between care providers and patients/families took place involving care processes that were part of a QI intervention. Pope Francis' quote above refers to the relational nature of interactions in general, and many disciplines have studied the patient–provider interactional dynamic. For instance, Bate and Robert (2007) refer to "how the interface between user and service is shaped" (p. 32), whereas sociologist Carl May (2007) writes:

the encounter between professional and patient is one of the basic units of analysis in the field of 'medical' sociology. From the very beginnings of the sociological investigation of medical practice it has been conceived as a dyadic encounter, defined by asymmetries of power, the negotiation of rational and authoritative scientific knowledge, and private, proximal, relations. (p. 29)

In this dissertation, I use the term *interaction* as encompassing similar terms such as interface and encounter. It is important to note that my interpretation of *relational interaction*, based on a concept of *relational* articulated by scholars such as Sherwin and colleagues (1998) described in Chapter 4, is broader than some other interpretations in the literature. For example, Weiste's (2018) paper conceptualizes therapeutic interactions as including participatory interactions (of a collaborative nature) and relational interactions (of an emotional nature). Weiste limits relational interactions to those "which involve clinicians' demonstrating listening and empathy, supporting clients and offering them positive feedback" (p. 45).<sup>140</sup> Upon entering my study with an awareness of the asymmetries of power amongst the agents involved in health care interactions (Baylis et al., 2008; May, 2007; Sherwin & Feminist Health Care Ethics Research Network, 1998), it became clear to me that adding a new QI intervention that required a new or changed patient/provider interaction at the point of care had the potential to change the context of both patient and provider experiences. As I described in my findings, I found that QI impacted patient–provider interactions in a range of ways, from subtle to dramatic. In order to explore the impact of a QI intervention on patient/family experience, I was initially drawn to those points of interaction at the point of care that were most obviously associated with the hand wipes process.

As I indicated in Chapter 6, observable patient–provider interactions introduced via the *patient hand wipes* QI intervention included, for example, when nurses/volunteers offered patients hand wipes, when volunteers asked patients questions about handwashing after using the bathroom, and when patients asked nurses/volunteers for hand wipes. May (2007) explains that his conceptualization of an encounter (cited above) is a simplified account because it is separated from its contexts: "the clinical encounter itself is only one part of an assemblage of complex organizational, institutional and disciplinary resources and practices" (p. 41). For example, in a relational sense, the context of **John's** ("nothing can get in the way of my transplant") health and illness journey reinforced the importance of preventing infection. Therefore, John was in circumstances that reinforced his vulnerability and the urgency of heightened hand hygiene.

<sup>&</sup>lt;sup>140</sup> See also Sadler and Hulgus' (1992) paper about the different components of a clinical encounter.

I also described my data about intentional non-interactions, such as when patients and families told me they "held themselves back" from asking for or sharing concerns about hand hygiene with staff. The interpretation I offer here is that while care providers and quality leaders may observe a single interaction at the point of care, such as a patient accepting a hand wipe, I learned that interactions related to the hand wipes QI intervention were much more complex. For example, the patients involved might be feel disempowered/unsure, clean/comforted, or somewhere in between. Indeed, Entwistle & Watt (2013) portray the ethical dimensions of patient–provider interactions as shaping experiences between moral agents.

## 7.2.1 Interactions between patients and care providers: a *moral relational space*.

Further, relational ethicist Vangie Bergum (2013) refers to "space where health care professionals and patients make connection" as "the true meaning of respect" (p. 127). This ethical analysis led me to situate patient–care provider interactions as *moral relational spaces*, which then opened up a broader exploration of the social exchanges I observed. Grant (2002) writes about "everyday ethics", stating, "the core of ethical behaviour between staff and patients may reside in the seeming minutiae of small social exchanges" (p. 173). For example, in my study, most patients seemed to interpret interactions with volunteers/nurses who offered them a hand wipe as moments that they were seen and valued as a person, reinforcing the psychological, emotional, and relational wants and needs of the person. Yet my data also indicated that most nurses and volunteers linked these same interactions to reducing microbes, reinforcing a biomedical paradigm that is focused on physiological and transactional aspects. In this way, my data reinforce other infection control literature such as Reilly et al. (2016) who state, "what might appear to be simple interactions and interventions in healthcare, such as hand shaking and hand hygiene, should be considered complex interventions taking account of behaviour at the individual and social level as well as contextual factors" (p. 29). Furthermore, as I began to unpack my data, I realized that what I observed was suggestive of interactions involving a complex range of human wants and needs. Interactional patterns I observed had quite different meanings that varied between individuals and stakeholder groups. I elaborate on such apparent disconnects later in this chapter.

Building on Bergum's (2013) guidance, I have come to see that "we need to consider ethics in every situation, every encounter, and with every patient" (p. 128). In my *Relational Safety Framework*, I use the term *relational interactions* to emphasize the political and social dimensions that relational persons engage in as they interact with others. In adopting this perspective, *all* interactions are seen as relational. I argue that a major theoretical implication of this research is that introducing new processes and interactions, such as via a QI intervention, can create moments of uncertainty in patient–provider relationships. In what follows, I describe how interactions form the foundation of my *Relational Safety Framework*, and how each interaction that patients and families experience in a health care context creates opportunities to strengthen or erode relational connections, relational safety, and trust.

#### 7.3 Relational Connection (Component 2)

Implications of the research centred on the value patients and families placed on positive relational connections with their care providers and health care settings.



"Human connection is the best medicine." (Poniewozik, 2017, para. 17)

As I explained in Chapter 6, relational connections were the common storyline beneath the surface of my data and comprised the meta-theme, with two important relational connections reflecting the patient and family experiences of QI interventions. First, patients and families experienced moving towards and moving away from connections with their *care providers*, reflecting Poniewozik's quote above. Second, patients and families also experienced relational connections with the *places* or *settings* in which they received health care. In what follows, I draw on my data analysis and key sources from the literature to elaborate on my articulation of *relational connection* presented in Box 6.1 of Chapter 6. I then discuss how connection links to the other components in my *Relational Safety Framework* (see Figure 7.1), and how my analysis led me to situate connection in the context of chronic conditions, and also to understand health care organizations as having moral agency.

## 7.3.1 Extending ideas about relational connection from the literature.

In this section, I elaborate on how my iterative data analysis led me to incorporate five complementary ideas<sup>141</sup> about patient/family experience of relational connection from different sources of literature and to apply aspects of existing models in a new way. First, the whole of my data drew me to understand the significance of relational connection in terms of a *relationship-focused* approach. For example, during my observations of how the hand hygiene intervention was planned and implemented, I gathered very minimal data about what personal hygiene meant to patients/families. In reflecting on this lack of data, I came to understand that QI's focus on the

<sup>&</sup>lt;sup>141</sup> The five complementary ideas about relational connection I discuss are: (1) the significance of a *relationship-focused* approach; (2) the need to take on responsibility and/or rely on other people and systems for a *common purpose*; (3) a *dynamic, fluctuating process* along a bi-directional continuum; (4) the potential disconnect between the *objectivity* and *subjectivity*; and (5) being 'seen' in *particular sociopolitical contexts*.

'patient' and/or the 'clinical problem/task' can come at the expense of acknowledging how the new clinical task might impact patients' sense of self and sense of agency, as well as the relationship *between* patients and care providers. While my data collection was aimed at prioritizing patient/family perspectives, I also collected data from and about staff and volunteers. These insights led me to consider existing models such as Kitson et al.'s (2014) fundamentals of care framework, and Kuhl et al.'s (2017) application of Beach et al.'s (2006) relationship-centred care ("care in which all participants appreciate the importance of their relationships with one another" [p. S3]) to educate critical care providers about organ donation. Kuhl's example of situating individuals as connecting to *self* and to *others* in health care relationships led me to consider how relationship-focused care models could advance QI, and I will elaborate on these ideas in Chapter 9.

In the context of hand hygiene, many participants described the need to take on responsibility and/or rely on other people and systems for a *common purpose*. This second complementary idea was highly reflected in the "we're all in this together" theme (see Figure 6.3) that led me to consider the significance of shared or common purpose as articulated by Boissy and Gilligan (2016), "By connection, we mean connection to patients, each other, and purpose – your meaning as you define it" (p. 9), and by Cross (2014), "allowing interactants to align their attitudes and motivations with each other" (pp. 814–5).<sup>142</sup> The explicitly stated "common purpose" of the QI intervention I studied was reducing the spread of microbes. Similarly, in a

<sup>&</sup>lt;sup>142</sup> Cross's (2014) context for this interpretation is how music provides a medium for interactive engagement between people (p. 814).

related public health context, ethicists Melnychuk and Kenny (2006) describe solidarity as a value in the relational sense, "we are all in this together, and protecting the public and hence ourselves will require society-wide collaboration" (p. 1394). A fundamental feature of my findings showed that patients/families had diverse expressions of common purpose, which I interpreted as a broad sense of relational solidarity. For example, Hannah and Noah felt cared for by nurses who shared their goal of restoring Noah's health, and John expressed a sense of working with staff to receive his kidney transplant. Conversely, Olivia expressed her despair about those interactions with care providers in which she did not have a sense of solidarity, and she felt irrelevant to the doctors and nurses. This analysis supports that *relational value* is an important part of positive connection and caring. Making a similar point, Henriques (2017) states, "the fundamental goal that drives social engagement is relational value, which can be defined as the extent to which an individual feels known and valued by important others [emphasis added]" (p. 13). Moreover, extending relational connection to a more abstract realm, such as recognizing that hospital QI projects about hand hygiene invoke cultural values about hygiene, suggests that people can connect beyond self and others to a sustained focus on coconstructed meanings. This insight reinforces the importance of considering the different layers of a person's experience when planning QI.

A third idea from the literature and a central feature of my analysis is the notion of a *dynamic*, *fluctuating process* along a bi-directional continuum of relational connection. In Chapter 6, I interpreted my meta-theme in terms of people *tending* to *move towards* or *move away from* relational connections. My interpretations were inspired by the work of Michael Crotty, who stated that sensemaking starts with what already is; people are always conscious "of something"

whether it occurs above or beneath the surface (p. 44). Crotty goes on to explain the "intent" of mental phenomena in terms of purpose, movement, and direction:

It is important to note that 'intentionality' and 'intentional' as used here have nothing to do with purpose or deliberation. The root stem of these words is the Latin *tendere*, which means 'to tend' – in the sense of 'moving towards' or 'directing oneself to'. Here 'in-tending' is not about choosing or planning but about *reaching out into* (just as 'extending' is about *reaching out from*). Intentionality means referentiality, relatedness, directedness, 'aboutness'.

The basic message of intentionality is straightforward enough. When the mind becomes conscious of something, when it 'knows' something, it reaches out to, and into, that object. (p. 44, emphasis in original)

I further constructed these data as patients and families *tending to* relational connections as a dynamic process that depended on each person's situatedness and specific circumstances. For example, during my 20-minute research interview with patient **Evelyn**, she described *moving towards* Nurse Kamala, *moving away* from her doctors, and she abruptly *disconnected* from me by stopping our interview. Evelyn's example also demonstrated that these movements were complex and sometimes seemed to happen at the same time. In my analyses I showed that patients and families often used the word "care" to describe what it felt like when providers *moved towards them*, showing concern about them.<sup>143</sup> Expressing a similar point, one of my patient partners described wanting to feel that her care providers understood where she was coming from, and cared that she was doing well.

<sup>&</sup>lt;sup>143</sup> My patient and family data describing what it meant to be "cared for" supports the work of nursing scholars who situate "care" in Western culture as a gendered characteristic of a "good nurse" (Rodney, Kadyschuk, Liaschenko, et al., 2013, p. 167). Jean Watson (n.d.) defines Caring Science as a perspective "grounded in a relational ontology of being-in-relation, and a world view of unity and connectedness of All."

The fourth idea about relational connection is the potential disconnect between objectivity and subjectivity. One example that arose frequently in my data was how eye contact (or lack of eye contact) made patients feel. For example, patients such as Olivia, Mia, and Sophia described feeling rejected when care providers walked by without making eye contact. These examples of perceived interactions (subjective) showed that patients and families experienced connections with care providers, even when the care providers might lack awareness that an 'interaction' had taken place. In related research, Duhn and Medves (2018) found that "When participants described negative attributes about an interaction with a health care provider it often centred on how they were made to feel" (p. 7). For example, Sophia described her thoughts to me when she asked for help and a nurse walked by without acknowledging her (emphasis by participant): "Well let's make eye contact here first. Hello, I'm not invisible." Importantly, Sophia did not actually say these words to the nurse. Rather, Sophia's silence was her "good patient" performance to meet societal expectations – but she expressed to me that inside she felt insulted and not cared for. Therefore, as Parnes and Isobel (2019) state, "For clinical engagement to occur, the clinician must become skilled in actively transmitting cues of physical and psychological safety through their use of voice, facial expressions, eye contact and body posture" (p. 596).

My interpretation led me to reconsider Crotty's (1998) conceptualization of constructionism; the bringing together of objectivity and subjectivity in human experience. As described in Chapter 6, my findings showed complexity and diversity, and included several patient and family descriptions of health care relationships that they did not experience as healing or beneficial. In accordance with several other authors, such as (Bacha et al., 2019; Rathert, Williams, et al., 2012), I note that the term "therapeutic relationship" between patient and care provider is an aspirational more than a descriptive term, and that patients/families can experience the relationship in different ways than care providers. Similarly, Kitson et al. (2013, 2014) and Rathert et al. (2016) state that many patient-centred care measures do not capture elements of a therapeutic relationship. This lack of subjective knowledge about relational connection may be particularly important in the context of QI activities. For example, in my study I saw how quality leaders were inclined to see the impacts of pilot QI projects as positive, and that patients/families were generally unaware of these care processes. This potential disconnect between *objectivity and subjectivity* can result in leaders overlooking the need to listen to important voices such as patients/families experiencing pilot processes as well as the staff doing the work. As I described in Chapter 6, despite these tensions, patients and families consistently placed high value on positive relational connections with care providers in their typical health care interactions.

The fifth and final complementary idea about relational connection which led me to apply aspects of existing models in a new way focused on the *particular sociopolitical contexts*. As noted above in reference to relational value, my data showed that it was of great import to patients and families to be "seen" and to "matter". For example, patients' comments about eye contact implied that patients suffered when made to feel that they did not matter. Similarly, in the context of children in care, Charles and Anderson-Nathe (2019) state that "mattering is at the core of connection" (p. 117). In the context of being a hospital patient, several participants in my study expressed that one gauge they had of feeling they "mattered" was in terms of the amount
of time the staff and volunteers took – or did not take – with them.<sup>144</sup> In particular, several patients and families in my study pointed out that they appreciated when the staff *reached out* to them even when the unit appeared to be busy, such as in the story Chloe told me about a physician who took extra time to explain her emergency surgery to her frightened young daughter. My interpretation of circumstances that fostered relational connection led me to consider a related research study by Matthews et al. (1993), who suggest that positive connections<sup>145</sup> are possible in a "favourable climate" (p. 973). And finally, my findings reinforced that the connections that patients and families experienced as significant (either positively [such as Chloe's story regarding her daughter] or negatively [such as Liam's story of hospitalization as a child]), could have lasting impacts throughout people's lives.

In summary, in my study, patients and families signaled their need for hope and optimism during interactions with care providers and health care settings. As I will expand on in the remainder of the dissertation, the patterns and themes in my data became more nuanced in terms of significant ethical strengths and tensions after I could see the relevance of *human connection* and *caring*. In this moral relational space, I interpreted patients and families describing virtues such as hope, safety, and trust (such as Evelyn's story with Nurse Kamala) but also describing these same virtues in terms of loss (such as Olivia's story of feeling abandoned). In the context of a QI

<sup>&</sup>lt;sup>144</sup> Interestingly, in a contemporary media example, Michelle Obama (2018) writes, "I knew from my own life experience that when someone shows genuine interest in your learning and development, even if only for ten minutes in a busy day, it matters" (p. 356). Obama's messages resonated with my findings of patient and family experience in several important ways: many people have constraints and busy days; yet individuals move towards connections with others who show them care and concern.

<sup>&</sup>lt;sup>145</sup> Matthews et al. (1993) state, "We proposed the term 'connexional' (from the roots 'co' [together] and 'nexus' drawing together of parts to form a whole) to describe the powerful and mutual experiences of shared understanding that characterize these moments" (p. 973).

intervention focusing on patient hand hygiene, my findings showed that patients/families balanced their desire to maintain positive relational connections along with their own hygiene values, identity, and goals, as well as being a "good patient"; and all within the context that only with group effort can infection control be accomplished. In what follows, I further explore the significance of complexity in my findings in terms of relational connections in patient populations with chronic conditions and with health care settings.

### 7.3.2 Patients with chronic conditions, and the specialized units that treat them.

As a researcher using interpretive description methodology, one of my aims is to convey the nature and diversity of participants in my sample to signpost how my findings might be useful in practice (Thorne, 2014). In Chapter 5, I characterized my study settings as chronic disease units (kidney dialysis and complex medical) with some shared characteristics in terms of patient population and unit operations. In this section, I discuss implications of my meta-theme in the context of patients/families managing chronic conditions. In so doing, I highlight some unique characteristics about relational connections for patients with chronic conditions that arose in my study, including the significance of long-term relationships for both patients and staff, extended boundaries of care, and how these areas potentially shape how patient populations with chronic illness may experience QI.

Various participants in my diverse patient/family study sample reflected general characteristics of people with chronic conditions including: having more than one chronic condition (e.g., kidney failure and cancer; or HIV and a mood disorder); being on disability; having familiarity with their medical condition; and self-managing and coping with the life impacts of their condition(s). Many of these characteristics I found in my study sample are reflected in the literature describing patients with chronic diseases (for example, see Stafford et al., 2018). In my study sample, many patients had received care on the same hospital unit on an intermittent or continuing basis over many years. Therefore, many (but not all) patients and their family members were familiar with the culture, processes and people, and conveyed an understanding of what was 'expected' of them in the unit. For example, I included examples of patients clearly describing their hand hygiene routines on the dialysis unit in Chapter 6. Furthermore, many chronic conditions have acute and chronic components which means that patients/families interact with several parts of the health care system including inpatient, outpatient and community services. For these reasons, I perceived that many patients/families in my sample were 'expert patients'.<sup>146</sup> As I have indicated in describing both my methodology and my findings, many patients and families seemed interested in talking with me. What I perceived as openness was consistent with what Travaglia and Robertson (2013) claim about patients with chronic conditions being more willing to talk about their experiences than other patient groups (pp. 208–209).

Specialized hospital units that treat patients with chronic conditions also have particular operational characteristics. For example, a feature of my study sample was that the study units

<sup>&</sup>lt;sup>146</sup> Note that I use the term *expert patient* to describe patient-participants in my study who, in my interpretation, conveyed a significant knowledge of their disease and treatment in addition to familiarity with the study care setting. This differs from the more formal notion of "expert patient" conceived in the UK National Health Service that initially focused on chronic disease self-management (Boulet, 2016; T. Greenhalgh, 2009).

had specialized and stable staffing, as compared to the transient staffing associated with general medical/surgical units that typically serve patients during 'one off' episodes of care. Moreover, as I will discuss as I proceed further in this chapter, I interpreted tension when patients and families sought to be "good patients" and prioritized their connections with providers over other wants and needs, such as aligning their values of personal hygiene (e.g., wanting to be clean before eating) with their behaviour (e.g., being able to wash their hands before eating). The "good patient" theme in my findings has particular relevance for patients/families with long-term relationships at stake. These findings are consistent with previous research, such as that conducted by Hor and colleagues (2013), who describe what 'safety' meant to patients:

For patients therefore, protecting their own safety is not only about moment-tomoment treatment decisions or actions; safety for them is also about developing relationships with, and maintaining the cooperation and goodwill of the health-care staff who manage and deliver their care. **This may be especially important for patients with chronic diseases**. (p. 575, emphasis added)

Entwistle et al. (2018) also note the significance of patient–provider relationships in enabling people with chronic conditions to live in accordance with their values. Similar to what many participants in my study conveyed to me, Buckwalter (2007) reflected on his motivation for maintaining positive connections with his health care providers, "As a disabled man, I must maintain lifelong relationships with health care providers. I typically feel compelled to be the good patient, the patient to whom medical professionals will respond" (p. 2535). In addition to patients, several of the family members to whom I spoke – all supporting loved ones with chronic illness – relayed how stressful the job of being an unpaid caregiver was (also noted by May et al., 2014). At the same time, some of these participants spoke about difficultly

relinquishing control and relying on hospital staff to take care of their loved ones. This complexity in my findings demonstrated that contextual features such as the diagnosis of a new illness, the accumulating burden and treatment of chronic illness, and the fear of being alienated by care providers can curtail patients' and families' agency, thereby shaping their experiences of interaction, connection, safety and trust. On the other hand, ongoing, familiar treatment for a stable chronic illness within a supportive climate can promote patients' and families' agency.

The chronic illness prevalence in my study sample also raised several interesting questions about connections and boundaries of care, for staff as well as patients and families. While my data prioritized patient/family perspectives, I also interacted with a diverse group of care providers and volunteers on the study units. Several of the care providers (primarily nurses) who had worked on the same unit for many years also referred to their workplace in a relational way, as "home", reflecting data gathered from several patients and families. From data gathered from conversations I had and observations I made, many staff and volunteer participants appeared to have genuine and enduring connections with particular patients also need human connection to be fulfilled in their work (Rodney, Kadyschuk, Liaschenko, et al., 2013). Several provider-participants in my study described their struggles to maintain professional boundaries with patients and families, reflecting nurse Christie Watson's (2018) portrayal of nursing relationships that emphasizes these enduring relational connections. In her portrayal, Watson refutes Peplau's

assertion<sup>147</sup> that nurse–client relationships are 'temporary'; that they end when a patient was discharged or died (p. 296). Understanding provider perspectives about navigating relational connections contributed to my understanding of why patients and families, particularly those with chronic conditions, might feel more connected and "at home" on particular hospital units. As I have discussed above, the chronically ill nature of my study sample led me to see complexity in my Relational Safety Framework. In particular, it was surprising to me that even some patient/family participants with long-term relationships with care providers and who describing feeling "at home" on the unit expressed to me their reluctance to ask for a hand wipe during the QI pilot project because they did not want the nurse or volunteer to "get mad at them". As I noted in Chapter 2 (see Section 2.4.1), characteristics of patienthood suggest there are many factors involved in patients' willingness to (and ability to) raise issues related to their health care. These characteristics include severity of illness, age, cultural background, and education level (for example, see Reader et al., 2014). And, as I have shown in my research findings, some factors (such as important aspects of personal identity, and motivation to recuperate) in the context of QI impacted patient/family relationships because these factors moved some patients/families towards and others away from valued relational connections with providers and care settings. This insight ought to shape the ways in which health care organizations pilot QI interventions, so that the interventions can build on other well supported strategies to bolster (as opposed to inadvertently weaken) long-term relationships between patients, families, and care providers. Such strategies have, for example, been promoted by (L. Berg & Danielson, 2007, p.

<sup>&</sup>lt;sup>147</sup> Nursing theorist Hildegard Peplau (1952) developed the widely known "Peplau's Theory" of interpersonal relations in nursing practice. Peplau emphasized the importance of understanding patients' experiences of care and the effect that patient–nurse relationships have on patient experiences.

503; Boissy & Gilligan, 2016, p. 11; Chou, 2018, p. 6; Kornhaber et al., 2016, p. 538; McCabe, 2004).

Questions about connections and boundaries also arose beyond hospital or specific treatment unit doors, illuminating the roles that 'important others' played in patients' journeys of care. For example, due to their disability, many dialysis patients travel to the hospital using HandyDART. From these patient stories, I learned that the HandyDART community and journey formed a significant context for their care experience inside and outside the hospital. For example, John mentioned he was much more fatigued on the days HandyDART picked him up first and dropped him off last because of the additional time in transit. Emily became stressed when a nurse did not bring her a wheelchair because she needed to catch her HandyDART. These examples and other data I collected suggest that journeys of care – especially for patients with chronic conditions - can have complexities that occur across functional, departmental, and organizational boundaries. For example, different governmental agencies operate hospitals and transportation, but patients can experience them in a more connected way. This finding supports the need to map patient experiences of the entire journey of a QI intervention in an inter-sectoral way (Bate & Robert, 2007; Patient Engagement Action Team, 2017; The Health Foundation, 2013c).

While I did not conduct research in contexts beyond hospital or specific treatment unit doors in this research, the uniqueness of my study sample raises related questions. Such questions include, for instance, similarities and differences in how patients and their families in other chronic care circumstances (such as cancer) value relational connections, and how the burden of

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illness impacts on capacity and agency might shape patient/family experience of QI in different health care settings. For example, Rhodes et al. (2016) suggest that patients in established family practice settings (compared to, for example, walk-in clinics) have the potential to exercise a high level of agency due to the predictable nature of primary care (p. 283) as well as the expertise and knowledge that patients can accumulate over time (p. 279). In contrast, patients attending medical/surgical hospital units for 'one off' episodes of care may have a lower level of agency. Overall, my analyses with my study sample and my examination of related literature show that relational connections are a priority for patients/families with chronic conditions, including in the context of QI implementation.

#### 7.3.3 Relational connections with health care settings: Hospitals having moral agency.

I quoted May (2007) above to say, "although we may go to *a* hospital or health centre, we invariably go to see *the* doctor" (p. 31, emphasis in original). As I embarked on this study of patient and family experience of care in relation to a new QI intervention, I focused on people (patients, families, care providers) as moral agents who are able to hold, express and apply values (Rodney, Harrigan, Jiwani, et al., 2013; Rodney, Kadyschuk, Liaschenko, et al., 2013). Interestingly, as I described in Chapter 6, many patient and family participants described a crucial part of their care experiences as being their connections with the hospitals or health centres in which they received health care – in other words, *places of care*.

Other researchers have also noted this. For example Rainey et al. (2015) reported, "Many patients described the significance of their long relationship with a trusted hospital" (p. 399). In my study, as noted above, my interpretation of meanings behind patient/family and staff

references to hospital units as "home" focused on the value of relational connection, safety and belonging; analogous to Métis-Cree Indigenous historian Jesse Thistle's (2017) description of home as "a metaphysical understanding of emplacement, rather than a built environment [(safe and secure habitation structures]" (p. 15).<sup>148</sup> For example, **Chloe**'s phrase "an *ethos* of care"<sup>149</sup> evoked a fundamental sense of at-homeness with the people and the Study Hospital. Similarly, in their study of the ontology of ethics and health, Östman et al. (2017) use the terms "ethos" and "ethic" interchangeably to describe a collective sensibility:

Ethos is values that have been formed through culture and history, a fusion of both internal and external ethics. Ethos is also referred to our habits, for example, the way we do things. (p. 6)...Furthermore, as ethos refers etymologically to home and a sense of at-homeness, finding a place in life where a human being is comfortable with his or her values is important. (p. 7)

My findings included data from Mia and other patients and families who explained why they felt more at home on one unit, and less at home on other units in the same hospital, as well strong preferences for one hospital over others. In this way, patient and family experiences of uncertainty about belonging (feeling less at home, or homeless) in health care settings reflect a complex loss of or lack of connection with people and place that often result from entrenched systems and institutions and other aspects of sociopolitical context. I elaborate on these ideas below.

<sup>&</sup>lt;sup>148</sup> The relational interpretation of the concept of the metaphysical "home" also resonates with Thistle and Smylie's (2020) framing of Indigenous homelessness "as a breakdown of healthy relationships with self, family, community, land, water, place, animals, culture and language resultant from colonial disruptions" (p. E257).

<sup>&</sup>lt;sup>149</sup> The Oxford Dictionary defines ethos as, "The characteristic spirit of a people, community, culture, or era as manifested in its attitudes and aspirations; the prevailing character of an institution or system" (OED Online, 2018a). Below, Östman et al. (2017) connect the meaning of ethos more closely to ethics.

A few patients and families described differences between health care systems on a provincial or country level. For example, stories about noticing that "even the nurses were unhappy over at that other hospital" suggested that patients, families and providers disconnected from some places of care. Such patient/family data led me to construct meanings about why participants tended to *move towards* or *away from* relational connections with their places of care. Patient safety researchers have made similar observations about the importance of relational dimensions of health care spaces (e.g., S. Grant & Collier, 2018). My interpretation of the data I collected and analyzed is that, optimally, patients and families want to feel that that their places of care have an "ethos of care" so they can feel at home. In other words, my *Relational Safety Framework* reflects that patients and family members conveyed that they enter hospitals wanting to feel welcomed, safe, and cared for.

As I described in Chapter 6, participants' histories and current circumstances impacted their connections with and experiences of more abstract health care entities such as "the health care system", which I have described in this dissertation as layers embedded in context. During my analyses, I came to view a health care setting, such as a dialysis clinic, as a proxy for (within or embodied by) an institution, and as further embedded and reflecting the social forces and values in larger structures. Patients and families expressed this idea of people connecting through institutional layers in my data in different ways. Several participants attributed 'the way they do things at this hospital' to the 'culture' or 'leadership' at both the unit and hospital levels. In the context of the QI intervention I studied, participant comments included references to varying norms of clinical care such as assisting patients with hand hygiene before eating. From a constructionist perspective Bate (2014) remarks, "culture is not something an organisation 'has'

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but what an organisation 'is'" (p. 16). In stating, "Each hospital is a country, unique and separate, with an infrastructure and philosophy different from the next one" (p. 113), Watson (2018) echoes what patient/family and staff participants conveyed in my study.

Another way of interpreting my data about the ethical nature of patients'/families' connections with places of care relates to virtue theory. Virtue ethics is typically associated with desirable virtues of health care professionals such as compassion, integrity, and trustworthiness (Rodney, Burgess, Phillips, et al., 2013, p. 62). In *After Virtue*, contemporary moral philosopher Alasdair MacIntyre (2007) connects virtue to the role played by an institution's sustained traditions:

So when an institution – a university, say, or a farm or a hospital – is the bearer of a tradition of practice or practices, its common life will be partly, but in a centrally important way, constituted by a continuous argument as to what a university is and ought to be or what good farming or good medicine is. Traditions when vital embody continuities of conflict. (p. 258)

An organization's moral commitment is reflected in its mission, vision, and values statements, and codes of ethics (Rodney, Harrigan, Jiwani, et al., 2013). People associated with an organization are bonded by a shared moral commitment, or 'the way *we want* to do things'. For example, a hospital claiming a patient- and family-centred care philosophy signals they have rejected notions of a more paternalistic approach. In arguing that certain practices are "good", it is implicit that alternate practices have been rejected. My findings showed that patients and families experience "the way *they* [organizations and the people who work in them] *do* things here". Each patient or family member connects relationally to the organization according to organizational virtues *as perceived by* each person. For example, most patients/families in my sample portrayed strong positive connections with the dialysis unit. One exception, Mia, described weak connections on the dialysis unit compared to the complex medical unit. My

relational analysis led me to view places of care as embodying the features of an agent that knows and acts, similar to what scholars in nursing and other fields have helped to articulate.<sup>150</sup> In other words, *organizations and institutions have moral agency* situated in specific contexts. In this sense, organizations can hold, express and arrange values into a hierarchical system of importance, and have the capacity and autonomy to direct their actions to some ethical end within wider societal structures (adapted from Rodney, Burgess, Pauly, et al., 2013, p. 96; Rodney, Kadyschuk, Liaschenko, et al., 2013, p. 176; Storch, 2013, p. 10). My analysis enabled me to interpret what other authors, such as Sokol-Hessner et al. (2018), describe as non-physical institutional harms (p. 1). Therefore, on the basis of my research data and subsequent related literature reviews, I have come to believe that characteristics of moral agency at different system levels can be ethically relevant to understanding how patients and families experience attempts at health care system improvement. This ethical relevance is particularly important given QI's optimistic framing that makes health care leaders prone to overlooking non-physical harms.

In summary, as I took on the broader interpretation of agency I have articulated above, I came to understand patient care units and hospitals as moral or ethical spaces within which patients and families connected relationally. To revisit May's (2007) quote at the beginning of this section, my analysis shows that many patients and families (particularly those in my sample with chronic conditions) connected relationally both with the doctor *and* with the hospital. Thus, I consider individuals *and* institutions to be agents of relevance in my research findings and implications;

<sup>&</sup>lt;sup>150</sup> A 1999 discussion paper by Bishop et al. (1999) considers the concept of institutions as moral agents. Some ethicists (e.g., Goodpaster, Ozar, Werhane, Wilson) characterize organizations such as hospitals as moral agents, while others (e.g., Ranken) argue that only individuals are relevant moral agents.

agents capable of knowing and acting. When organizations such as hospitals try to change practice by piloting QI projects on one unit, my analysis suggests that patients and families interpreted their experiences in a larger context. As noted in Chapter 3, many authors (e.g., Greenhalgh (2009)) acknowledge that in addition to organizational mandates, fiscal pressures, and legitimate concerns around patient safety, structural factors that promote and resist system change, include "powerful vested interests and entrenched social inequalities" (p. b49). Taking a view of *places of care* having moral agency may inform – and potentially change – the practice of QI. As many examples in my findings have shown, a patient's or family member's relational connections with (or at) one layer (such as one specific unit) can extend through other layers (the entire hospital). My data further suggests that patient/family experiences of QI interventions shape their connections with specific health care settings, contributing to their overall experiences of care. Therefore, in the context of my study, an important implication is that organizations undertaking pilot QI projects at the point of care ought to take patients' and families' connections with health care settings into account. As I will argue in the pages that follow, relational connections are closely linked to safety and trust.

# 7.4 Relational Safety (Component 3)

Relational connections are linked to relational safety. When people have a sense of relational safety, they move towards connections with others, fostering trust.

"Relational safety: the tensions between power and voice." (Hernández, 2008, p. 14)



In what follows, I elaborate on *relational safety*, the third and penultimate component of my *Relational Safety Framework*. I interpreted the implications of my meta-theme (the value patients and families placed on positive relational connections in their health care relationships) as centering on the importance of relational safety, situated by Hernández (2008) as "the tensions between power and voice" (p. 14). In fact, during my analysis, it became apparent to me that *relational safety* was the linchpin<sup>151</sup> of my *Relational Safety Framework* (see Figure 7.1). I propose that relational connections can serve as a conduit from patients'/family members' health care interactions to feelings of relational safety. In the next sections, I describe how I came to my definition of relational safety and how my conceptualization relates to similar concepts.

### 7.4.1 What is relational safety?

### 7.4.1.1 The concept of relational safety as informed by my study data.

I learned about relational safety indirectly or directly from every participant. My data was largely based on my own observations and people's words about their motivations and feelings as a precursor to their behaviour (with the caveat that mine was an observational study). In constructing my findings, I explored how study participants described safety in relation to QI interventions and health care more generally. As I engaged in the process of interpretive description, I initially focused on the socio-emotional, psycho-social or sociopolitical aspects of relational safety in my data. Based on my findings, I would suggest that, in conceptualizing safety, it essential to consider how patients and families experience relational danger (or potential relational harm) in the contexts of health care settings. I observed some unexpected

<sup>&</sup>lt;sup>151</sup> Linchpin: a key component or governing principle "linch-pin, n." (OED Online, 2018h).

downsides experienced by patients, families, and staff in relation to the patient hand wipes intervention. Examples arising in my data of with a relational component included: (1) *offence* taken by a small number of patients (Ethan's and Ben's stories) when interpreting actions about hand hygiene as an insult, and corresponding guilt expressed by care providers/volunteers; (2) *misunderstanding* by a small number of patients who assumed (incorrectly) that the wipes contained an antibacterial agent and who wanted to avoid encouraging antibiotic resistance (e.g., Logan, Lorenzo); (3) *concern* (e.g., Bill, John) by patients who were not offered a hand wipes after introduction of the process; (4) *distress* from at least one patient (John) upon seeing other patients refuse wipes; (5) *apprehension* from patients (e.g., Olivia, Liam) who expressed feeling too awkward to ask for a hand wipe even though they wanted one; and even (6) a sense of *abandonment* (e.g., Olivia). In taking a broad relational interpretation of safety, my analysis corresponds with other writers such as Rhodes et al. (2016), who write about what safety means to patients:

Much of the writing from the patient safety literature has focused on minimising risks and hazards drawing on lessons from the aviation industry. The result has often been a focus on rules and checklists intended to prevent error (Waring 2009). This approach tends to neglect the different ways in which safety is conceptualised by different groups within such systems (Brown 2008). (p. 283)

As my analysis progressed, I recognized complex meanings associated with the theoretical construct of safety. Specifically, some patient participants (in particular Evelyn, Liam, and Mia), described stories or exhibited behavioural cues that encompassed *physiological* aspects of relational safety.<sup>152</sup> For example, **Evelyn**, had been in the hospital for several weeks after

<sup>&</sup>lt;sup>152</sup> Advances in neuroscience contribute a physiological dimension to our understanding of how people perceive and experience feelings of safety in relationships with others. This research shows that people are only physiologically able to engage socially when their nervous system perceives safety (Geller & Porges, 2014; Porges, 2009).

suffering a serious assault by her boyfriend. She explained to me how frightened she became every time someone approached her hospital room, saying "they're soooo scary when they [doctors and nurses] come." Evelyn explained that most of the staff knew about her fears and called out to identify themselves before they opened the curtains around her bed. I interpreted these patient and staff behaviours as responses that acknowledged and linked the relational and physiological aspects of safety, danger and fear.

Furthermore, while patients and families often described notions of relational safety specific to certain people, places, and situations, some described the sense of relational safety in a physical or concrete way, such as liking when nurses covered them with warm blankets. These patients said that blankets warmed them up if the unit was chilly and also comforted them. I interpreted that warming patients up represented the functional<sup>153</sup> aspect of care, whereas comforting patients evoked the relational aspect of care. I came to think of warm blankets as a metaphor for the concept of relational safety; feeling warm and safe in a relationship. According to this interpretation, with warm blankets, the nurses signaled what Geller and Porges (2014) describe as the "intention of being with and for" their patients (p. 179). As noted throughout Chapters 6 and 7, my data led me to understand that patients and families often emphasized the value of relational aspects of their care, including care via QI interventions. However, this too was complex. For example, in contrast to the data I shared above based on patient remarks about the importance of eye contact in interactions with care providers, Liam implied that he felt disrespected when the nurses "fiddled with the machines rather than looking at me", and a

<sup>&</sup>lt;sup>153</sup> I described functional, transactional and relational aspects of care in Chapter 2 (Section 2.4.3).

different patient told me, "You know, I'd rather have them concentrate on doing <u>this</u> [referring to the dialysis machine] properly than covering me up with a blanket." In other words, relational safety can encompass both relationship and competence in functional medical tasks.

It happened that patient/family participants who were also health care professionals spoke to relational safety even more directly, emphasizing the importance of having conversations that matter. For example, patient **Sophia** spoke about the techniques she used in her practice such as using humour to put her patients "at ease". Along these lines, Pittet (2017) says, "addressing the determinants of patients' participation is essential to encourage their involvement" (p. 199). In the context of the hand hygiene QI intervention studied, I found that the problem most patients/family members had with the intervention was that the providers did not follow through with the hand hygiene process, and patients/families were reluctant to prompt them. Thus, a patient's or family member's feeling of relational safety with providers and the place of care was one determinant that shaped their ability and willingness to participate in QI activities. This insight illustrates that care providers (as moral agents) provide an important part of the context of their patients' sense of relational safety.

# 7.4.1.2 The concept of relational safety as informed by accounts in the literature.

Relational safety was not a term or concept I was familiar with before this study, and, indeed, it reflects an emerging approach to ethical theorizing focusing on context, power dynamics and agency (Baylis et al., 2008; Sherwin & Feminist Health Care Ethics Research Network, 1998). In keeping with interpretive description methodology, I expected my study to generate "some insights, observations, and ideas that were not entirely anticipated on the basis of [my] review of

the original literature" (Thorne, 2016, p. 220). As I strove to understand the deeper meanings of patient and family experiences of quality and patient safety interventions at the point of care, my findings pointed to (1) negligible references to the concept of relational safety in the health care quality literature; and (2) the need to explore potential linkages between interaction, connection, safety and trust.

In health care, while the term relational safety is not often used to depict patient–provider relationships, the idea of a safe environment in which to interact relationally is not new. Literature citing the term *relational safety* appears most frequently in the counselling psychology literature and is frequently attributed to Rober (1998). This body of literature centers on interpersonal relationships subject to power asymmetry, such as between care provider and client/patient, for example see (Geller & Porges, 2014; Knudson-Martin et al., 2015; McBride et al., 2017; Parnas & Isobel, 2019; Wells et al., 2017), and between supervisor/teacher and student, for example, see (Hernández, 2008; Hernández & McDowell, 2010; Hernández & Rankin, 2008; Proctor & Rogers, 2013; Sanders et al., 2016; Whitfield, 2018).

My *Relational Safety Framework* builds on the work of others across multiple disciplines, acknowledging that dynamics related to power and control are integral to safety in relationships. In my findings, this showed up as, for example, patients striving to be "good patients" with high sensitivity to the specific context and based on different and overlapping motivations, several of which reflected the uneven power dynamics they found themselves in as patients (or family members). These data resonate with how Garfat (2016) describes relational safety in the context of children in care: "in this relationship with this person, in this context, I feel safe from harm from self or other" (p. 2). Thus, the context-nuanced interpretations in my findings led me to explore the literature to articulate this idea of relational safety as the crux of what patients and families wanted and needed in their health care experiences.<sup>154</sup> Moreover, in describing relational safety, the psychology literature goes beyond patient–provider scenarios of power asymmetry to include a wide range of contextual aspects, including social location, legacies of loss and trauma, migration, privilege, and oppression (Ford & Russo, 2006; Geller & Porges, 2014; Hernández, 2008; Hernández & McDowell, 2010; Proctor & Rogers, 2013). These contexts of power asymmetry overlap with the broad interpretations of cultural safety described in Chapter 2 (Section 2.4.1.1). Indeed, the term relational safety in the psychology and mental health literature appears to be increasing in frequency in the last several years with the rise of trauma-informed approaches to care.<sup>155</sup>

I constructed my understanding of the complexity of relational safety from diverse voices and accounts in my research findings as well as from related literature. In our society, health care professionals (especially physicians) write about transformational experiences when they unexpectedly find themselves in patient roles (Ansen, 1991; C. Davis, 2015; Grainger & Pointon, 2017; Kalanithi & Verghese, 2016; Verghese, 2018) and in family roles (Berwick, 2009; Goldman, 2018b). For example, physician Abraham Verghese (2018) writes in the *New York Times*:

<sup>&</sup>lt;sup>154</sup> While I did not gather data from patients about placing unwarranted trust, in some situations people may experience a state of relational safety, but if others are not trustworthy, then it could be a false sense of safety. <sup>155</sup> The term "trauma-informed" recognizes that trauma is often linked to challenges such as substance use, mental illness, stigma and barriers to accessing health care. A trauma-informed approach to care strives to help people feel safe so they are not re-traumatized or triggered by their care (e.g., Geller & Porges, 2014; Wells et al., 2017).

Five years ago, I experienced a sudden asthma attack while visiting another city. The E.R. physician was efficient, the exam adequate. The nurse came in regularly, but not to visit me so much as the screen against the wall. Her back was to me as she asked, "On a scale of 1 to 10, with 10 being great difficulty breathing ...?" I saw her back three more times before I left. My visit recorded in the E.H.R. would have exceeded all the "Quality Indicators," measures that affect reimbursement and hospital ratings. As for my experience, it was O.K., not great. I received care but did not feel cared for. (para. 12)

Accustomed to being in the health care professional role, Verghese experienced a downside of technology as a patient, echoing patients' and families' comments in my study such as "they don't look at me but they're *really good* at fiddling with the machines." As Calabrese (2013) states, "patients tended to describe good medical care as involving an interacting form of communication that blends listening and active problem-solving and in which the patient is viewed 'as a person' rather than 'as a patient'" (p. 24). In the context of this literature, I interpreted these data as patients expressing discomfort with being relationally avoided, which I elaborate on in Chapter 8.

### 7.4.1.3 Coming to my study conceptualization of relational safety.

In what follows, I explain how theoretical and methodological framing and analyses of my data (described in Section 6.4.1.1) enabled me to interpret and elaborate on descriptions of relational safety in the literature (described in Section 6.4.1.2). Here, I conceptualize a definition of relational safety in terms of three salient features, that is aided by the work of many authors who further informed my understanding. The first feature of relational safety reflects a *state*, or a combination of circumstances at a particular time, in which people (moral agents) feel safe in a relational way. Characteristics of my interpretation of relational safety that were reinforced in the literature included feeling safe, secure, straightforward, nonthreatening, logical, open, reciprocal

and/or negotiable (Garfat, 2016; Hor, Godbold, Collier, & Iedema, 2013, p. 576; Prisbell & Andersen, 1980, p. 24).

While I did not observe study participants using the phrase relational safety, participants did describe and exhibit behaviours I came to associate with feeling safe in a relational way. The second feature of my definition of relational safety encompasses *behaviours* that are possible when people feel this sense of safety (Geller & Porges, 2014, p. 178; Hernández & Rankin, 2008, p. 255). Examples of these behaviours I observed included patients/families asking questions about their health condition, asking for things they wanted such as hand wipes, expressing concerns about aspects of their care, and articulating ideas that were important to them.

In contrast, some participants (such as Ben's nurse) described situations that resulted in feelings of having given or received offence. These examples suggested relational *unsafety* between provider and patient and, perhaps an awareness that opened up relational safety possibilities. During my observations, in addition to their words, I interpreted that participants expressed feelings of relational safety or unsafety indirectly non-verbally, such as smiling, laughing, or speaking certain words in a lower voice. For example, family member **Lucas** told me, "I'm glad I was standing looking down on [the doctor] because he's such a…you know…I just appreciate when doctors have [laughs] good manners with people. And when they don't, I'm like ugh. So I was glad. That balanced it all out [laughs]." Lucas' denoted 'laughs' were non-verbal cues that, along with facial tension and the content of the words he expressed, alerted me to his

awkwardness related to a situation that I interpreted as a state of relational unsafety between a family member and care provider within hierarchical power structures.

The third feature of my definition of relational safety positions relational safety as an *emergent product*, one that evolves over time from relational interactions between moral agents and their different environments (Geller & Porges, 2014; Hernández & McDowell, 2010, p. 34; Rhodes, McDonald, Campbell, Daker-White, & Sanders, 2016, p. 280; Ringdal, Chaboyer, Ulin, Bucknall, & Oxelmark, 2017). In my analysis, I considered relational safety in ways that accentuate the sociopolitical dimensions that influence a person's capacity for agency in relation to others. Thus, my data led me to see the importance of acknowledging how particular sociopolitical aspects of context shape people and structures in relational safety (Doane & Varcoe, 2013, pp. 150–151, 2015, p. 41; Hilton & Anderson, 2018; Rhodes et al., 2016; Ringdal et al., 2017; Rodney, 2013, p. 314; Rodney, Burgess, Pauly, et al., 2013, p. 85; Sherwin & Feminist Health Care Ethics Research Network, 1998, p. 19).

In conclusion, I present the following definition of relational safety as expressed by my study participants in Box 7.2. I propose that a sense of relational safety allows patients and families – people who are often in vulnerable circumstances – to attain the information and caring relationships that they want and need.

# Study Conceptualization of Relational Safety

In the context of what I learned from my study participants, *relational safety* is a state that exists when a person (a moral agent) experiences a relationship as safe, secure, straightforward, nonthreatening, logical, open, reciprocal and/or negotiable. In this state, a person can be present and engaged, and it is possible to raise questions, challenge points of view, ponder issues, articulate ideas, and express concerns. Relational safety is an emergent product of relational interactions between people and between people and their environments that occur within particular sociopolitical contexts and evolve over time. In this way, relational safety is more than the absence of relational danger and/or harm.

#### Box 7.2 Study Conceptualization of Relational Safety

# 7.4.2 Relational safety: complexity and nuance.

My learning about relational safety in the context of my study sample prompted me to reflect on the moral status of the agents whom I learned from in collecting my data, and meanings of patient safety and cultural safety, concepts introduced in earlier chapters.

# 7.4.2.1 Reflecting on moral agency through the lens of relational safety.

On the basis of my findings, I interpreted that patients/families who expressed a sense of relational safety also conveyed that they were more able to express their preferences and values and maintain a sense of self and dignity, central elements of the concept of moral agency that I described in Chapter 4 (see Section 4.2.2.3). To illustrate, I argue that John's sense of relational safety on the dialysis unit enabled him to ask these nurses for hand wipes introduced during a QI pilot project. This example shows the role and importance of relational safety in patients being willing and able to influence and shape the direction of their own health care and safety in ways that align with their values. In contrast, patterns in my data also involved scenarios in which patients and families described feeling relationally 'on guard'. Examples included feeling

silenced (such as Lucas's, Evelyn's, and Emily's stories about care providers refusing to listen to them), and Liam's reluctance to point out what he believed to be an error in his chart for fear of backlash. I came to understand this disquiet as patients *feeling relationally unsafe* or *relationally endangered*, or *fearing relational danger*.

My interpretation of participants' descriptions of relational safety were complex and highly situational (e.g., feeling safe with one care provider but not another; or in one health care setting but not the next). In the meta-theme of my findings, the dynamic nature of moving towards and away from relational connections suggests that the combination of circumstances at a particular time shapes the ability for a person to feel relationally safe and enact agency, supporting the notion that agency is bounded (Shanahan, 2000; Sherwin & Feminist Health Care Ethics Research Network, 1998). Furthermore, Glăveanu's (2015) interpretation of *co-agency* – "the intentions, actions, and reflections that make up our agency are constantly distributed between person and his/her environment [social and material]" (p. 258) responds to the complexity in my data by reinforcing the relational nature of agency. Aspects of my findings, such as patients/families who expressed the value of having assistance with hand cleaning when they identified hygiene as being of benefit to them, reinforce that positive connections and shared meaning between patients/families and care providers ought to be important health care system goals. In the context of my study, acknowledging the role of co-agency is highly significant because it might facilitate positive connections and shared meaning between patients/families and care providers when undertaking new care processes at the point of care. Therefore, from an ethical perspective, one implication of my research is that a person's sense of relational safety may be related to their ability to enact moral agency. Acknowledging the idea of relational or co-

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agency is consistent with my relational ecological view (see Figure 4.4) and draws from perspectives in the education, sociology and health care literature (Baylis et al., 2008; Burkitt, 2016; Doane & Varcoe, 2013; A. Edwards, 2005; Hart et al., 2004; Sherwin & Feminist Health Care Ethics Research Network, 1998).

### 7.4.2.2 Reflecting on patient safety through the lens of relational safety.

My analysis shines a light on three important aspects of patient safety (the reduction of preventable harm in health care, see Chapter 2, Section 2.3). First, as I have emphasized in Chapters 6 and 7, at times patient/family participants appeared to prioritize their *relational safety* at the expense of *patient safety*. For example, while infection control was often a concern for patients/families, it was usually not a dominant enough concern to risk their relational safety with staff. My findings are consistent with other research noted above (including systematic reviews e.g., R. E. Davis et al., 2015) describing patients' reluctance to ask if care providers have cleaned their hands. My findings also resonate with research on health care relationships more generally – for example, Towle et. al. (2003) and Frosch et al. (2012) report that power-related obstacles inhibit patients' ability to engage in shared decision making. However, it is not clear from my study that the need to achieve relational safety necessarily took precedence over other patient, family, (or staff) needs or desires, or over other personal characteristics or contexts.

Second, the majority of current patient safety literature neglects to address and acknowledge the significance of relational safety (as I have conceptualized it in this dissertation) in patient safety. However, I did observe in my study that patients/families felt comfortable (and in some cases compelled) to fill in hygiene gaps, such as bringing their own hand sanitizer. These examples in

my data are consistent with literature arguing that patients are already involved in ensuring their own safety, for example, see (Hor et al., 2013; Wyer et al., 2015). To this end, several of these articles situate a " 'relational' approach to safety" (Hor et al., 2013, p. 577), as one that is coproduced by patients and care providers (M. Batalden et al., 2016; P. B. Batalden, 2018; Fond et al., 2017; Hor et al., 2013; Mackintosh et al., 2017; Rathert, Brandt, et al., 2012; Rhodes et al., 2016). For example, Hor et al.'s (2013) use of 'relational' focuses on interpersonal relationships between patients/families and providers, "[for patients] 'being safe' is about being able and enabled to navigate interactions with staff in the health system without coming to harm" (p. 576). Thus, my analyses support building on the work of these others to investigate the role that relational safety plays in patient safety as well as other dimensions of high quality health care.<sup>156</sup>

My findings also illuminated a third aspect of patient safety. That is, the significance of relational safety as part of patient/family experience of care contrasts with the patient safety movement's largely biomedical focus, as illustrated by the priorities of the Canadian Patient Safety Institute.<sup>157</sup> For example, traditional measures of harm typically relate to functional impairment (such as ability to perform routine activities of daily living) and health outcomes (such as mortality or skin breakdown) (World Health Organization (WHO), 2009b), rather than sociocultural aspects (such as emotional comfort) (Kelly 2018). Yet, my findings build on several other studies (for example, see Fond et al., 2017; Kuzel, 2004; Rhodes et al., 2016) that

<sup>&</sup>lt;sup>156</sup> As outlined in Chapter 2 (Section 2.3.1), quality health care is described in terms of dimensions through which it is expressed, typically including safe, effective, patient-centred, timely, efficient and equitable (for example, Institute of Medicine (US) Committee on Quality of Health Care in America, 2001; World Health Organization (WHO), 2010).

<sup>&</sup>lt;sup>157</sup> Medication, surgical care, infection prevention and control, and home care (Canadian Patient Safety Institute, n.d.-e).

emphasize the significance of non-physiological harms (such as psychological and emotional harm) on patients' and families' experiences of care and their ability to navigate the health care system (see also Chapter 2, Section 2.4.3.2). Moreover, a recent focus on patient-oriented research<sup>158</sup> by organizations across Canada and internationally reflects an attempt to study outcomes that patients and families often view as equal to or more important than traditional – often physiological – outcomes. For example, the Patient-Reported Outcomes Measurement Information System Global Health (PROMIS GH) Scale measures "social health" in addition to traditional health domains (Katzan & Lapin, 2018). According to the interpretation of my findings proposed here, conceptualizing patient safety to include lowering preventable harm that encompasses non-physiological harms inclusive of *relational* harm (such as Olivia and Emily feeling abandoned by their caregivers) is a new way to understand the role relational safety plays in patients' and families' experiences of QI interventions, care and trust in health care systems.

#### 7.4.2.3 Reflecting on cultural safety through the lens of relational safety.

Finally, my analyses about relational safety in the context of my study sample prompted me to learn about and reflect on meanings of cultural safety, a concept I introduced in Chapter 2 (Section 2.4.1.1), and distinguish relational safety from cultural safety. Study participants perceived and described safety in relation to QI interventions and health care in ways that shared some similarities to cultural safety. I interpreted my findings through a lens that acknowledges that participants described their experiences from perspectives of various social locations such as

<sup>&</sup>lt;sup>158</sup> As evidenced by initiatives such as BC's SUPPORT (SUpport for People and Patient-Oriented Research and Trials) Unit (n.d.), the Canadian Institutes of Health Research's (2019) Strategy for Patient-Oriented Research (SPOR) and the U.S. Patient-Centered Outcomes Research Institute (PCORI) (n.d.).

age, gender, skin colour or physical ableness – aspects of a broad understanding of cultural safety.<sup>159</sup> For example, I interpreted **Chloe's** journey of disability on the basis of the stories she relayed to me situating her early adulthood as a professional working overseas in terms of a position of relative social power. As her health conditions compounded, Chloe described to me what it felt like to become invisible to care providers, invisible within health care settings, invisible amongst her peers, and how even parts of her own body became invisible to herself. Through the examples she narrated to me, Chloe showed that being invisible made her feel vulnerable. As Clark and Preto (2018) state,

To be human is to be vulnerable. This does not relieve us of an obligation to address vulnerability, but instead mandates an ethical duty to create just and equitable health care systems that promote autonomy, foster engagement, enhance cultural safety and support the well-being of all. (p. E309)

In my research, I came to see cultural safety as particularly relevant in the sense of each individual's well-being and personal history, including relational interactions with care providers and health care settings over their life course.

Interestingly, one of my patient partners shed some significant light on the connection between cultural safety and relational safety – an example of the valuable insights that patient partners contributed throughout my analyses. This patient partner compared my (anonymized) data involving patients such as Ben, Evelyn, Sophia and Mia, who were homeless to her own

<sup>&</sup>lt;sup>159</sup> For the purposes of this study on patient/family experience of QI, I restricted my data on the social locations of patients and families relevant to care providers and health care settings. Gerlach (2012) notes that in health care education and practice, 'culture' is most often aligned with cultural awareness and sensitivity in relation to ethnicity and race (p. 153). The concept of cultural safety also has relevance to care providers (Hawkins, 2013) in that social locations play a role in providers' attitudes, education and practice. For example, writing about clinical supervision, Hernández (2008) describes the importance of creating relational safety with junior therapists from minority groups.

experiences as an older patient. My patient partner told me that in recent years, she had experienced many instances of what she termed ageism<sup>160</sup> in her health care interactions, such as a doctor asking her a question but looking at her son for the answer. Rather than feeling safe and cared for in these situations, she told me that she felt insulted, disempowered, and vulnerable. It became apparent to me that a broad interpretation of cultural safety (social location) and ideas about vulnerability in health care may contribute to a person's sense of relational safety. Thus, I interpret relational safety in the health care context to be a process that is linked to the concept of cultural safety.

In summary, my analyses of *relational safety*, the third and penultimate component of my *Relational Safety Framework*, led me to frame relational safety – complex reflections of "the tensions between power and voice" (Hernández, 2008, p. 14) – as a prominent feature of patient and family experiences of QI. Furthermore, underlying relational safety is concomitant vulnerability and risks to patients' and families' moral agency. The concept of relational safety I have articulated in this dissertation proposes that a sense of relational safety is one precursor to patients and families having agency within the structures of health care. Approaches to agency and safety share the notion that how patients, families and care providers relate to each other in health care settings and what they accomplish together is a joint enterprise that requires trust. In what follows, I therefore discuss links between relational safety and trust.

<sup>&</sup>lt;sup>160</sup> Gerontologist Robert Neil Butler (1975) coined the term "ageism" in his study "Why Survive? Being Old in America". More recently, Goldman (2015) and Ahn et al. (2015) describe the diversity of ways in which ageism in health care influences the treatment that older patients receive in Canada and their experiences of that care.

# 7.5 Trust (Component 4)

When people have a sense of relational safety they move towards

connections with others, fostering trust.

"You must trust and believe in people or life becomes impossible." Attributed to Anton Chekhov, physician and author (as cited in Bykova, 2011, p. 3)

I came to understand that patients' and families' stories often began with statements about trustrelated interactions, reinforcing Beitat's (2015) claim that a "trust relationship is formed at the first encounter and builds or deteriorates with every interaction" (p. 314). For example, Evelyn initially told me that the nurses were lazy because they were slow to empty her commode and respond to her call bell. As our conversation continued, her story became more nuanced. For example, in Chapter 6, I included an interview excerpt of Evelyn talking about the specific nurses to whom she had grown close because she could count on them to help her and they made her feel safe and special (see Section 6.2.2.1). Building on Chekhov's quote above, Evelyn might have said, "I must trust and believe in some nurses, or being a patient here would be unbearable." Identifying such patterns in my data expanded my understanding of Bergum's (2013; and with Dossetor 2005) ideas of respect in the "moral space" between patients/families and care providers. Evelyn's story is an example that relays trust as an evolving process, one that extends beyond interactions. Because the concept of trust arose repeatedly and significantly in my findings, I therefore incorporated interaction, connection, safety and trust as the four components of my Relational Safety Framework.



Furthermore, interpreting my study data through Baier's (1986) and Beitat's (2015) models of trust (introduced in Chapter 2, Section 2.2.4) resonated with my interpretations of patient/family experiences of the *patient hand wipes* intervention and related aspects of their care. For example, in creating Figure 7.2, where I incorporated Baier's (1986) will-based view of trust, I reflected that patient and family participants had not used Baier's words *competent* or *competence* when describing their health care providers.<sup>161</sup>



Figure 7.2 Interpretation of Baier's will-based view of interpersonal trust in the patient-provider context.<sup>162</sup>

Rather, participants inferred competence by describing provider behaviours that I interpreted as Baier's *dependable habits*: "they are professionals, and professionals perform good hand hygiene", "she's smart", "he always knows what I need", or "they sure know what they're doing here". These findings resonate with how Howe et al. (2019) propose that "patients assess competence by judging whether the provider "gets it" (i.e., demonstrates efficiency, knowledge, and skill)" (p. 3). While references to competence were certainly evident in my data, the significance of patients/families perceiving the *willingness* of their care providers *to care for and about* them was an overwhelming part of participant stories, a theme that is also reflected in the

<sup>&</sup>lt;sup>161</sup> In Baier's (1986) view, the truster (the person doing the trusting) relies on the competence and good will of the trustee (the people and agencies being trusted). Given the patient/family focus in my study, I considered patients and family members as the 'primary' group of trusters, and care providers and health care organizations to be the trustees.

<sup>&</sup>lt;sup>162</sup> Patient/provider Graphic (©2013 Six Seconds, by permission)

literature (for example, Allen et al., 2016, p. 191). In **Chloe's** words, for example: "The time [the nurses] take. The willingness, the good-naturedness of them." In a meta-synthesis of patient experience in the Emergency Department, Graham et al. (2019) portray patients' emphasis on caring as, " '[Patients] do not care how much [providers] know until [patients] know how much [providers] care'." The prominence of Baier's (1986) *good will* quality in my data reinforced my construction of *relational connections* as the central theme in my findings.

Indeed, in exploring meanings of patient safety, Fond et al. (2017) also found that "both the public and health care professionals view an individual practitioner's caring and competence as the main determinants of safety" (p. 28). The emphasis on relationship and trust that came through clearly in my data highlights the importance of understanding how QI activities can also impact patient and family interactions and experiences of care. Thus, trust models helped me to unpack the trust process grounded in my patient and family data, and to emphasize both the importance of warranted trust in health care, and the role context plays in patient/family articulations of trust.

# 7.5.1 Warranted trust when in vulnerable circumstances.

Trust is a crucial ethical process and outcome in health care that rests on warranted, or wellplaced trust (McLeod, 2015). Perceptions about a care provider's competence and good will required patients and families in my study to go beyond available evidence. In what follows, I discuss the idea of warranted trust when people are in vulnerable circumstances. For example, most patient and family participants relayed high confidence in their care providers' attention to hand hygiene. However, these optimistic perceptions contrasted with published hand hygiene rates that routinely fall well below 100 per cent,<sup>163</sup> revealing that while patients and families have a powerful motive for trusting their care providers (as I explored in Chapter 6), such trust is not always warranted.

At the same time, however, my data showed that the need to rely on health care systems and structures did not necessarily mean that patients/families always trusted the care providers in the places they sought care. For example, **Emily** described that each time she came for dialysis she assessed her nurse: "*if* I can trust a nurse during my dialysis treatment, *then* I have no problem taking my nap or whatever" [emphasis added]. McDonald and colleagues (2008) use the term *trustwary* to describe this inherent caution involved when placing trust in another. My analysis further supports the notion of trust operating as both an attitude/perception and a corresponding behaviour (McLeod, 2015), or as involving feeling, thinking and acting. In addition to hierarchical structures in health care, part of the power on the side of care providers is that patients and their family members can move in and out of vulnerability (May et al., 2014), and thus they need to *rely on* care providers [Baier, 1986). As one of my patient partners explained, "I don't really trust them [care providers], yet I'm not distrustful" (Fieldnote #30). In this comment, my patient partner pinpointed the complexity and situatedness of navigating trust in health care. **Emily** explained to me that things often turn out badly for her when "nurses miss

<sup>&</sup>lt;sup>163</sup> For example, BC infection control experts note the provincial hand cleaning compliance target for care providers is 80% (Provincial Hand Hygiene Working Group of British Columbia (PHHWG) & Provincial Infection Control Network of BC (PICNet), 2019, p. 1). During April to June 2019, the publicly reported compliance in BC acute care facilities was 81%. Of note, "In acute care facilities, compliance before contact with a patient or the patient's immediate environment was significantly lower than compliance after contact (75% vs. 85%), and compliance among physicians (70%) was lower than other healthcare providers" (p. 1).

signs that I'm not doing well during my dialysis treatment." In this way, Emily's need to collect 'evidence' that her care providers met a certain trust threshold before she could let her guard down during her dialysis treatment is an example of what Cohn (2015) explains as a "careful and considered investment of appropriate trust" (p. 2).

Overall, my diverse patient and family data showed that aspects of the QI interventions studied (among other care processes I observed) contributed to building trust, while other aspects eroded trust (and created what Baier (1986) labels "antitrust"). For example, patients and families described that unmet expectations (such as inconsistent provision of hand wipes when they were anticipated, lack of eye contact and other perceptions of not caring, or a sluggish response to a call bell) made them trustwary. On this basis, trust is crucial to patient safety (Gandhi et al., 2020, p. 11). Interestingly, I observed that patients and families who conveyed a tentative sense of relational safety with care providers also conveyed an attitude of trustwariness (and vice versa), signifying the bi-directional nature of relational safety and trust.

Furthermore, my data supported ways in which misplaced trust can be dangerous for patients/families, supporting legitimate reasons for a healthy sense of trustwariness. In a recent report about quality of health care, the OECD (2019) assert: "All patients expect and deserve to be treated with respect" (pp. 42–43). However, my interpretation of several instances in my data revealed that, in fact, not *all* patients *expected* to be treated with respect. For example, in the pages above I noted that Liam claimed he did not speak up about a medical error for fear of retaliation from the health care staff – in other words, he did not expect to be treated with respect. Yet, when Liam spoke to me about his accounting company – a situation with a different

power dynamic – he portrayed a high level of assertiveness and authority. Thus, I interpreted Liam's story about his previous hospital trauma (where his trust had been betrayed) as curtailing his agency in clinical situations, but not necessarily applying to all aspects of his life. McDonald et al. (2008) maintain that a certain level of trustwariness is a "realistic and ethically appropriate goal" that enables patients and families to become informed and advocate for themselves (p. 41). Liam's story is one example in my data that illustrates the difficulty of rebuilding failed trust relationships, supporting the notion that building trust is more difficult than losing trust (Baier, 1986; M. McDonald et al., 2008). In what follows, I elaborate on my analyses about the difficulty that patients and families have gauging appropriate trust in complex, dynamic, powerladen clinical situations.

# 7.5.2 Gauging appropriate trust in complex adaptive systems.

As explained in Chapters 6 and 7, implications of study findings centered on patients and families *moving towards* or *moving away* from relational connections in health care contexts, while striving to maintain a state of relational safety. Carolyn Canfield, a citizen-patient from BC, argues that health care system complexity makes it difficult for patients and families to gauge appropriate trust and have real agency in clinical settings. Canfield (2017) states, "Trust must often be presumed with no time to weigh individually the merits of each dependency, care complexity is so massive" (p. 30). In what follows, I discuss three ways my findings about QI implementation may further complicate trust for patients and families. First, several themes in my findings reflect a fluid, adaptive quality. For example, "we're all in this together" points to the interdependence of people, microbes, and health care settings, and systems. This fluid quality is resonant with Baier's and Beitat's models of trust building and trust erosion and is well

documented in the literature (for example, see L. Berg & Danielson, 2007; Cohn, 2015). For example, Cohn (2015) states:

To acknowledge [trust's] complex and often multivalent nature, and the very indeterminacy and instability which fosters it, means that trust is always contingent on a particular context and specific associations. Arguing that trust is a subjective quality of a set of relationships reiterates the point made by others that it is not simply associated with a patient trusting the health professional, or vice versa, but should be broadened to include all manner of relationships, including trusting oneself, one's body, the health service, and other significant people. All these forms coalesce around a person at times when they feel vulnerable and try to make sense of their situation by locating themselves in a network of relationships that might [provide a] sense of stability. (p. 7)

Second, Cohn and other authors similarly situate patienthood within relational ecological layers of trust. As discussed above (see Section 7.3.3), I found health care settings to play such an important role in patient and family experiences of care that I characterized organizations as having moral agency. My study has shown that the nature of QI interventions has important implications because QI typically extends beyond patient/family–provider interactions and specific organizations through systems, governments, and national (e.g., CPSI) and international (e.g., WHO) organizations. Importantly, I observed that introducing QI initiatives such as patient hand hygiene interventions can make clinical care and patient/family experiences of that care complex, and thus further challenge the ability of patients and families to gauge appropriate trust. Together with the contingent nature of trust, my study reaffirms the need to take a relational view of QI, given evidence that trust results from patient/family interactions in health care settings that are shaped by many layers.

A third way QI may complicate patient/family trust arises from my contextual findings that revealed gaps between how quality leaders imagined the QI intervention, how I observed the
intervention to be implemented, and how various patients/families experienced it. An example from my data is the disconnect between an evaluation report documenting "patients love the hand wipes" and the patients who told me (for example) hand wipes were unnecessary because their hands were already clean, or other patients who did say they loved the *hypothetical idea* of hand wipes but were not offered any. I posit that this is an example of how experts' 'optimistic' views of QI pose a problem for patients/families trying to reconcile trust and safety in health care. Consistent with my interpretations, Fond et al. (2017) report that experts prioritize the role that systems play in high quality, safe health care (p. 29). These researchers further argue that "[the public] see systems [as] the enemy of quality care, which is defined in terms of personalization and caring. Members of the public think people get lost in systems; they are less safe, not more, in systems" (p. 29). Thus, to feel safe, patients and families may be likely to prioritize relationships with people rather rely on systems.

In my study, the QI intervention may have contributed in some way to patients, families, care providers and health care systems working together as individual entities towards the same infection control goal. But, given that QI further increased the complexity of care, the intervention also introduced disconnects and downsides. QI activities therefore have the potential to pose potential challenges to trust and agency, particularly for some patients/families and care providers. The perspectives on trust described in this dissertation helped illuminate my findings about experiences of a QI intervention. Therefore, to help patients and families gauge appropriate trust in complex adaptive systems we need to consider the relational ecological backdrop that shapes patient/family experiences of care, and apply this insight into our attempts to improve the health care system.

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## 7.6 Chapter Summary

The *Relational Safety Framework* presented in this chapter is my interpretation of my patient/family-grounded findings that link interaction, connection, safety and trust at the interpersonal, organizational and societal levels. I close this chapter with two key points. First, in my study, when patients/families felt supported by people and places of care they felt 'at home'. Under these conditions, patients and families were better able to enact their values and preferences, even when sick and vulnerable. This insight reinforced that while I position trust as the end goal in my *Relational Safety Framework*, relational safety is the linchpin component. Second, patients' and families' expressed need for relational safety focused on the micro-system level, however, relational safety also exists across systems. Therefore, my analyses reinforce the need to strengthen relational safety throughout organizations and systems to enable patients and families to feel welcomed, safe, and cared for in health care organizations undertaking quality and safety initiatives. In the following chapter, I build on the theorizing in this chapter to examine the implications of applying relational safety in the context of QI implementation.

# **Chapter 8: Discussion – Examining Relational Safety and QI in Practice**

## 8.1 Chapter Overview

In the previous chapter, I advanced a *Relational Safety Framework* on the basis of my findings about patient and family experience of pilot OI interventions at the point of care. In this chapter, I build on my discussion in Chapter 7 and further my relational view<sup>164</sup> by linking experiences of relational safety to QI in practice and relevant literature. I first discuss the implications of attending to relational safety in the context of how I observed QI interventions to be implemented at the point of care. I then discuss my interpretations about how patients and families experienced these interventions. Next, I build on my interpretive description of patient/family experiences in the context of QI by offering analyses about how tensions and trade-offs related the broader organizational context that I described in my findings (Chapter 6, Section 6.3) contributed to difficulty sustaining QI interventions. In so doing, I use Figure 8.1 to illustrate the visual metaphor of a stone dropping into a pond to reflect the way pilot QI projects often start with a splash. The ripples reflect change; a second pattern in QI implementation. Some of these ripples are intentional, created by (for example) the PDSA cycles associated with QI implementation. However, some aspects of these ripples are also unintentional, such as those I observed when the QI intervention began to drift and dissipate (and eventually disappear) in the absence of consistent monitoring and reinforcement.

<sup>&</sup>lt;sup>164</sup> As defined in Chapter 4, I use the term relational view as one that considers the full range of interpersonal, interpersonal, and contextual relations (Doane & Varcoe, 2013, pp. 150–151; Rodney, 2013, p. 314; Rodney, Burgess, Pauly, et al., 2013, p. 85; Sherwin & Feminist Health Care Ethics Research Network, 1998, p. 19).

This discussion sets up a deeper analytic exploration regarding the *Relational Safety Framework* I presented in Chapter 7 to show how particular features of the QI project implementation shaped patients' and families' experiences of a changing care process and related relational interactions.<sup>165</sup> I then further delve into these patient and family experiences to show how evolving pilot QI interventions at the point of care can present specific challenges to patients' and families' sense of relational safety. In doing so I again draw on the concepts conveyed in Figure 8.1, where relational safety is shown as occurring within a moral relational space between patient and care provider (discussed in Chapter 7, Section 7.2.1).



Figure 8.1 Moral relational space between patients and care providers: Relational Interaction, Connection, Safety and Trust in the context of patient/family experiences during QI implementation.<sup>166</sup>

<sup>&</sup>lt;sup>165</sup> All of my study participants described their experiences of the patient hand wipes QI intervention, including the experiences of patients who said they had never seen a hand wipe being given out. I described this aspect of my results in Chapter 6 (see Section 6.3.2.1).

<sup>&</sup>lt;sup>166</sup> Patient/provider Graphic (©2013 Six Seconds, by permission); Liquid Drip (©Max Pixel photos, by permission. Creative Commons Zero - CC0).

Finally, I close this chapter by showing how ethical strengths and tensions resulting from the way QI interventions are designed and QI projects are implemented have important implications for patients/families and other stakeholders, including care providers and health care organizations. I also summarize how I incorporated a diverse array of salient ethical concepts and frameworks into my inductive relational analyses. In Chapter 9 I will elaborate on these implications and suggest recommendations for change.

#### 8.2 The Gap Between Work-as-Imagined and Work-as-Done

This study focused on patient and family experience of new or changing care processes in a transition zone: a QI "project" being tested in a "pilot study".<sup>167</sup> According to my review and interpretations in Chapter 6 (Section 6.3), QI interventions involve care processes that occupy a space that is somewhere between: (1) ideas of how routine care usually happens; (2) optimistic expectations that the QI process will bring about immediate and positive changes in the delivery of health care in particular settings; and (3) salient features of the QI processes as they are actually implemented. This analysis of my study findings led me to Erik Hollnagel's (2015) model, which indicates that what happens at the point of care is often different from what is imagined by those who plan the work. Hollnagel (2015) explains:

....the difference [is] between how work is being *thought of* either before it takes place when it is being planned or after it has taken place when the consequences are being evaluated, and how work is actually *carried out* where and when it happens. The two terms commonly used to describe this difference are work-as-imagined (WAI) and work-as-done (WAD). (p. 249, emphasis in original)<sup>168</sup>

<sup>&</sup>lt;sup>167</sup> I described general characteristics of QI activities in Chapter 3 (Section 3.2.1.2) and specific aspects related to the case studies in my research in Chapter 5 (Section 5.5.5.1).

<sup>&</sup>lt;sup>168</sup> Hollnagel (2015) first conceptualized this WAI-WAD gap in 1983. He and his colleagues built on the research of others who distinguished between the French "*tâche* (task) and *activitié* (activity)" (p. 249).

Hollnagel, an expert in industrial safety, applies the WAI–WAD concept to many types of work. Health care, the area of my study, has been described by health services researchers as a complex adaptive system (for example, see Braithwaite et al., 2015; Braithwaite, Wears, et al., 2017; Clay-Williams et al., 2015; Dekker, 2011). Data gathered enabled me to appreciate that issues I identified with the *patient hand wipes* design are consistent with complex adaptive systems (Clay-Williams et al., 2015). For example, the design did not delve far enough into *how* people do their work, and the *meaning* of this work to staff and patients/families. I will reflect on the implications of these contextual findings in Chapter 9. In complex adaptive systems, these researchers state, people with a management perspective develop policies, procedures and plans with a significant dependence on others to carry out the work, thus setting up the divide between WAI and WAD. Further emphasizing the complexity of the phenomenon I explored in this study, complexity is characteristic of interventions designed to improve such systems (Greenhalgh & Papoutsi, 2018).

In looking to interpret my findings, I considered ways in which the WAI–WAD concept resonated with how the patient hand hygiene QI intervention was implemented at the front lines of patient care. As described in Chapter 6, after the four-week pilot period of the QI intervention, I observed that the care processes dropped off in the absence of consistent monitoring and reinforcement. In other words, staff did not generally implement the hand wipes intervention as planned or reported. That this gap was *not acknowledged* in the QI project reports (see Section 6.3.2.2.5) is an important contextual feature of implementation. After a health care organization introduced a hand wipe initiative, theoretically care providers and volunteers ought to offer *more* hand wipes to patients, not fewer. Rather than attributing the lack of uptake I observed to

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staff/volunteers not following directions, or inadequate planning or commitment, my data support a larger explanation. My findings resonate with Anderson et al. (2017), who state what we already know about the WAI–WAD gap, and point to what is less clear:

This gap between WAI and WAD is a key feature of many complex work environments but is nevertheless unacknowledged in most patient safety discussions. These are powerful insights that are in direct conflict with many of the assumptions and accepted practices of quality improvement, rooted as they are in biomedical models of disease and illness that imply that quality problems can be diagnosed and remediated by targeted treatments. It is less clear, however, how these insights can be harnessed to inform quality improvement efforts. (p. 134)

Similarly, Clay-Williams et al. (2015) write about reducing the gap between WAI and WAD when implementing clinical guidelines.<sup>169</sup> Notably, these authors state that if health care leaders imagine that care providers are following new guidelines when they are not, then safety and quality may be compromised.

In my study, I interpreted the QI project reports I observed as reflecting positive intentions and what Dixon-Woods et al. (2014) describe as "evidence of 'magical thinking'" (p. 112). Moreover, my data showed further gaps between WAI and WAD related to patient hand hygiene in general. For example, I observed that alcohol hand-rub was often positioned out of patients' reach, which contrasted with how some staff talked about the accessibility of hand hygiene supplies for their patients. Secondly, quality/safety interventions often involve new or changed processes that come without a clear sense of people 'knowing' who is supposed to do what in the first place. For example, in my study nurses helping with patient hand hygiene just before meals

<sup>&</sup>lt;sup>169</sup> Clay-Williams et al. (2015) describe a clinical guideline as "description of a series of actions or activities that are considered as necessary and sufficient to achieve a given result" (p. 2). Clinical guidelines are understood to be evidence-based, meaning that unlike QI projects, clinical guidelines have already been tested and are endorsed by authoritative medical or health organizations overseeing clinical practice.

was a brand-new process; it was not a change to an existing, routine process. Because staff did not normally assist patients with hand hygiene before meals (which, according to my observations, appeared to be a surprise to some quality leaders in the organization), the hand wipes were new for care providers and patients.

Thus, my data showed that leaders and managers sometimes made decisions based on incorrect or incomplete assumptions about patient hand hygiene resources and behaviour on clinical units. For example, as a result of making decisions based on how staff *imagined* things worked in my study, infections could increase, PDSA cycles were not repeated, and other patient hand hygiene interventions may not have been undertaken. In addition, as I have discussed above, the way in which the interventions were designed may have lacked sensitivity to the responsibilities, needs, values and preferences of those involved (patients/families and staff), which I further elaborate on below. The reasons behind the implementation challenges I observed were not fully explored in my study, and, as I note in Chapter 9, would constitute good foci for related future research. In the meanwhile, my analysis here does reflect the importance of studying QI initiatives from various stakeholders' perspectives in real-time because the WAI-WAD gap can potentially result in preventable harm.

#### 8.3 Exploring Work-as-Experienced

In Chapter 1, I launched this study with the argument that patient and family experience of QI at the point of care was understudied in related literature. As a result of my research interpretations, I have come to think about how patients and families perceive and construct meanings about health care they receive – the work done to (functional), for (transactional), and about or with (relational)<sup>170</sup> (Murrells et al., 2013, p. 2) patients/families by care providers and others – as *Work-as-Experienced* (WAE). Through my relational view, my analyses led me to envision WAE as a logical extension of Hollnagel's (2015) original work, which is different from both WAI and WAD. Hollnagel explains in the above quote that WAI is work being *thought of*, and WAD is work actually being *carried out*. Thus, I claim that WAE is work being *experienced (by others)* (see Box 8.1).

# Study Definition of *Work-as-Experienced*

*Work-as-Experienced* refers to how patients and families perceive and construct meanings about health care they receive; the 'work' done to (functional), for (transactional), and about or with (relational) them by care providers and others.

## Box 8.1 Study Definition of *Work-as-Experienced*

In Figure 8.2, on the basis of my research interpretations, I illustrate the three concepts of WAI,

WAD and WAE and the gaps between them. Implicit in these three concepts are three

perspectives: managers, care providers/others, and patients/families. In what follows, I provide a

full explication of my construction of WAE based on my findings about patient/family

experiences of ethical impact, my Relational Safety Framework, and related relational literature.

<sup>&</sup>lt;sup>170</sup> In Chapter 2 (Section 2.4.3), I described three aspects of care as including the: (1) *Functional aspect of care:* heavily task-related work done 'to' patients (Adapted from C. Graham et al., 2018; Kelly et al., 2018, p. 174; Murrells et al., 2013); (2) *Transactional aspect of care:* patient is cared 'for' such as establishing and maintaining channels to exchange information on a nominal level (Adapted from Cross, 2014, p. 815; Hilton & Anderson, 2018, p. 16; Longtin et al., 2017, p. 211; Murrells et al., 2013); and (3) *Relational aspect of care:* patient is cared 'about' with respect, dignity, compassion as a unique person not a 'checklist' and as part of an ongoing relationship (Adapted from Chew, 2014; Child and Youth Mental Health and Substance Use Collaborative, 2017; C. Graham et al., 2018; Kelly et al., 2018, p. 174; Kornhaber et al., 2016; Murrells et al., 2013, p. 2; Robert et al., 2011).



Figure 8.2 A relational view (self/others/context) that *Work-as-Experienced* is different than Work-as-Imagined and Work-as-Done.

Adapted from (1) WAI and WAD: Hollnagel, Erik. (2015 Why is Work-as-Imagined Different from Work-as-Done? Chapter 18 p. 249. In Resilient Health Care, Volume 2); (2) WAE: Bate, P., & Robert, G. (2007 pp. 32–33); Murrells, T., Robert, G., Adams, M., Morrow, E. & Maben, J. (2013, p. 2); (3) Relational context (Doane & Varcoe, 2013, Ch 8, pp. 150–1; Rodney 2013 p. 314; Rodney, Burgess et al., 2013, Ch 5, p. 85; Sherwin et al., 1998, p. 19). ① denotes the gap between WAI and WAD; ② denotes the gap between WAD and WAE; ③ denotes the gap between WAI and WAE.

My research indicates that for patients and families, WAE represents what they experience as the reality of their interactions with the health care system. In the context of my study on QI, such experiences include the diverse ways that organizational quality and safety initiatives can impact on patient/family sense of relational safety; can add or ease burdens of illness and treatment; and can affect values, preferences, and other aspects of ethical impact. For example, in my study patients had diverse reactions when they were asked questions about their hand washing, ranging from neutrality to offence. While QI interventions at the point of care are often implemented (and perhaps even envisioned at the outset) to be pilot or 'one-time' process changes, my relational exploration of patient/family experience revealed that patients and their families – particularly those with chronic diseases who return over and over to the same places – can

experience QI more broadly. I elaborate on WAE and the implications for patients' and families' journeys of care below.

## 8.3.1 Relational gaps in WAE in QI.

Given that there continues to be a paucity of evidence about how patients and families experience QI reflects, as I argued in Chapters 1 through 3, the deeply embedded bias in health care that the outcomes of QI activities are positive or imperceptible for patients and families (for example, see (Armstrong et al., 2013; G. R. Baker, 2014; Balik et al., 2011; Berger et al., 2014; Entwistle & Watt, 2013; Sari et al., 2011; The Health Foundation, 2013b; Wiig et al., 2013). My relational ecological approach to studying patient/family experiences of QI helped me to explore important contextual and experiential features of this understudied area. My analyses and relevant literature helped me to identify two pertinent gaps in thinking about patient/family experience and QI that may currently be limiting robust understandings of WAE and embedding QI interventions more fully into practice. These gaps are: (1) QI's focus on functional and transactional aspects of care, with relational aspects of care typically assumed, thus relegated to the background; and (2) QI evaluations of patient/family experience are often superficial (i.e., satisfaction) and not necessarily related to their larger experiences of care. In what follows, I discuss the implications of these gaps, and I will pick up these points again in Chapter 9 to recommend strategies for change.

#### 8.3.1.1 Functional and transactional aspects of care privileged over relational aspects.

As shown in the central themes I presented in Chapter 6 and discussed in the context of a

Relational Safety Framework in Chapter 7, I interpreted significant ethical strengths and tensions

of a patient hand hygiene QI intervention. Overall, patients and families in my study appeared to prioritize relational connections and relational safety over other concerns, yet I also noted a prioritization of functional aspects of care in my observations of how the hand wipes project was implemented. Given the nominal input from patients and families into the QI project, this indicated that the focus of the intervention was a means to decrease infection and was, to a lesser extent transactional in nature. Given also that the hand hygiene intervention fell into the patient safety domain, my observations about the functional/transactional approach to project implementation are consistent with the biomedical focus that is prevalent in patient safety and QI fields (J. E. Anderson et al., 2017; Canadian Patient Safety Institute, n.d.-e) and in nursing practice (Kitson et al., 2014, p. 332). For example, Kitson et al. (2014) describe that nursing research focuses on preventing complications such as infection control through hand hygiene (a depersonalized task) rather than focusing on the patient as a whole person and studying the systematic effects of "basic nursing care" such as personal cleansing (p. 332). Similarly, this biomedical focus is conveyed with, for example, CPSI's stated focus on areas such as infection control and surgical checklists (Canadian Patient Safety Institute, n.d.-e).

In Chapter 6, I shared many examples from my data that patients and families expressed appreciating and longing to be 'cared about', in other words, valuing for the relational aspect of care. For patients and families, being valued as a person reflects ethical concepts such as equity and trust. So, while the focus of QI on the whole tends to be on functional and transactional aspects of care processes (Bar et al., 2018, p. 51; Cribb et al., 2019, p. 3; Entwistle & Watt, 2013, p. 29; Farmanova et al., 2016, p. 836; Harrigan, 2000; Ovretveit, 2014), the implications of my findings (as well as related sources in the literature such as (Bate & Robert, 2007; Hor et al., 2013; Rhodes et al., 2016; Robert et al., 2011) support a strong need to integrate more relational aspects of care into the QI design, implementation and evaluation. For example, to avoid unintended consequences when implementing QI interventions similar to the one I studied, a presurvey about hand hygiene could ask patients and families, in addition to questions about how often a patient washes their hands after using the bathroom and barriers to washing, open-ended questions such as:

- What does being able to wash your hands mean to you?
- How might being able to clean your hands before eating while you're in the hospital change your experience as a patient?

According to my analyses, the lack of relational follow up regarding how patients and families experienced the intervention (WAE) in my study is problematic because project evaluations that were done and reported to senior leaders did not capture the range of benefits, harms, and burdens on patients and families (the ethical impact<sup>171</sup>) that I captured in my research study of the same intervention. For example, my data showed that patients/families interpreted, in different ways, hand hygiene as an aspect of their personal identify and value. This knowledge might have influenced the organization's implementation of current and future hand hygiene interventions. Moreover, when QI activities did seek to gather patient/family perspectives, my observations in this study support the explanations of other researchers (Bate & Robert, 2007; Murray, 2012; The Health Foundation, 2013c; Tsianakas et al., 2012; Wiig et al., 2013), who

<sup>&</sup>lt;sup>171</sup> As described in Chapter 2, in my study, the term *ethical impact* refers to the totality of the effect of an episode of care (or more specific aspects of that care, such as a QI intervention) that may positively (benefit) or negatively (risk of harms and burdens, or risk of being denied benefits) affect the rights, interests and experiences of patients and families (Adapted from Faden et al., 2013; Jardine, 2008; M. McDonald et al., 2014).

claim that these evaluation data usually consist of generally superficial assessments favouring process and satisfaction rather than outcomes and experience. Patient/family evaluations of QI with purposeful attention to functional, transactional, and relational aspects have not, to my knowledge, been previously explored and are not a routine approach in the QI field. This gap in meaningful evaluation data highlights the need to focus on the expressed and covert values of the organization as well as ethical impacts on patients and families. In so doing, enhanced evaluations could reveal how relational aspects of the intervention carry through perspectives of WAI, WAD and WAE in QI activities.

## 8.3.1.2 QI evaluations lack context of patients'/families' larger experiences.

A second relational gap in what is currently known about WAE is that formalized evaluations of patient/family experience of QI do not typically take into account patients' larger experiences of care. In this way, these WAE data are superficial in a second manner, in that the data miss a vital context. This gap is due in part to typical methods of evaluating (e.g., brief closed-ended survey versus in-depth interview), as well as survey questions limited to, for example, bounds of the hand hygiene intervention. In my study, I was able to capture a more complex understanding in part due to my relational approach to studying patient/family experiences, which involved triangulated methods of observing the QI case studies in the context of people's larger hospital care experience and their larger lives. I was able, for example, to learn about patient/family ideas and concerns about how other areas of their health and health care may be impacted by a QI activity. Emma's story is perhaps the most extreme instance of this in my data in that I interpreted Emma's refusal of hand hygiene as an act to avoid prolonging her life.

As I noted in Chapter 6, while the QI project teams in my study did collect some post-pilot project evaluation data from patients, the focus of the project evaluation did not tend to go deeper than a short survey (e.g. "did you like it?"), which Bate and Robert (2007) describe as an isolated satisfaction measure. My analyses showed me that it was the context of patient/family experiences that held the significance. For example, Olivia described feeling neglected on the days she was not offered a hand wipe, and safer, more valued and empowered on days she was offered a hand wipe. And John perceived that he was safer with the addition of hand wipes before eating, yet expressed that that having to manage his own hand hygiene was an additional burden for a process that should be automatic in a hospital. Furthermore, in my data collection when interacting with patients/families, if I had limited my line of inquiry to what participants liked or did not like about the hand wipes instead of conducting fuller inductive qualitative interviews, I would likely have missed understanding the diverse meanings and depths of feeling about past, present and future that hand hygiene and the related interactions generated for participants. In other words, I would have been unable to have a sense of the more significant ethical impacts that the QI intervention generated for patients, families and staff in the context to their lives.

According to the interpretations I present in this dissertation in Chapters 6 and 7, in many instances the QI interventions I studied did, in various ways, impact the rights, interests, and dignity of patients and families. Furthermore, while the impacts some patients/families experienced as negative were not intentional, they were nonetheless real for the participants experiencing them. This point is also articulated in Canada's *Tri-Council Policy Statement* (2018, p. 111) regarding research with Indigenous peoples, which warns that power imbalances

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can compromise justice in ways that researchers are not even aware of. Other related patient safety research makes a similar point by showing that QI and patient safety activities can have a range of psychological, emotional, and relational impacts on patients/families (for example, see Fond et al., 2017; Kuzel, 2004; Rhodes et al., 2016; Sokol-Hessner et al., 2018). The data I have shown and the analyses I have offered support the point that a person's journey of care is temporal and cumulative, and thus it is sometimes difficult to disentangle a new care process from the person's (and possibly others') larger experience of care. However, the interpretation I advance here does not mean that patients'/families' experiences of QI cannot and should not be evaluated. Instead, consistent with the theoretical grounding I established in Chapter 4 (Section 4.2.2) for this research, I argue that it is important to evaluate QI experiences in the context of each person's larger experience in order to consider the unique challenges and enablers to relational safety that shape each patient/family experience of a given QI activity.

Finally, on the basis of my study analyses together with related literature, it appears that current thinking about the impacts of QI on patients and families could be further aligned with patient/ family values and lived experience. Without meaningful WAE data, and without a better understanding of the disconnects between WAI, WAD and WAE, people leading QI interventions are not likely able to articulate, measure and improve the clinical and ethical impacts of their interventions. Of particular significance in the context of my *Relational Safety Framework*, this gap in understanding WAE means that quality leaders may not know whether QI interventions are increasing or decreasing patients' and families' trust in the context of health care interactions, or more broadly related to the institutions of the Canadian health care system. As noted in Section 7.5.1, warranted trust is a value that is important to all stakeholders at all

levels, including patients, families, care providers, health care organizations, and the public (Beitat, 2015). In what follows, I expand on my exploration of WAE by outlining the implications of how the unique context of WAD in QI can be linked to patients' and families' expressed need for relational safety.

#### 8.4 The Analytic Context of Work-as-Done and Work-as-Experienced in QI

My findings about the disconnect between WAI and WAD substantiate two aspects of the difficulty implementing new practices that are reported in the implementation science literature I reviewed in Chapter 3. First, it is known that organizations and people experience challenges when integrating new processes – such as processes that are part of a QI activity – into their routine practice (Carl May 2013; 2016; 2009.). Second, to narrow the known gap between WAI and WAD, health services researchers typically study how care providers work in real time, and how providers assign meanings to work processes (for example, see Carayon et al., 2014; Dekker, 2014; Russ et al., 2013; Sheps & Cardiff, 2011). In other words, typical approaches to advancing improvement science and implementation science focus on the people working in health care, and examine the systems with which they interact. In this research, I took a different approach by focusing on studying patient/family and values-based perspectives (WAE) of QI interventions.

In the pages that follow, I further discuss the implications of my findings about how the context of QI implementation in practice *shapes patient/family experiences* of these activities. Building on Hollnagel's (2015) reasoning that gaps exist between WAI and WAD, on the basis of my findings I apply a logic similar to Hollnagel in my analysis of the concept of WAE in relation to

gaps between both WAI and WAD. I posit that having a better understanding of gaps between WAE, WAI and WAD generates an appreciation of important implications for a QI intervention's ongoing sustainability. I outline three significant contextual features (liminality, workload, and change fatigue) that arose in my data and explain how my analysis of these features shaped my thinking about WAI, WAD, and WAE, and how together these features have important implications for the context of how patients and families experience QI. In Chapter 9, I then expand on how my analyses led me to develop recommendations to strengthen relational safety across the health system as a way to advance QI.

## 8.4.1 Liminality leads to uncertainty.

The first feature of the context of WAD and WAE I discuss is the liminality,<sup>172</sup> or state of transition, that is associated with QI interventions. In my analyses, I connected the liminal nature of an intervention as a source of tension for both staff and patients/families. As I have noted above, the patient hand wipes QI intervention was typical of many change projects in that staff, volunteers and patients expressed *uncertainty* about project processes and duration. One example that arose during my fieldwork was that I, as a person associated with the patient hand wipes project, received occasional questions from hospital staff such as "are we still doing the wipes?" and patients/families such as "are they still doing the wipes?" A second example of this uncertainty was expressed by a unit leader who told me that "we don't expect casual nurses to

<sup>&</sup>lt;sup>172</sup> The term 'liminality' has anthropological origins and refers to a social state of ambiguousness (being "in limbo") that is often transitional or intermediate between two states, situations, etc." (OED Online, 2018g). QI interventions undergo transitions, such as from a pilot project to a larger project, as part of their design.

know about our active QI projects."<sup>173</sup> One reason for this uncertainty is that the complexity of typical QI interventions (described in Chapter 3, Section 3.2) is greater than routine clinical processes (Broughton & Marquez, 2016, p. 2). The implications of this uncertainty in my findings were that care providers, volunteers, patients and families experienced the ripples from the stone dropping in the pond (Figure 8.1), whereby initially the hand wipes were routinely available and eventually they were not (based on my observations) regularly available.

A lack of clarity in communications and expectations was especially notable during transitions in the project phases I observed. As described in Chapter 6 (Section 6.3), my findings showed that after the pilot period ended, the hand wipes pilot projects, which were led by champions from organization-level departments, were deemed successful on both units, as expressed in meetings and the project reports. After this assessment, the hand wipes process transitioned from 'pilot project' to 'routine care', at which time my findings showed that responsibility for the hand wipes process fell on the clinical units to manage. As Dixon-Woods et al. (2012) note, "Sustainability can be vulnerable when efforts are seen as 'projects' or when they rely on particular individuals....Clinicians' and managers' interest may dwindle when, at a project's end, they are faced with new, competing priorities" (p. 882). Indeed, sustained plans and resources to support adoption of the new hand wipes process after the pilots ended were difficult for me to identify during my fieldwork. For example, I was unsure about the responsibilities of the designated intervention 'champions' on each unit, and how liaising with the point of care

<sup>&</sup>lt;sup>173</sup> *Casual* employees work on intermittent, or as needed basis, such as when nurses who are full- or part-time employees take time off for vacation, illness, etc., or a position is vacant.

providers and volunteer groups would occur. Further, hospitals such as the one where I conducted my fieldwork have a level of bureaucracy that showed up in unexpected ways. For example, when the hand wipe product needed to be re-stocked, I observed that unit staff did not appear to know how this process would happen. My observations highlight the complexity of communication and accountability in health care settings related to embedding a new care process into routine practice.

These examples of my observations about the liminal nature of both implementing and experiencing QI interventions at the point of care reflect what I described in Chapter 3 (Section 3.2.3) as an abundant body of literature documenting the general difficulty sustaining quality and safety initiatives across a range of topic areas (for example, see Alexander & Hearld, 2011; Bastian et al., 2010; National Patient Safety Foundation, 2015; Pronovost et al., 2015). In their article "How to get started in quality improvement", for instance, Jones et al. (2019) encourage readers: "The intervention will not be perfect first time. Expect a series of iterative changes in response to false starts and obstacles" (p. 2). These words are consistent with my observations that tension and uncertainty are an expected part of QI. Overall, the kind of project-level uncertainty I have described above influenced how the unit staff and volunteers did the QI intervention, and therefore how patients/families experienced the intervention. However, as I noted in Chapter 6 and above, quality leaders and unit leaders did not seem to be aware (or fully aware) of the contextual challenges I have described above. According to the project reports and my observations, leaders conveyed an assumption that point of care staff and volunteers would continue to assist patients with hand hygiene according to the original plan. According to my findings, this assumption represented a clear gap between WAI and WAD. I interpret this to

mean that the liminal nature of QI may amplify differences between how quality leaders and staff perceive interventions rolling out, how observers observe the interventions, and how staff and patients/families experience the interventions. Moreover, it was my observation that some of the intentional and unintentional uncertainties I have pointed to in terms of how the QI projects were implemented had important implications (upsides as well as downsides) for staff and patients/families in my study, which I elaborate on in the sections below.

#### 8.4.2 Workload, environmental distractions and workarounds.

The second feature of the context of WAD and WAE I discuss is on the basis of my observations about the day-to-day activity on acute care units. I observed that care providers (in the case of my study, primarily nurses) work in complex, dynamic health care settings with constant environmental distractions. My findings are similar to observations made in previous research (for example, Douglas et al., 2017; Westbrook, 2010). Also consistent with other research (for example, Alteren et al., 2018; Hickerson, 2017; Saint et al., 2009), I observed that day-to-day work flow, previous clinical training, interruptions, and fluctuations in patients' medical conditions shaped how care providers navigated conflicts in values and goals. Care providers reprioritized and sometimes made trade-offs in the care processes they provided as well as the ways in which they provided this care. Examples from my data included nurse Ella who told me she intentionally did not offer hand wipes (the QI process) to quarrelsome patients as a way of prioritizing more 'important tasks' such as administering medication. In constructing my *Relational Safety Framework*, such analyses helped me to understand how the complexity of care can increase further when QI processes introduce new interactions between patient/family and

care providers.<sup>174</sup> Thus, my research indicates that patient/family–provider interaction is a central contextual feature of QI in busy clinical practice contexts. Patients/families are often facing pain, discomfort, vulnerability and fear, but do not want to bother 'busy' hospital staff. In turn, Gandhi et al. (2020) state, "The frantic pace of health care means that caregivers are often rushed, overburdened, and distracted" (p. 6). The complexity of patient–provider interactions in QI contexts may require observational follow up in order to better understand patterns from both staff and patient/family perspectives that can help to reinforce and sustain the positive aspects of these initiatives. Typically, in my data, nurses (and in some cases volunteers) explained to me that they were well intentioned regarding complying with the QI process, but due to momentary inattention or distraction, they forgot.

In my research I also observed that, at times, care providers coped with workload and other challenges using *workarounds*.<sup>175</sup> For example, as I noted in Chapter 5, the main task of the QI intervention was nurses offering each patient a hand wipe from a canister as the patient's meal tray was delivered (see Section 5.5.5.1.1). However, because patients were not always available as the nurses came by with wipes, on occasion I observed the nurses 'working around' the QI plan by placing a hand wipe on top of a sleeping or absent patient's meal tray. In so doing, the nurses told me that they were hoping that the wipe would not dry out and that the patient would know to use it before (not after) eating. These data revealed some of the logistical challenges that

<sup>&</sup>lt;sup>174</sup> This context of the patient wipes QI intervention implementation further shaped patient/family experiences because the intervention indirectly targeted patients. Nurses and volunteers were responsible for the new process, and assisting patients with hand hygiene before meals was not previously part of any provider's routine practice. <sup>175</sup> Debono et al. (2013) define workarounds as strategies "to circumvent or temporarily 'fix' work flow perceived hindrances to meet a goal or achieve it more readily" (p. 1).

one of the QI project reports reflected. Problem solving and adaptability has been identified as an important feature of QI (M. S. Bauer et al., 2015; Dixon-Woods et al., 2012; Marshall et al., 2013; Reed & Card, 2016), and Debono et al. (2013) situate workarounds as potentially framed positively in the professions as an act of critical thinking. However, I interpreted that providers' perceived need to create workarounds for new QI processes could also contribute to a sense of uncertainty for themselves and for patients. When I observed that care providers perceived their workload did not enable them to take on new, additional work (e.g., when they said there was no time in between tasks to give hand wipes to their patients), or if the additional work seemed too difficult to accomplish (e.g., the patients had to be "tracked down" for nurses to offer hand hygiene), the QI process was less likely to happen, especially if it was not monitored by the hospital. In the ways I have described above, which are similar to how other authors describe challenges implementing new practices (e.g., Debono et al., 2013; Hollnagel, 2012; Rathert, Williams, et al., 2012), I saw that creating work processes that people need to work around widened the WAI–WAD gap and created barriers to achieving the goals of the intervention I studied. On the other hand, this finding highlights an important and well documented benefit of QI, in that studying work flows and workarounds presents an opportunity to adapt processes so that they work in particular contexts (for example, see Carayon et al., 2014; Dekker, 2014; Russ et al., 2013; Sheps & Cardiff, 2011).

In contrast to the complexity of nursing staff's work, I did not observe workload and timing to be a barrier for volunteers offering patients hand wipes hand wipes, in that the volunteers appeared to have had adequate time and few interruptions. For example, as I shadowed volunteers, they told me that their roles were usually (but not always) limited to walking around the unit designated times, and offering drinks and snacks to each patient. Yet, when I observed on the same units several months post-pilot, volunteers did not appear to be familiar with the hand wipes process. I spoke with the QI project teams designing the hand wipes intervention as well as clinical unit and volunteer supervisors, who all told me that that they did convey information to their staff/volunteers about the new process and had general support for the project when it was initiated. However, I did not observe detailed or ongoing dialogue with volunteers to determine how the new care process fit in with existing work, how new volunteers were trained, or how volunteers conceptualized and completed their work on a day-to-day basis. In other words, despite my engagement in the study units over a period of eight months, I did not observe ongoing interaction with the volunteer group in relation to the hand wipes process. According to my interpretations based on the qualitative data I was able to gather, I attributed this decline in volunteers' engagement with (and potentially knowledge) of the QI care process to a lack of communication and follow up between unit staff and/or the volunteer group due to an assumption that the work was ongoing. I comment on the implications of this finding as an area for future inquiry in Chapter 9.

## 8.4.3 Change fatigue.

The third significant feature that arose in my data in the context of QI and WAD (and thus WAE) reflects care providers expressing a sense of 'tuning out' to continuous changes in their workplace, known as *change fatigue*.<sup>176</sup> Data collected throughout my study reflected provider

<sup>&</sup>lt;sup>176</sup> As described in Chapter 3 (Section 3.2.2), McMillan and Perron (2013) define change fatigue as "broadly understood as the overwhelming feelings of stress, exhaustion, and burnout associated with rapid and continuous change in the workplace" (p. 26).

views of patient hand hygiene before eating as "a good idea" and "common sense", as well as an openness to adopt the new care process into their practice. However, with several QI projects and other practice changes coming and going, change fatigue may have shaped provider attitudes and behaviours about the new hand wipes process. While participants did not use the phrase "change fatigue" directly, they implied it through statements such as "I'm not sure how much to invest...this QI initiative will be gone by next week and a new one will be in its place." This expression of change fatigue I observed reflects insights from related literature that QI projects can be "seen as time-limited risk simply being tolerated or ignored until they go away by coming to an end" (Dixon-Woods et al., 2012, p. 880).

Thus, in addition to constrained abilities to follow through with new processes, I interpreted some care providers as expressing a *limit to the energy* they were willing or able to devote to changing their behaviour under these uncertain conditions. Overall, my research findings support that when people allocate attention to change (such as adopting new QI processes), a significant consideration is a real or perceived feeling of being overworked and overwhelmed with systems already in place (Dixon-Woods et al., 2012, p. 880). Indeed, in support of this finding, family physician Danielle Martin (2017) states, "Change requires that providers and policy makers be brave when too often we're just tired, trying to get through the day" (p. 232). Furthermore, Boissy and Gilligan (2016) note that care providers can disengage when they feel that new initiatives put patients 'first' and providers 'last' (p. 1). Some providers even grow to distrust QI more broadly (Dixon-Woods et al., 2012, p. 882; Hayes & Goldmann, 2018, p. 158; Sollecito & Johnson, 2018, pp. 41–42), as evidenced by Marck's (2013) comment, "We are all too familiar with the 'doing more with less' ethos that permeates the short-lived efficiencies of so many

health care re-engineering activities" (pp. 221–222). Thus, a constant steam of quality and safety initiatives can wear care providers down, especially if the staff does not feel that they have been consulted regarding the change and/or its implementation process (Boissy & Gilligan, 2016; Dixon-Woods et al., 2012; The Health Foundation, 2010). In addition, my findings reported downsides directly related to the QI intervention I studied for staff and volunteers. For example, several participants expressed distress and frustration that they had been thrust in a situation whereby they offended their patients under the aegis of "quality improvement."

It is beyond the scope of this dissertation to delve into care provider experience, yet my findings reflected the possibility of an important connection between provider experience and patient/family experience. However, this aspect of QI is important because Rodney, Kadyschuk et al. (2013) note that when care providers feel supported by organizational systems and structures in their relationships with patients, families and colleagues, they are more likely to have a sense of agency (p. 163). In addition to benefiting patients and families, strengthening relational connections in practice is known to enhance the experiences of staff, and help protect providers from occupational stressors such as burnout, change fatigue and compassion fatigue (Boissy & Gilligan, 2016; Parnas & Isobel, 2019; Rodney, Kadyschuk, Liaschenko, et al., 2013). In turn, these occupational stressors impact the journeys of QI interventions, care provider experiences, patient/family experiences and the ability of health care organizations to increase quality and lower preventable harm.

## 8.4.4 QI is particularly vulnerable to the margins of mainstream activity.

In Chapter 5, I situated the case studies in my research (patient hand wipes and organizationwide hand hygiene) within a complex environment of other practice innovations and routine patient care (see Figure 5.2). During my fieldwork, I observed that care providers performed the hand wipes process less and less often until the wipes were not easily apparent to me visually or through patient/family accounts. This trend contrasted with what I observed about providers' usual hand hygiene routines (such as wearing gloves) that appeared to be very consistent. In the sections above, I provided an interpretation of how I observed the work of implementing QI in terms of three contextual features: both intentional and unintentional sources of uncertainty about QI projects and processes; perceived and/or real workload constraints; and a sense of change fatigue.

On the basis of my analysis, I suggest that taken together, these features may contribute to care providers, staff, volunteers and subsequently even patients/families consciously or subconsciously setting QI on the periphery and treating QI activities as an optional extra. Dixon-Woods (2012) describes what I witnessed as an observer of the hand wipes process as the "margins of mainstream activities" (p. 880). This is not to say that other activities in health care, such as other practice innovations and even routine care, do not involve uncertainty. However, this argument elaborates on what May and colleagues (2013) articulate as difficulty incorporating new activities in general, in that the new activity "is never isolated from its social, technical, and spatial contexts" (p. 26). In other words, the patient hand wipes intervention was situated within existing beliefs and behaviours at the individual and collective levels, such as

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how important this new process was in relation to established routines and the context of a dynamic work environment.

Furthermore, consistent with the work of Greenhalgh et al. (2005), Hollnagel (2012), and Pannick et al. (2016), among many others, my findings point to explanations that are more complex than simplistically blaming frontline staff for not adopting new initiatives. For example, in my study the same nurses who told me they knew their patients "liked getting hand wipes because they wanted to be clean" also told me "I simply forgot the wipes once the unit got busy." Furthermore, given intentional characteristics of QI that I have described above such as frequent project transitions, flexible techniques (e.g., Plan-Do-Study-Act cycles), pilot projects of short duration, and a focus on discrete processes often out of context of the larger picture of patient care, it is my interpretation that *QI interventions may be particularly susceptible to being pushed to the margins* of patient care given the potential disruption to work routines. That is, there are likely several linked reasons why QI processes are overlooked in the context of everyday work at the point of care, or potentially even in comparison to less transient innovations/learning activities such as clinical trials or comparative effectiveness studies.

In summary, the complex context of how health care staff carry out QI work where and when it happens (WAD) helps to explain why QI's impacts on patients and families (WAE) may be difficult to observe. Part of this difficulty is the optimistic way health care leaders and quality leaders have framed QI (thus we do not go looking for impacts on patients/families because we assume we know what they are and that they are positive, even when context validity has not been met), and part is that QI projects are not always well-planned, well-executed and well-

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supported (so it is difficult or impossible to measure impacts on patients/families). As I have shown in my data analysis, a significant downside of quality leaders and care providers assuming that patients and families are not aware of the care process and related interactions that comprise QI interventions at the point of care is that this assumption can lead to them thinking that engaging with patients/families in a meaningful way about QI is unnecessary and potentially time-consuming. Yet, my study has shown that QI does have ethical impacts on patients and families, and that these impacts can be diverse, complex, situational, and difficult to predict. Given the context of WAD in QI, my analysis presented here substantiates that there is an urgent need to make better efforts to understand ethical impacts of QI on patients and families (WAE) in the context of their lives.

#### 8.5 Challenges to Relational Safety in QI Implementation

In further discussing my findings, I return to the uneven actions and uptake that care providers demonstrated in the context of a QI intervention, and what this might mean for patients/families through the lens of my *Relational Safety Framework*. Using this lens, I further elaborate on implications of the ways in which the disconnect between WAI and WAD played out in relation to my study themes describing patient/family experiences (WAE) of the hand wipes intervention. Based on the *Relational Safety Framework* that I developed through my analyses, I note that intrapersonal, interpersonal and/or contextual factors shape each patient's or family member's interactions in health care settings and their overall experience of care. Second, I posit that at the micro-system level of patient/family–care provider interaction, the separate but related features of QI interventions I have described above (in the context of WAD and WAE) may contribute to patients and families feeling a sense of uncertainty. At the end of this chapter, I make a link

between uncertainty and safety. I apply these insights in Chapter 9, where I suggest strategies to promote a relational approach to QI.

# QI care processes: performed less consistently, with less relational attention. 8.5.1 As I described in Chapter 6, the whole of my data surfaced many instances of diverse relational interactions. For example, my analyses of how patients and families feel safe and valued in health care settings centred on notions of personal identity, being a good patient, and hand hygiene as a shared concern. However, my data captured surprisingly few examples of conversations between nurses or volunteers and patients that captured *shared meaning about* the hand wipes QI intervention. These observations led me to note that providers seemed to pay less relational attention to these QI-related interactions than regular care processes. The importance of studying QI interventions within the context of patients' larger point of care experiences also appears in the literature. For example, in their evaluation of a new intentional rounding (IR) process in hospitals,<sup>177</sup> Harris et al. (2019) wrote that "many of the IRs observed had very little relational interaction and often involved asking closed questions or simply completing documentation without any communication at all" (p. 101). The researchers go on to posit that "it is probable that the interactions in which nurses develop a relationship with patients occur when nurses are delivering other nursing care activities and not IR" (p. 101). In contrast, Huq

<sup>&</sup>lt;sup>177</sup> Intentional rounding is an intervention that involves nurses in acute hospital wards systematically and routinely checking on each of their patients each hour to ensure "regular interaction and engagement between nurses and patients and those close to them" (Harris et al., 2019, p. 1). The UK government implemented a policy requiring intentional rounding as one of the responses to care failures at Mid Staffordshire NHS Trust (summarized in (Francis, 2013).

and Woiceshyn (2018) studied characteristics of what they identified as a successful, complex QI initiative. These authors did not focus on patient/family experiences of the particular QI initiative, however they recommended strategies such as establishing a foundation for relational connecting to counter the tendency of the health care system "to hold actors apart" (p. 1). According to my interpretation of my own research, care providers not only have a tendency to perform QI care processes *less consistently*, but also have a tendency to allocate *less relational attention* to QI than to other activities that comprise their routine practice.

From the perspective of patients and families, othering is an important aspect of patienthood because both being othered and feeling othered can have a profound impact on every aspect of a patient's/family member's experience of care. Moreover, given that consistency (i.e., care providers showing dependable habits and caring) is part of interpersonal trust building (Baier, 1986) and a central element of a good patient and family care experience (Fond et al., 2017; Gerteis et al., 1993) it is essential to consider that there may be significant downsides to care providers marginalizing QI processes. In addition, through inattention to QI care processes intentionally or unintentionally in a way that is not tracked and accounted for (perpetuating the WAI-WAD gap), care providers and health care organizations may foster distrust in an organization's ability to be informed by their own data and improve. Organizational learning in itself is an important system goal and value (for example, see Faden et al. (2013, p. S17). Yet, my findings raise fundamental questions about how quality leaders and care providers understand and value patient autonomy and the need to inform and to engage patients/families in meaningful conversation about care processes undergoing testing and change. My findings therefore underscore the importance of purposefully taking a relational approach to

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understanding the role of connections in how new QI interventions are planned and implemented, and how providers and patients/families can then experience that the new care process has positive (or acceptable), shared meaning to them.

## 8.5.2 Absence of relational connectivity in intervention design.

In tandem with discovering the tendency for providers to perform QI care processes less consistently and with less relational attention I also explored how the QI projects in my study were designed at an organizational level. As noted above (see Section 7.3), I observed that QI project team members (primarily from the nursing profession) appeared to conceptualize and operationalize the patient hand wipes intervention with a focus on function and care provider task, and with an absence of attention to relational connectivity within and across provider and patient/family groups. For example, during my observations of the *patient hand wipes* project planning meetings I noted an assumption that hand wipes would be welcomed by patients and nursing staff as an infection control strategy. I also observed that the main focus appeared to be on logistics that prevented frontline nurses from complying with the new process, such as timing delivery of the hand wipes. This interpretation supports claims that care providers (Boissy & Gilligan, 2016, p. 11; Chou, 2018, p. 6), and perhaps nursing more so than other health care professions (L. Berg & Danielson, 2007, p. 503; Chou, 2018, p. 6; Harris et al., 2019; Kitson et al., 2014; Kornhaber et al., 2016, p. 538; Nagle, 2019), can be vulnerable to an excessive task orientation. Kitson et al. (2014) describe one of the ongoing tensions in the nursing profession as "between a depersonalized and mechanistic approach to the basics of care (termed the "task and time" driven culture) and the need for consistency around understanding and managing the dynamics of the nurse-patient relationship or encounter" (p. 332). In fact, Nagle (2019) states

that, "nurses themselves have also frequently fallen into the trap of delineating their practice in terms of tasks and time" (p. 1). Overall, in my study I interpreted that the project teams and care providers conceptualized and operationalized the QI intervention in a way that was primarily limited to the functional and transactional aspects of the task – hand wipes were seen as a mechanism to remove microbes.

Yet, once the QI intervention was situated in a clinical context, my findings illustrate the gap between staff's task orientation and patient/family participants' expressed emphasis on relational aspects of their experience. This gap allowed me to recognize the *absence of relational connectivity* in the intervention's design. Specifically, I came to recognize that in the QI intervention planning, I had not observed discussions of relational aspects of the hand wipes process, such as *how* nurses/volunteers and patients would *talk together* about hand hygiene at the bedside, and how the hand wipes process would *affect* patients.<sup>178</sup> In other words, my finding that patients and families highly valued positive relational connections (WAE) appeared to contradict how the health care organization conceived of relational aspects in the patient hand wipes QI intervention (WAI and WAD).

This interpretation indicates that in optimistic efforts to improve health care delivery through QI such as the hand hygiene intervention I studied and related initiatives, we in the health care system think we are doing things 'about' and 'with' patients. But, rather, we too often do things

<sup>&</sup>lt;sup>178</sup> For example, as I noted above, my data did not capture project team discussions about relational aspects of care, such as: what cleaning hands before eating might mean to different patients and why; the range of possible interpretations of a new hand hygiene strategy; or what the role of families in supporting patient hand hygiene was or might be.

'to' and 'for' patients.<sup>179</sup> For example, I noted conflicts (such as a patient misunderstanding the intent of a hand wipe) or relational avoidance behaviour (such as nurses saying they did not have the time to explain the purpose of a hand wipe to a patient, or to offer a hand wipe at all). Doane and Varcoe (2013) emphasize that nurses' abilities to have "relational moments" with patients occur within multiple and possibly competing contexts (p. 149).<sup>180</sup> My observations and insights made me wonder if the manner in which QI interventions are conceptualized and operationalized may diminish care providers' abilities to have relational moments with patients and families, and might even construct structural and relational barriers between patients/families and care providers – in other words, "hold actors apart" (Huq & Woiceshyn, 2018, p. 1).

Moreover, in what became a significant theme in this dissertation, I did not observe significant follow up or analyses in the QI project concerning how staff and volunteers *did interact with* patients and families *about* the new hand wipes process, or what role, if any, patient/family– provider interactions played in the intervention's successes and challenges. These gaps in my data may reflect what authors such as Tobiano et al. (2015) and Mitchell and McCance (2012) describe as care providers portraying an aura of 'busyness' to deter interactions with patients, or what Koven (2016) describes as "avoid[ing] the kind of intimacy that not only helps the patient, but also nourishes us [care providers] and keeps us from feeing burned out" (p. 609). Therefore, I interpreted my observational findings to be rooted in the possibility that the QI project teams unintentionally designed the QI intervention to remain on the surface, rather than aiming to

<sup>&</sup>lt;sup>179</sup> This depiction of work done to (functional), for (transactional), and about or with (relational) is based on Murrells et al.'s (2013, p. 2) paper.

<sup>&</sup>lt;sup>180</sup> I interpret Doane and Varcoe's research as applying to care providers more broadly.

develop a deep cultural shift that was grounded in what the new care process signified to staff, patients, and families. Hradcová (2017) noted a similar trend in her study of people with dementia, where the time to build relationships was not built into improvement efforts or quality measures.

I have argued above that relational connection is an essential part of the patient/family experience, and my analysis is consistent with that of Sokol-Hessner et al. (2018), who note that organizations do not typically account for non-physical harms in QI and safety systems (p. 2). Similarly, Chavan (2013) states that "the 'human' perspective" of process improvement is often ignored in explanations of why QI programs fail (para. 7). My findings, along with these examples from the literature about the absence of relationality in the QI project design, resonate with Berwick and Fox's (2016) summary of Donabedian's reflections in 1998 about his highly influential model of health care quality (1966; 1980, 2005) (see Chapter 2, Section 2.3). In this account, Donabedian reflected that what was essential to quality – and seemed to be missing in how quality was interpreted and applied – was "the ethical dimension of individuals", and love (p. 237). "Toward the end of his life," Berwick and Fox further note, "Donabedian recognized, and worried about, the ascendancy of what he called an "industrial model" of quality improvement" (p. 237).

#### 8.5.3 Implications: Uncertainty, relational mismatch and point of care QI interactions.

Based on my analyses of the contextual features of implementation in my study through the lens of my *Relational Safety Framework*, I have suggested that an absence of relational connectivity in QI intervention design augmented tendencies of care providers to perform the QI process differently – less consistently and with less relational attention – than their regular care processes. Notwithstanding the positive aspects of patient/family accounts in my data and some meaningful organizational learning about patient hand hygiene, the task-focused approach to QI that I observed in this study (and that is reflected in studies I have cited of other projects at other locations) lacked sensitivity to what I learned is important to patients and families, which I have conceptualized as relational safety. My relational analyses supports that of Entwistle et al. (2010), who emphasize that "all communication with patients [is] potentially significant for their autonomy, and treat any interactions that belittle or undermine patients as potentially problematic" (p. 742). In addition, however, my analyses point to patients and families seeking increased relational safety particularly in times of uncertainty, including the uncertainty that patients/families picked up on when a QI intervention was piloted. This means that ethical tensions can arise when a patient/family may seek to move towards a relational connection (e.g., seeking to assure themselves that they are not being singled out as a "dirty patient"), while care providers may be more focused on incorporating the new task into their current workload (e.g., remembering to fit in giving each patient a hand wipe after medication rounds but before the meals arrive). At the same time, opportunities for ethical strengths can occur when a patient and care provider move towards a relational connection (e.g., when patient and nurse agree that handwashing before eating is something the patient can do to help their recovery and be discharged from the hospital faster).

My relational analyses also build on related work about the impacts of practice changes on patient–provider relationships (for example, S. Grant & Collier, 2018, p.244; Hor et al., 2013, p. 576; Rhodes et al., 2016, p. 283). In writing about the ethical dilemmas that providers face when
implementing new mental health practice standards, for instance, Park et al. (2015) state that the significance of "small social exchanges" between care providers and patients is "heightened during moments of uncertainty" (p. 2). On the basis of my interpretations about relational safety, I extend Park et al.'s analysis to sources of ethical tension that changing care processes – especially those being iteratively tested as QI – might introduce for *both* provider and patient/family. In such circumstances, my findings suggest that providers may be inclined to approach interacting with patients from a functional or task-focused perspective. On the basis of my analysis of my findings, relational safety is a continuum ranging from a sense of safety to a sense of danger, rather than a binary. This means that patients and families may perceive providers' demeanor in these instances (i.e., during the QI process interaction), as *less relational than they need*. I use the term *relational mismatch* to describe this disconnect between what a patient needs and what their care provider offers in a specific moment. The mismatch is rooted in the disconnect between how each person imagines, enacts and experiences the new care process (see Box 8.2).

#### Study Definition/Conceptualization of Relational Mismatch

In the context of what I learned from my study participants, *relational mismatch* describes the disconnect between what a patient needs and what their care providers offer in a specific moment. Uncertainty (e.g., during QI implementation) heightens the potential for relational mismatches at the point of care. For example, if the care provider approaches a patient interaction from a functional or task-focused perspective and the patient/family seeks increased relational safety, then a relational mismatch occurs. This means that the patient/family may perceive their provider's demeanor in this moment as less relational than they need. The mismatch is rooted in the disconnect between how each person imagines, enacts and experiences the care process.

#### Box 8.2 Study Definition/Conceptualization of Relational Mismatch

In Figure 8.3, on the basis of my research interpretations, I illustrate the relational mismatch in the context of patient/family experiences of care during QI implementation. Figure 8.3 builds on Figure 8.1 (where relational safety is shown as occurring within a moral relational space between patient and provider, and uncertainty associated with QI is portrayed by splashes and ripples), and Figure 8.2 (where *Work-as-Experienced* is different than Work-as-Imagined and Work-as-Done).



Figure 8.3 The *Relational Mismatch* between patients and providers is heightened during periods of uncertainty, such as during QI implementation.<sup>181</sup>

In the context of how QI interventions are implemented at the point of care, my analyses also indicate that uncertainty during care can present opportunities to strengthen or weaken relational safety, as evidenced by my data showing patients' and families' attempts at positive relational building as well as defensive actions to avoid negative impacts from care providers. For

<sup>&</sup>lt;sup>181</sup> Original patient/provider illustrations by Jim Fee for the sole purpose of this dissertation. Liquid Drip (©Max Pixel photos, by permission. Creative Commons Zero - CC0).

example, some patients used humour in asking for what they wanted, while others put themselves at physical risk by choosing not to ask for help. A major theoretical implication of this research is that if new QI processes are marginalized by staff, with patients/families possibly feeling othered or relational unsafe, the impacts may include weakening of patient/family relationships with providers and institutions, and unsafe patient care. In addition, a relational mismatch has the potential to limit the ability of patients/families *and* care providers to adopt the new attitudes and behaviours required to sustain a new care process. On the other hand, attending to the concept of relational safety in a QI intervention's design and implementation could address this relational mismatch and add meaning to care providers' work and therefore bring the new care process closer to their other, mainstream activities. In Chapter 9 I will provide several examples of how to purposefully integrate relational safety into QI.

In summary, my study points to the need to strengthen relational safety for patients and families at the point of care during care processes such as QI that are characterized by complexity and uncertainty. My emphasis on the significance of relational safety complements literature advocating the need to consider QI interventions within a broader understanding of cultural and social factors, and to challenge assumptions about the appropriateness of 'quick fixes' without a more systematic and systemic understanding of causes and solution (for example, see G. R. Baker & Black, 2015; World Health Organization (WHO), 2009a). The insights from my study also suggest that designing QI interventions ought to address the perspectives of the patient/family, which require more integration of the *relational*, functional, and transactional aspects of care processes into QI. Furthermore, evaluating WAE in context could enable quality leaders and QI project teams to create opportunities to strengthen relational safety in QI and

health care overall by better understanding areas of relational mismatch during QI processes. Thus, I see QI as playing an important role in linking relational safety and trust as depicted in my *Relational Safety Framework* – a form of safety which, I have argued in this study, is an oft-overlooked component of QI interventions.

#### 8.6 Inductive Ethical Analyses

As I established in the rationale for this research, patient/family roles in QI raise significant values-based questions, especially when QI interventions are integrated into patient care. In my dissertation, I have aimed to inductively show how salient ethical principles, constructs and frameworks that traverse research and practice domains (described in Chapters 2 and 3), together with my theoretical (Chapter 4) and methodological (Chapter 5) framing, emerged in my analyses. On the basis of my empirical findings grounded in patient/family perspectives (Chapter 6), throughout Chapters 7 and 8, I incorporated a diverse array of salient ethical concepts and frameworks into my inductive relational analyses across micro, meso and macro layers. I then drew on new literature that helped me to interpret particularly prominent patterns and themes, such as safety and trust.

During my ethical exploration of subjective and experiential phenomena in a practice context, I drew from two main areas: (1) frameworks relevant to QI that I described in Chapter 3 (in particular, the learning health care system (Faden et al., 2013; Kass et al., 2013), and project ethics (Hagen et al., 2007; Lynn et al., 2007)); and (2) relational accounts of public health ethics (Baylis et al., 2008; Melnychuk & Kenny, 2006). In my analyses, I interpreted these frameworks in new ways in response to my findings. The ethical concepts that appeared to be most

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significant on the basis of my findings included, but were not exclusive to, expressions related to relational interpretations of: *welfare* (benefits, harms in a broad sense, and burdens) (Faden et al., 2013; Hagen et al., 2007; Klingler et al., 2020; Lynn et al., 2007); *equity* (Baylis et al., 2008; Dixon, 2017; Faden et al., 2013; Lynn et al., 2007); *trust* (Klingler et al., 2020; Melnychuk & Kenny, 2006); *solidarity* (Baylis et al., 2008; Klingler et al., 2020; Melnychuk & Kenny, 2006); *solidarity* (Baylis et al., 2008; Klingler et al., 2020; Melnychuk & Kenny, 2006); *solidarity* (Baylis et al., 2008; Faden et al., 2013; Hagen et al., 2007; Klingler et al., 2020; Lynn et al., 2007). Furthermore, in health care systems where resources<sup>182</sup> are scarce even in ordinary circumstances, in the interest of economic and other interpretations of well-being resources should be allocated towards activities with the best potential to achieve clinical, ethical and other relevant goals across the continuum of care (Broughton & Marquez, 2016; Dixon, 2017; Faden et al., 2013; Lynn et al., 2007).

Together, this relational inquiry produced an interpretive description from my location as a health care administrator, REB member, and doctoral researcher working in the field. My *Relational Safety Framework* arose inductively from my analyses, with ethical concepts rooted within its components of connection, safety and trust. Similarly, the constructs *Work-as-Experienced* and *Relational Mismatch* arose more specifically in the context of how I observed QI to be implemented at the point of care.

<sup>&</sup>lt;sup>182</sup> As noted in Chapter 4, an organization's resources form part of the structural context of QI and include "financial, material, human, and informational resources" (Robert & Fulop, 2014, p. 37).

#### 8.7 Chapter Summary

I began this chapter examining relational safety and QI by discussing implications of the disconnect between WAI and WAD in the context of my study findings, and I linked this disconnect to the significance of relational safety for patients and families. I introduced a new concept, *Work-as-Experienced* (WAE), to reflect how patients and families perceive and construct meanings about health care they receive. I then discussed how, in the context of QI at the point of care, WAD and WAE can amplify challenges to patients' and families' sense of relational safety. I have argued that even QI interventions designed to be flexible, short-term pilot projects can lead to patients, families and care providers experiencing uncertainty. Uncertainty in QI implementation may heighten patients' and families' need for relational safety. For these reasons, the significance of relational safety may be especially apparent in QI interventions that involve patient/family–provider interactions.

My study also affirms that how QI interventions are designed and implemented at the point of care may influence relational safety between patients/families and care providers, and, ultimately, the quality of those interventions in clinical contexts. My research points to the need to consider the role of relational safety in how QI activities are planned, implemented and evaluated. Understanding how patients and families experience QI interventions is essential to understanding the disconnects between WAI, WAD, and WAE. My goal in this chapter has been to enable people undertaking QI work to see and to acknowledge gaps between WAI, WAD and WAE more clearly, and to ground my inductive analyses in salient ethical principles, constructs and frameworks that traverse research and practice domains. In Chapter 9, I elaborate on the

implications of these gaps and posit actionable strategies to narrow them by integrating a relational ethical approach into QI policies and processes.

# **Chapter 9: Recommendations and Conclusion – Appreciating Ethical Implications of QI Implementation**

#### 9.1 Chapter Intent

The overarching argument of this dissertation is that ethically-oriented research and evaluation need to focus on the impact of QI initiatives on patients' and families' lives. In this final chapter, it would not be appropriate to recommend grand structural changes as a result of one qualitative study. Based on the insights generated from my study and related literature, however, I summarize my key findings and analyses, articulate the results health care leaders need to aim at, and make suggestions about how to achieve these results. I close the dissertation with reflections on the strengths and limitations of my study, point to priorities for future related inquiry, and offer concluding reflections about the value that an expanded relational ethical approach might offer health care system improvement.

#### 9.2 Summary of Key Findings and Analyses

My study has shown that QI interventions and the dynamic contexts in which they are implemented, particularly at the point of care, involve areas of considerable ethical sensitivity. As explained in Chapters 5 and 6, in my research, I studied hand hygiene interventions that the Study Hospital conceptualized as QI activities to reduce harm caused by nosocomial infection. Based on this assessment, the Study Hospital assumed these QI activities to be beneficial, ethically unproblematic endeavours. While preventing danger and harm through attention to hand hygiene is certainly an important ethical action, in my study I observed that the context of QI project implementation revealed strengths as well as several patterns that are ethically troubling. Specifically, I observed gaps in how people imagine QI (WAI), how QI interventions happen at the point of care (WAD), and how patients/families experience the interventions (WAE). Indeed, my research about what matters to patients and families at the point of care exposed important downsides of such optimistic framing.

Over the course of my study analyses that led me to relevant literature, I came to understand the significance of the interactions and relationships<sup>183</sup> between patients, families, care providers and health care settings in new ways. This insight, reflecting what was important to participants in my study, led me to develop my *Relational Safety Framework* (Chapter 7). Strengthening patients' and families' feelings of relational safety is critical when patients/families perceive themselves as taking on a new or changing role and/or interactions with health care staff. I found that notwithstanding its beneficent goals, QI can have complex ethical impacts on patients, family members, and care providers, as well as on the interactions between these stakeholders in the near and long terms.

Furthermore, in Chapter 8 I have argued that the context of implementing new QI processes poses particular challenges for relational safety for patients/families because frontline care providers typically work in dynamic, complex environments (see Section 8.5). Interruptions, distractions, and competing priorities can pose particular challenges to relational connections and relational safety. I explored the gaps between Work-as-Imagined (WAI), Work-as-Done (WAD)

<sup>&</sup>lt;sup>183</sup> In Chapter 7 (Section 7.1), I quoted Beach et al.'s (2006) description of *health care relationships*, a portion of which states: "Within relationships, we exchange information, allocate resources, arrive at diagnoses, choose treatments, and assess the outcomes of care" (p. S4). Sherwin and Stockdale (2017) describe "persons as essentially relational beings who exist and develop within a web of relationships" (p. 9).

and *Work-as-Experienced* (WAE). For example, the QI projects were conducted without a clear understanding of impacts on the health and/or well-being of patients and families, a pattern that is also documented in the literature (Bate & Robert, 2007; Berger et al., 2014; Murray, 2012; The Health Foundation, 2013c; Wiig et al., 2013). Thus, for patients/families, having a sense of relational safety in interactions with care providers may be even more important during times of uncertainty, such as when QI is implemented at the point of care. As articulated in Chapters 7 and 8, my central claim in this study (Box 9.1) is that *QI implementation ought to attend to relational safety between patients/families and care providers to improve the quality and impact of those interventions in clinical contexts*.

#### Central Claim: Implementing QI is an Ethical Endeavour

QI implementation ought to attend to relational safety between patients/families and care providers to improve the quality and impact of those interventions in clinical contexts.

#### Box 9.1 Central Claim: Implementing QI is an Ethical Endeavour

#### 9.3 Recommendations

Worthy, real-world action is a significant goal of interpretive description methodology (Thorne, 2016). Insights about relational safety drawn from my nuanced exploration of patient/family and organizational perspectives of a QI intervention led me to relevant literature, and then enabled me to offer those interested in QI a set of recommendations. To operationalize my *Relational Safety Framework*, I offer recommendations built on three assumptions, the first of which embraces Wade's (2005) assertion that "ethical (moral) aspects should be considered for every action within health systems" (p. 471). The second assumption is that health care organizations, as moral agents, bear a responsibility to ensure that QI is performed ethically (Rolnick et al.,

2017, p. 1). And the third assumption positions QI as a product of human activity that is built on social practices and cultural assumptions, and therefore is capable of shifts over time (Burr, 2015, p. 51; Glasby, 2019, p. xiv; MacIntyre, 2007).

Quality improvement is constant work in progress. *My central recommendation from this study is that health care leaders ought to more fully appreciate the ethical implications of QI implementation, such that explicit ethical attention to QI, including relational safety, becomes integral aspects of health care improvement* (Box 9.2). More specifically, in the elaboration that follows I argue that adopting a relational (self/others/context), learning approach to relationship-focused QI (what I term a *relational ethical approach*) would be a new, ethically-based, values-added strategy to further advance health care system improvement. An important insight of this study is that broader sociopolitical contexts shape how agents operate in complex clinical practice contexts as well as in the unique structures and context of a QI activity, which I describe in this study as agents embedded in layers of context.<sup>184</sup> I subsequently outline a series of actionable strategies at the micro, meso and macro levels requires to implement this recommendation and reinforce how these levels influence each other.

<sup>&</sup>lt;sup>184</sup> As I described in Chapters 2 and 4 an emphasis on the importance of sociopolitical contexts supports the work of many other scholars, for example (Doane & Varcoe, 2013, pp. 150–151, 2015, p. 41; Rodney, 2013, p. 314; Rodney, Burgess, Pauly, et al., 2013, p. 85; Sherwin & Feminist Health Care Ethics Research Network, 1998, p. 19).

### Central Recommendation: Appreciating the Ethical Implications of QI Implementation and Relational Safety

Health care leaders ought to more fully appreciate the ethical implications of QI implementation, such that explicit ethical attention to QI, including relational safety, becomes integral aspects of health care improvement.

# Box 9.2 Central Recommendation: Appreciating the Ethical Implications of QI Implementation and Relational Safety

#### 9.3.1 Implementing recommendations.

It is my hope that my recommendations towards integrating a relational ethical approach to QI have the potential to enhance QI implementation by building on the strengths of QI's history (described in Chapter 3, Section 3.2) and existing ethical frameworks (described in Chapter 3, Section 3.4), while learning from the new opportunities and challenges I identified through my research. Based on my interpretations of the ethical strengths and tensions in my findings and subsequent review of relevant literature, in the pages that follow I outline a series of actionable strategies that can be simultaneously implemented across micro, meso, and macro levels to strengthen ethical conduct of QI in health care. Similar to others' recommendations for meaningful health care system transformation (for example, see Bailey et al., 2018; Dixon, 2017; J. K. Johnson & Sollecito, 2018a; Kaplan et al., 2012; Reed & Card, 2016), I acknowledge that my recommendations require organizational commitment, leadership, expertise, support, and resources (especially in terms of adequate staffing and funds). I encourage academic and practice communities to trial and evaluate these promising strategies in an effort to better balance tensions between the managerial, clinical, and experiential priorities in QI, thereby advancing health care system improvement.

# **9.3.2** Micro level implementation: The point of care, where care providers and patients make connection.

I use "micro-system level" to describe the point of care: these are the moments when patients, families and care providers move towards or away from connections with each other, including during QI interventions. The recommendation in this section targets the *managers of programs or units in which QI projects are being implemented, frontline care providers/staff, and possibly patients/families who may be directly involved*.

Importantly, it was striking in my study that patients and families expressed a desire to feel relationally *safe enough* to take action (e.g., asking for a hand wipe); this is not to say that this would be the experience of all patients/families. In addition to the need to explain new quality/safety processes to patients and staff (for example see (Fond et al., 2017, p. 32; Longtin et al., 2017, pp. 212–213), my study findings and analyses support a need to pay more attention to the relational aspects of patient–provider interactions that involve QI processes. Patients/families feel safer and valued when their nurses and doctors take the time to communicate to them, "just so you know, we're asking you to do this now, and this is why." On the basis of this insight, I turned to the literature for examples of strategies to bolster relational patient–provider interactions during routine care. Positive patient–provider/staff connections during QI interventions can contribute to trustworthy patient–provider relationships.

#### 9.3.2.1 Rewriting the QI script at the point of care.

One recommendation to increase relational safety at the point of care is for project teams to develop *model scripts to accompany roll outs of new QI care processes*.<sup>185</sup> Scripting is one strategy to create the expectation and prepare care providers to attend to relational dynamics in QI by, for example, responding to the unspoken relational needs of patients/families. In turn, this strategy can allow the relational aspect of a QI process to become more explicit and measurable during brief clinical interactions. Scripts are not intended to trivialize interactions such as those described in this study in terms of complexity or gravity, to be reductionist or formulaic from a conceptual perspective, or to be directive on what to say and how to feel (Matthews et al., 1993). To help "rewrite the script" at the point of care, general features of QI scripts should include: (a) establishing positive connection by showing concern and validating the patient/family experience and emotions; (b) transparency about the QI intervention (e.g., explaining what it is for, why it is important, who is involved in it, if it is temporary); and (c) encouraging questions and inviting patient action (e.g., asking for a wipe,) (S. Berg, 2017; Cleveland Clinic, n.d.; Grainger & Pointon, 2017; Institute for Healthcare Improvement, 2019, pp. 3–7; StuderGroup, n.d.).

In what follows, I provide two scripts that I began to develop during my fieldwork observing a range of interactions between patients and providers about hand hygiene.<sup>186</sup> The first is an

<sup>&</sup>lt;sup>185</sup> Model scripts can be similar to the case studies that combine context and theory in training health care professionals (Heale & Twycross, 2018; Sherwin, 1989, p. 60), improving QI processes (P Bate & Robert, 2007), expanding professionalism skills (Berkhof et al., 2011), and increasing relational, values-based communication (Goldman, 2018a; Lally et al., 2019).

<sup>&</sup>lt;sup>186</sup> The model script I developed here is based on the patient hand hygiene case study in my research. However, my recommendation applies to any quality and patient safety intervention that involves interactions with patients/ families. Other published scripting examples include: (1) falls prevention (Centers for Disease Control and Prevention, 2017); (2) Ask Me 3<sup>®</sup> educational program to promote health literacy (Institute for Healthcare

example of an interaction based on the functional aspect of the QI process (Box 9.3). The second example sets up a contrasting exemplary conversation that incorporates relational as well as functional aspects (Box 9.4).

Improvement, 2019, p. 5); and (3) CPSI's (2019) campaign to introduce compassionate "clean care conversations" between providers and between providers/patients.

# 9.3.2.1.1 Before: Functionally-focused example.

Box 9.3 describes an interaction focusing on the functional aspect of the new patient hand wipes process that represents what I typically observed on the study units. In this example, the relational connection between patient and care provider is weak, creating the potential for a relational mismatch.

#### **Interaction #1: Functional Approach**

*Care Provider:* Hello Mr. Smith. Lunch is coming soon. Can you please clean your hands with this hand wipe? [offers hand wipe to patient]

Patient: Oh...ok ... [accepts hand wipe and cleans hands]

Care Provider: It's important to stop infections.

#### Box 9.3 Interaction #1: Functional Approach

# 9.3.2.1.2 *After: Relationally-focused model script.*

In contrast, the model script in Box 9.4 illustrates the difference when a point of care interaction accompanying a new patient hand wipes QI intervention incorporates relational aspects that ought to be part of larger relational practice (Doane & Varcoe, 2013, 2015). This second interaction is aspirational: it represents my interpretation of what patient and family participants in my study expressed they needed or longed to experience (as described in Chapter 6). I acknowledge that additional time, relational intent and relational skill is required to do what Watson and Fu (2016) describe as "quickly connect with others to work collaboratively, creating emotionally honest, unscripted interactions" (p. 591). The interaction in this example suggests a positive relational connection, creating the potential for relational safety and trust between

patient, family member, provider, and the health care organization, and potential for higher

levels of commitment to a new care process.

# Interaction #2: Relational Approach (Model Script)

Care Provider: Hello Mr. and Mrs. Smith, my name is Chris. I'm your nurse again this afternoon.

Patient: Hi.

Care Provider: Lunch is coming soon. How're you feeling at the moment? [pause, listen]

Patient: I'm still tired, but feeling stronger. More like myself [smile].

Care Provider: And, it sounds like you're pleased you're improving? [pause, listen]

Patient: For the first time since my surgery, I'm actually looking forward to eating.

*Care Provider:* That's really encouraging! Just so you know, we're asking patients who can't get to the sink to please clean your hands with these hand wipes before eating [offers hand wipe to patient]. It's important for you to wipe your hands because everyone has germs on their hands. This month we're trying out hand wipes to cut down infections on the unit.

*Patient:* Oh, I doubt I could make it to the sink anyway. So, a hand wipe is nice [smiles]. I'll feel clean, more like at home ... thanks so much [accepts hand wipe and cleans hands].

*Care Provider:* I appreciate you letting me know that because we're interested to learn what you think about these wipes. Mr. Smith, during your hospital stay, since this is a new process for all of us, if your meal tray arrives and no one has offered you a wipe ... would you or your wife [gestures to Mrs. Singh] feel comfortable reminding us for a hand wipe, or taking a wipe from this canister [points] that I'll leave on your table?

Patient: Ok, I understand why hand hygiene is important and I can do that. Thanks Chris.

Patient's Family Member: [Nods and smiles]

Care Provider: Great. I'll be back with your meds after lunch.



## Box 9.4 Interaction #2: Relational Approach (Model Script)

*Adapted from* (S. Berg, 2017; Cleveland Clinic, n.d.; Grainger & Pointon, 2017; Institute for Healthcare Improvement, 2019, pp. 3–7; StuderGroup, n.d.)

**9.3.3** Meso level implementation: Processes to incorporate a relational approach into QI. I use "meso level" to describe how QI gets prioritized and operationalized at an organizational level. This meso level sets the tone for the way trust gets negotiated at the point of care between patients, families and providers within health care organizations. Flowing from my central recommendation that health care leaders ought to more fully appreciate the ethical implications of QI implementation, my meso level recommendations aim to help organizations more systematically integrate a relational ethical approach to further strengthen their QI policies, processes, and ultimately QI activities at the point of care. The recommendations that follow target those people undertaking the work of QI, primarily *health care leaders and quality leaders implementing QI activities*.

As noted in Chapters 6 and 8, my findings reinforced that despite following accepted QI processes, quality leaders and QI project team members whom I observed had aspirational views of their ability to effect change, and an incomplete picture of *how* others implemented and/or experienced QI interventions at the point of care. My findings also suggested that notwithstanding generally clear QI guidelines, important gaps remain in understanding how best to plan QI and assess its impacts in practice. Understanding the gaps between WAI, WAD, and WAE, as I described in Chapter 8, creates the potential to harness strengths of the QI philosophy that may not always come through when QI initiatives are implemented in clinical contexts.

#### 9.3.3.1 QI Project Charter: Integrating relational approaches to process change.

In Chapter 3, I introduced the QI project charter, a project management tool that quality leaders use to organize and communicate the bounds of a QI project (as an example, see Appendix A).

On the basis of my findings and analyses about what was of moral importance to patients and families, I began to view the process- and provider-focused characteristics of QI<sup>187</sup> that come through in project charter tools in new ways. Specifically, I came to see that project charters seemed to inadvertently overlook several of the relational aspects that were of such prominence in my patient/family-focused findings and analyses. I then consulted new literature for ideas to enhance the effectiveness of these project charter tools in ways that also support best practices in QI – such as including patient partners (representing patients and families who experience the work) and point of care staff (representing those who do the work) as early as possible in the planning, and tailoring new/changed processes for the local conditions of a particular health care context.<sup>188</sup>

Therefore, on the basis of my findings, I argue that integrating a relational ethical approach to QI requires novel interpretations of existing tools such as project charters.<sup>189</sup> For example, in the QI field, the measures chosen to describe new/changed care processes influence which aspects of the intervention are tracked and evaluated. Boulton et al. (2020) caution that, "Any interpretation of improvements either needs to be translated as 'evidence' or will be ignored" (p. 193). While

<sup>&</sup>lt;sup>187</sup> In Chapter 3, I described some of these process- and provider-focused characteristics of QI (Bar et al., 2018, p. 51; Cribb et al., 2019, p. 3; Entwistle & Watt, 2013, p. 29; Farmanova et al., 2016, p. 836; Harrigan, 2000; Ovretveit, 2014).

<sup>&</sup>lt;sup>188</sup> Power dynamics is a theme throughout my dissertation, a theme that also applies when engaging patients, families and staff on QI project teams. Relational safety, accountability, and partnerships are essential *beyond* the point of care to different levels of the organization, for groups, teams, and organizations working together towards health care system improvement (for example, Patient Engagement Action Team, 2017; Patient Voices Network, n.d.-b). For example, the importance of "psychological safety" (Hilton & Anderson, 2018, p. 23) a term used in organizational literature, is essential for QI team members.

<sup>&</sup>lt;sup>189</sup> Other literature documents a similar disconnect in that while patients are known to value the relational aspects of interactions with care providers, relational aspects are not always features of protocols for new initiatives (for example, see Harris et al.'s (2019) evaluation of intentional rounding).

not all QI initiatives involve process changes at the point of care, many initiatives do have implications for patients and families. Also on the basis of my research findings, in Box 9.5, I outline an additional set of considerations to raise the relational content of project charter tools. These considerations are of particular importance if part of the new/existing process(es) occurs at the point of care and involves interactions between patients/families and staff/providers.<sup>190</sup>

Although the relational approaches to QI implementation I have suggested above are as yet evolving strategies, they have potential to narrow the gaps between WAI, WAD, and WAE and thus to better inform future QI implementation and decision-making. On the basis of my research findings I have learned that if more purposeful attention to relational aspects of a QI intervention occurs from the outset of planning through to evaluation, then the QI process itself is more likely to happen when implemented in busy health care settings where staff are often running from task to task, monitoring and reinforcements stop, systems change, and/or the QI project champion leaves (Bate & Robert, 2007; J. A. Wolf, 2017).

<sup>&</sup>lt;sup>190</sup> After my dissertation is published, I plan to follow up with quality organizations such as IHI and BCPSQC to discuss my recommendations for consideration as they further develop their QI tools and programs.

# **Integrating Relational Approaches to Process Change**

My post-study reflections on QI project charter templates (and similar planning tools) led me to recommend the following six key considerations:



- (2) Distinguish between type of care process(es): functional (work done *to*); transactional (work done *for*); and relational (work done *about or with*) (Murrells et al., 2013);
- (3) Ensure relational process measures are incorporated in assessments of improvement (e.g., *Relational Aspects of Care Questionnaire* (RAC-Q) (Kelly et al., 2018)<sup>192,193</sup>);
- (4) Consider what relational processes for patients/families could reinforce staff/provider actions, and what parallel processes could give patients/families autonomous ways to interact with the QI activity;<sup>194</sup>
- (5) Conduct meaningful evaluations of patient/family experiences of QI interventions (*Work-as-Experienced*) that go beyond basic satisfaction measures (e.g., based on experience-based co-design (P Bate & Robert, 2007), and instruments such as the *Relational Aspects of Care Questionnaire* (RAC-Q) (Kelly et al., 2018)); and
- (6) Apply ethical screening to the initial project plan *and* the evaluation (e.g., the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2017a) (see Section 9.3.4.2).

## Box 9.5 Integrating Relational Approaches to Process Change

<sup>&</sup>lt;sup>191</sup> My study framing drew particular attention to the importance of understanding ways the various processes and interactions that make up a QI intervention may be neutral, bolster or erode patients' sense of relational safety in the context of their larger health care journey. Moreover, at times, some significant benefits, harms and burdens of the QI intervention borne by patients/families that I observed as part of my study data went unnoticed by the organization. Similar findings have been noted by others, for example (Reynolds et al., 2014; Sokol-Hessner et al., 2018).

<sup>&</sup>lt;sup>192</sup> As described in Chapter 8, a relational perspective is not typically captured in evaluations of patient/family experience of health care generally (as noted by, among others, Bate & Robert, 2007; The Health Foundation, 2013c). Furthermore, despite some progress, patient/family care experience itself is not systematically captured (OECD, 2019, pp. 42–43).

<sup>&</sup>lt;sup>193</sup> Kelly et al. (2018) developed the RAC-Q in response to recommendations coming out of the Staffordshire Hospital Scandal (Francis, 2013; National Advisory Group on the Safety of Patients in England, 2013) which recognized that inattention to the relational aspect of care resulted in significant harm. The RAC-Q built on older surveys that include questions on all three aspects of care, such as the *Patient Evaluation of Emotional Care during Hospitalisation* (PEECH) survey (Murrells et al., 2013).

<sup>&</sup>lt;sup>194</sup> In my study, one of my patient partners commented, "What is needed is changing two habits within a supportive environment. The patient asks, 'where are the hand wipes today?' and the provider gets in the habit of offering."

**9.3.4 Macro level implementation: Societal ideologies and values shape power and voice.** I use "macro level" to describe the social forces such as ideologies, values, and social norms (Bronfenbrenner, 1993) that inform national and international trends such as how health care systems are funded and organized (Carman et al., 2013) and thus shape the complex ethics and quality landscapes in which patients and families receive health care. In applying my central recommendation that health care leaders ought to more fully appreciate the ethical implications of QI implementation at the macro-system level, I point to some practical recommendations to strengthen relational capacity and relationships in health care systems. Kouzes and Posner (2017) describe exemplary leaders as those who clarify and affirm shared values, and then align actions with these values. My study has significant insights for health care leaders, and the recommendations that follow target *senior leaders in health care organizations, policy-makers, and academic communities*.

# 9.3.4.1 The moral climate: Strengthen relational capacity in health care systems.

My research echoes the work of others, such as the Francis Report (2013), the US National Patient Safety Foundation (2015), and Hilton and Anderson (2018) in emphasizing the need for long-term, system-wide policies and strategies to strengthen relational capacity throughout health care. A relational ethical approach reinforces the importance of considering QI from perspectives of all stakeholders, as well as adopting "a sense of efficacy—the belief that changes are feasible and would improve matters" (Hendricks et al., 2019, p. 14). In what follows, I first offer reflections about two health care system philosophies that, as I acknowledged in Chapter 2, play prominent roles in shaping system policies and priorities at the macro level: the patient-centred care philosophy; and the IHI *Triple Aim* of health care system improvement. Along with

relationship/communication skills, I consider these areas particularly relevant to the way reconsidering relationships can further the ethics and efficacy of QI processes and better balance the goals of all health care stakeholders: current/future patients and families, communities, care providers/staff, health care organizations, funding agencies, and the public or common good.

#### 9.3.4.1.1 Patient-focused and relationship-focused philosophies.

In Chapter 2, I introduced literature supporting a moral mandate for patient-centred care. At the beginning of this study, I explored and accepted patient-centred care as a valid, aspirational concept and a key aim of high quality health care as outlined by the Institute of Medicine (2001). An important insight of my analyses led me to relevant literature advocating that health care system improvement, as a field, could benefit from an explicit focus on the significance of relationships (Beach et al., 2006; Chou, 2018; Safran et al., 2006). For example, Chou (2018) states that the *relationship-centered care* (RCC) philosophy offers benefits over traditional views because it "focuses on the space between patient and clinician, not exclusively on one person or the other" (p. 5). Specifically, QI activities at the point of care include the care process itself (e.g., nurse offers hand wipe to patient) and also the relational interactions within which these care processes occur (e.g., what an offer of a hand wipe means to the people involved). On the basis of my findings, I believe that accrediting bodies such as Accreditation Canada's (n.d.) Qmentum program could assess health care organizations on their ability to uphold features of relationship-centred care.

#### 9.3.4.1.2 The Triple and Quadruple Aims of health care system improvement.

In Chapter 2, I also acknowledged the prominence of the IHI *Triple Aim* of health care system improvement (Berwick et al., 2008).<sup>195</sup> As noted in Chapter 8, the context of QI at the point of care situates both providers/staff and patients/families in complex and changing environments. My findings suggest that to enhance QI through strengthening relational safety, it is important to consider the *needs and experiences of care providers/staff* along with patients/families. Relevant literature led me to link patient–provider and family–provider relationships to a larger conceptualization of health care system improvement. In particular, in 2014 Bodenheimer and Sinsky proposed the *Quadruple Aim*, arguing that improving the experience and work life of clinicians and staff is an essential fourth aim to health care system improvement (see also Dhalla & Tepper, 2018; Havens et al., 2018; J. K. Johnson & Sollecito, 2018a; Mery et al., 2017; Rathert et al., 2018; Sikka et al., 2015). In acknowledging the role of health care staff along with that of patients/families, the *Quadruple Aim* is consistent with what I view to be a relationship-focused philosophy.

#### 9.3.4.1.3 Strengthen relationship and communication skills for all stakeholders.

Along with shifts in the larger system perspectives that I outlined above, my analyses signposted the significance of "missing conversations" in QI interventions at the point of care (e.g., as outlined in Section 9.3.2.1). On the basis of my findings, I propose that addressing these missing conversations has particular relevance to improving patient/family experiences and the efficacy/sustainability of QI initiatives. A wide body of literature advocates strengthening

<sup>&</sup>lt;sup>195</sup> The three aims of the *Triple Aim* are individual patient experience, population health outcomes, and reduced cost.

relationship and communication skills for leaders, staff/providers, and patients/families/citizens with emphasis on the following concepts: collaboration, shared decision making, cultural sensitivity, language literacy, health literacy, effective listening, respect in personal interactions, compassion and empathy, and how to participate in focus groups and family meetings (Bernabeo & Holmboe, 2013; Boissy & Gilligan, 2016; Browning et al., 2007; Chou, 2018; National Patient Safety Foundation, 2015). Chou (2018) suggests that people in general overestimate their effectiveness as communicators. Yet, experts acknowledge that people can learn relational skills, but these skills must be practiced (for example, see Boissy & Gilligan, 2016; Canadian Interprofessional Health Collaborative, 2010; Chou, 2018; Coutre, 2016; Goldman, 2018a; Gordon et al., 2013; Kulhan, 2013; Reynolds et al., 2014; K. Watson & Fu, 2016).

My *Relational Safety Framework* reinforces that *every* health care interaction is potentially a "conversation that matters" because interaction is linked to a patient's and family's sense of relational connection, relational safety and trust as well as their values and preferences. Furthermore, the insights from my study suggest that we need to consider the kinds of approaches that explicitly acknowledge contextual power differences when designing, implementing and evaluating QI interventions that involve patients, families and care providers at the point of care. As I was writing this dissertation, I became aware of several strategies in BC that demonstrate what I came to think of as a moral climate of accountability and relational safety. These examples include: (1) BC Patient Safety & Quality Council's (2018) "What matters

to you?" campaign;<sup>196</sup> (2) WorkSafeBC's (2018a, 2018b) campaign promoting conversations between young workers and experienced workers to prevent workplace injuries;<sup>197</sup> (3) Kuhl et al.'s (2017) model of a relationship-centred approach to organ donation; and (4) Towle and Godolphin's "Talking With Your Doctor" community workshops and booklets (UBC Health, Patient and Community Partnership for Education, n.d.).

#### 9.3.4.2 Incorporate relational aspects into ethical frameworks for QI.

Given the experienced-based questions driving my study, I was particularly interested in how my key learnings resonated with the ethical frameworks promoted for non-research activities I described in Section 3.4.3. Specifically, these frameworks include: the commonly used project ethics approach (*A pRoject Ethics Community Consensus Initiative* (ARECCI) (Alberta Innovates, 2017a, 2017b); and the newer learning health care system approach (*Ethics Framework for a Learning Health Care System* (Faden et al., 2013). McDonald (2001) states, "From an ethical perspective, good governance involves the translation of collective moral intentions into effective and accountable institutional actions" (p. 1). While it is beyond the scope of my dissertation to outline recommendations for ethical oversight (a term that implies overseers, processes and mechanisms) of QI activities, my analyses do have implications for the role of ethical frameworks outside the highly regulated research ethics system I described in Chapter 2 (Section 2.2.3.2), as well as implications for how researchers and REB members

<sup>&</sup>lt;sup>196</sup> Also see Barry and Edgman-Levitan's (2012) paper about the "conversations that matter" concept that prompts care providers and patients/families to think and talk about their values in the context of shared decision making.
<sup>197</sup> The WorkSafeBC "listen to your gut" stream targets young workers and acknowledges that speaking up about feeling that something may not be safe is intimidating. The complementary stream, "what I know now" targets experienced workers, encouraging them to initiate conversations about workplace safety with young workers.

interpret research ethics guidelines. However, I caution that replicating the limitations of current systems of research ethics should be avoided.<sup>198</sup>

As a result of my learning over the course of my study and in the context of relevant literature, I propose that leaders in organizations undertaking QI initiatives take four actions related to existing ethical frameworks to increase and enhance ethical conduct of QI. First, organizations should require (rather than suggest) ethical policies and processes such as the project ethics approach (see, for example Rolnick et al., 2017)<sup>199</sup> or a broader learning health care system approach (see, for example Klingler et al., 2020)<sup>200</sup> during the QI planning phase. Second, during continuous cycles or as QI projects near completion, part of the project evaluation ought also to include a post-implementation ethical assessment. In other words, the QI team should reapply the same ethical framework they applied at the beginning of their project, reflect on their original assessment, and identify learnings about ethical strengths and tensions during QI implementation that may have been unappreciated or underappreciated at the outset.

Third, on the basis of my research, I have learned that an underappreciated point is that QI activities ought to be able to respond to patients' and families' expressed need for connection and safety, needs which I articulated in my *Relational Safety Framework*. Overall, such a

<sup>&</sup>lt;sup>198</sup> Examples of limitations in current research ethics processes (as I outlined in Section 3.4.1) include slow and sometimes inconsistent reviews, a focus on procedures, and ex ante perceptions of ethical impacts on participants without considering the context of their lives or the impacts they actually experience.

<sup>&</sup>lt;sup>199</sup> The *ARECCI* tools are one of the ethical approaches BC health care organizations use for QI projects. For example, Northern Health's improvement charter template includes a space for an *ARECCI* score as part of the design phase (BC Patient Safety & Quality Council, 2019, p. 6).

<sup>&</sup>lt;sup>200</sup> Klingler et al. (2020) describe existing ethics review mechanisms in the World Health Organization, the US Centers for Disease Control, and Public Health Ontario.

relational ethical approach to QI offers potential not only to identify, minimize and mitigate risks, but also to increase benefits of a QI intervention across stakeholder groups. Fourth and finally, as part of a broader ethical QI learning process, quality leaders ought to provide feedback to researchers and decision-makers about their experiences with ethical frameworks for QI to enhance the context validity of these frameworks. In this way, reconciling ethical assessments of QI activities is one way to balance patient/family experiences and preferences with legitimate clinical and health care system goals, and to empower patients and families by signaling that learning is taking place and health care organizations are in fact listening to them. As a way of modelling this practice, I reflected on my own experience applying the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2010) to the patient hand wipes project in this study.<sup>201</sup> In so doing, I applied my post-study reflections of the ARECCI tools in three areas: (1) risks and burdens; distress, discomfort or anxiety; (2) sensitive issues; and (3) being informed and expressing consent (see Appendix N for a detailed account of these recommendations).

#### 9.3.4.3 Incorporate relational aspects into QI publication guidelines.

Given the applied practice orientation of my study, I was also interested in how my key learnings resonated with the SQUIRE publication guidelines for QI initiatives (Ogrinc et al., 2016) (introduced in Section 3.2.1). The SQUIRE guidelines shape ethical conduct of QI because they reflect how people in different health care systems conceptualize QI efforts at the macro level, and how organizations operationalize and externally report QI outcomes. As a result of my

<sup>&</sup>lt;sup>201</sup> See Section 5.5.6.2.1 for a description of the *ARECCI Ethical Screening Tool* and my initial ARECCI screening results to identify areas of "ethical risk" for the patient hand wipes QI projects. See also Appendix C.

learning over the course of my study and on the basis that patients and families are key stakeholders in health care improvement efforts, I propose that QI publication guidelines have untapped potential to prompt those who plan improvement activities to conceptualize and report QI's impacts more broadly. To this end, my suggestions to enhance the current SQUIRE guidelines have particular relevance for the following items: *ethical considerations* (Item 12), *results* (Item 13), and *interpretation* (Item 15) (Ogrinc et al., 2016, p. 678). For example, in describing examples of potential harms from QI as "opportunity costs, invasion of privacy, and staff distress resulting from disclosure of poor performance" (Revised Standards for Quality Improvement Reporting Excellence, n.d.; Baily et al., 2006), SQUIRE may unintentionally reinforce the mistaken perception that a narrow range of ethical impacts of QI is limited to staff, processes, and organizations. Additionally, given my findings that patients and families had diverse experiences of pilot QI interventions, the role of patients and families *in* QI and the diverse impacts of QI *on* patients/families at the point of care (WAE) must be made more explicit in ethically-oriented QI research and evaluation reports.

#### 9.3.5 Summary of recommendations.

The problem my research set out to address revolved around disconnects between research and QI, and between QI efforts and patient/family experiences of the health care system. In my analyses above, I offered a relational ethical approach to QI implementation as a new way to think about expected features of health care improvement. I also offered practical strategies to enhance QI implementation at the point of care (see summary table in Appendix O). It is my hope that my recommendations will enrich discussions about the need to strengthen ethics (broadly) and relational safety (specifically) in QI by integrating ethical considerations into:

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existing and new operational review processes for QI; existing and new ethics frameworks and processes for QI; and, most importantly, appreciating the ethical implications of QI implementation in the context of the larger health care system. When health care leaders have richer understandings of QI's unique ethical concerns and opportunities, this knowledge could generate discussions of how particular QI activities' ethical impacts (including benefits, harms and burdens) are likely to be distributed among stakeholders. Equally important is to understand afterward how these ethical impacts actually were distributed among stakeholders. In my envisioned future, strengthening relational safety in patient/family–provider interactions at the point of care can become an important indicator for ethical implementation of QI interventions and can build on the evolving strengths of the field of QI.

#### 9.4 Study Strengths and Limitations

In what follows, I describe aspects of my theoretical/methodological approaches and findings as a combination of strengths and limitations, and interpret their impact in my study.

**Researcher background.** Strengths of this study include my health care background in dietetics, administration and research ethics that, combined with the diverse professional backgrounds of my supervisory committee (health services research, medicine, nursing, ethics, and philosophy), provided new motivations and avenues to explore the patient and family experience of QI. In attending to patient and family experience as the main entry point, through my research I widened my gaze beyond the quality and safety literature and questioned assumptions, including those that I brought into the study. Attending to reflexivity throughout this study was critical, as I explained in Chapter 5.

**Research relationships at multiple levels of the organization.** As an unaffiliated researcher, studying an embedded pilot QI intervention required me to cultivate trust between my health care partner, my patient partners, and study participants. The research relationships I developed gave me views into power and interactions related to the QI intervention at multiple levels of the organization. These views enabled me to understand the context and complexity of patient/family experience in ways I would not otherwise have had access to.

**Theoretical and methodological approaches.** Interpretive description methodology (Thorne, 2016) is a strong approach to accessing and understanding distinctions and interrelationships amongst relational and ecological levels of activity (Bronfenbrenner, 1993; Doane & Varcoe, 2015). This a priori methodological and theoretical framing did not prescribe how I constructed my data, but it did shape how I interacted with participants and interpreted diverse behaviours and interactions I observed. One distinctive feature of my framing is that it allowed me to see and understand QI in a new way. Using this framing to explore relationships in the context of a QI intervention allowed me to elaborate on the work of Bergum (2013; 2005), May (2007) and others who have described interactions between patients, families and care providers, and to construct a Relational Safety Framework. It is my hope that my Relational Safety Framework will be a unique and beneficial addition to the way we look at QI and patient care more generally. Triangulating methods of data collection and perspective increases the likelihood that my findings will be reflective of a broader context (Thorne 2014 p. 108). At the same time, I acknowledge that my interpretation is not the only way to view the phenomenon I have explored (Thorne, 2016).

**Patient partners.** My strategy to purposefully recruit volunteer patient partners via the BC Patient Voices Network<sup>202</sup> resulted in an ongoing and rich collaboration with two partners who enhanced my ability to understand patient and family experience through a 'patient/family interpretive lens'. Engaging with patient partners meant that while as individuals they were differently situated from many patients and families in my study sample, they contributed valued patient-focused expertise and insight. My two patient partners were active advocates in health care and other communities, experiences that would have familiarized them with health care structures and processes (Renedo et al., 2015) and in turn enabled and empowered (Ocloo & Matthews, 2016) them to offer wide-ranging input into my study. At the same time, some of my patient partners' characteristics reinforced what is well documented in the literature (for example, see Coulter, 2016; McGavin & Holmes, 2014; Shimmin et al., 2017), that currently the typical patient partner is affluent, with high educational levels, and represents mainstream groups culturally and linguistically. Some of my findings from patients and families with diverse lived experiences underscored how important it is to try to expand the range of people participating in supporting research activities, so we can better understand impacts of QI initiatives on all patients and families.<sup>203</sup> For example, efforts are ongoing in Canada to remove barriers to patient participation and to recruit individuals from under-represented populations (Bar et al., 2018; Patient Engagement Action Team, 2017, p. 33). Ongoing political support and resources should

<sup>&</sup>lt;sup>202</sup> PVN (described in Chapter 2) receives support from the BC government.

<sup>&</sup>lt;sup>203</sup> People who experience social exclusion are less likely to have the resources (broadly defined) to participate in health care system planning or even in their own or their family members' care. For example, the UBC Learning Exchange located in Vancouver's downtown eastside neighbourhood (DTES) offers programs and a safe drop-in environment where DTES residents can expand their digital literacy, English language skills, personal development and social networks (Ono, 2017). This is an example of a strategy that might bring less privileged patients and family members into empowered roles along the continuum of patient/family engagement.

continue the growing normalization of involving patients, families and the public in health care planning (Canfield, 2018).

Patient care units studied. I followed one hospital's journey of implementing a particular patient hand hygiene intervention, and thus I did not select the clinical units on which I observed. This plan meant that my sampling was, to a significant extent, predetermined. As described in this dissertation, my two study units had important similarities and important differences. Similarities between study units were adult patient populations with long term conditions and stable staffing. This meant that many patients and family members had ongoing relationships with the unit and the unit staff, which was helpful to control the scope of this unfunded study. I found this context to be a strong methodological choice because it provided a contrast in care interactions between patients, family members, staff, and volunteers who were less familiar with one another and unit routines. If, instead, I had studied more diverse units (for example, a chronic disease unit and a post-surgical unit), my ability to gain a deep understanding of these relational dynamics could have been more difficult. Nonetheless, some aspects of the experiences of patients and families with chronic conditions whom I studied likely differ from those in other settings.

Access to study participants at the point of care. My methodological design was built on a foundation of prolonged fieldwork as a participant observer and access to participants (patients, family members, staff in administrative roles, and care providers/volunteers) on two busy clinical units. During fieldwork, I learned that gaining and retaining access required relational skills to obtain data, whilst simultaneously negotiating the ethical and professional boundaries of a

participant observer. My observations enabled me to understand aspects of the QI case studies through a 'patient/family lens', as well through an 'organizational lens', and also generated a possible source of bias that needs consideration. For example, most often, I interacted with participants who asked to be in my study or were suggested to me by unit staff. Therefore, my participant sample may present a different picture than a randomly selected sample. In addition, participants may have assumed I was hospital staff, which may have given me credibility but could also have shaped participant responses. Finally, as an external observer, I do not fully know what aspects of the context, experience, and history are relevant to another's experience.

Scheduling fieldwork. Prolonged participant observation as method of collecting data is an investment of time and emotion (Gill et al., 2014; Kleinman & Copp, 1993). Strengths of my research included flexibility to schedule my presence on the units according to patient/family and staff availability, and to avoid becoming bothersome on the units. Studying the real-time implementation of a QI intervention introduced additional challenges, such as uncertainty of plans and timing regarding project activities, and maintaining a consistent enough presence to develop some relationships and to employ theoretical sampling to generate and challenge my data. For example, since at times I was unable to be in the field as much or exactly when I would have liked, I was not always able to follow up with individuals (such as when patients were discharged or died, and when staff worked different shifts). I learned to embrace this uncertainty and remain focused on my goal to be open and to listen deeply, thereby enriching the depth and diversity of my data.

**Boundaries of data collection.** Using the primary and a secondary informed consent process described in Section 5.5.6.3 meant I did not obtain written or verbal consent for many study observations. In other words, unless an individual specifically declined to participate,<sup>204</sup> their data was included in my study (Canadian Institutes of Health Research et al., 2018). Without explicit consent, at times I was unsure what data was appropriate to include in my study. One example of my uncertainty involved a subgroup of the patients and family members who declined to participate in shadowing or an interview. In three instances, after formally declining, the patient/family member proceeded to share many details about their experiences – in fact, I found it difficult to extract myself from the conversations. As a researcher, I was aware of a conflict of interest because I wanted to include all of the data I deemed relevant in my analysis. However, even though I had rich conversations with such individuals I excluded their data from my analysis if they declined to provide informed consent.

**One researcher conducting a small study.** As a solo researcher, I was the interpretive instrument. Working with my research team (supervisory committee, patient partners, research sponsor), this study was limited to a small sample of study participants, one primary case study (a QI intervention implemented as two pilot projects), and one health authority. Although the idea of involving patient partners in health care improvement is common in BC and beyond, my study focused on one acute care hospital that strives to pay attention to the patient/family perspective. A larger funded study with multiple team members could influence the breadth of

<sup>&</sup>lt;sup>204</sup> Stated reasons patients/families declined to participate in my study were: did not feel well enough, do not like to sign papers, too overwhelmed with own or family member's condition.

discussion topics and provide deeper opportunities for data collection and analysis. However, gaining entry and building trust with staff, patients, and families would likely have been more difficult with multiple team members.

**Portrait of patient/family experience of a specific time and place.** My findings presenting a portrait of patient and family experiences of QI at the point of care show that these experiences are rife with complexity. As noted above, my data collection period encompassed two QI project teams planning and implementing a similar intervention in pre-determined sites and at predetermined times. I followed a significant piece of the journey of a QI intervention that reflects the specific time period and location of my data collection. I found that selecting more than one case study with related topics (i.e., two different patient hand hygiene interventions) was a strong methodological choice because study participants and I were able to create a fuller picture of patient/family experience in context. Participant experience of a new QI intervention (*patient* hand wipes, Case Study A) built on baseline knowledge of previous interventions (hand hygiene signage and posters, Case Study B). If instead I had selected QI case studies tackling two different patient safety priorities (for example, one hand hygiene intervention and one falls prevention intervention) I might not have gathered data to such depth, particularly in terms of the context of project implementation. That said, however, at the end of my data collection I was interviewing patients and families rather than shadowing staff and volunteers. Because my study focused on patient and family experiences, I collected minimal data on why frontline staff stopped 'doing' the *patient hand wipes* intervention after the pilot period. As Thorne (2016) emphasizes, data in qualitative work is not a finite set and I acknowledge that there is more to learn in future studies.

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Finally, as I was closing my dissertation, the World Health Organization (2020b) declared the novel coronavirus (Covid-19) outbreak a pandemic.<sup>205</sup> Had my data collection occurred during the Covid-19 pandemic period, it is likely that my study sample would have reflected higher levels of hand hygiene awareness, preferences, knowledge and behaviours amongst patients, families and staff, as well as a broader range of infection control practices and policies in the Study Hospital and across society more generally. The 'ordinary' sociopolitical context in which my study sample was created – especially in contrast to an 'extraordinary' pandemic context – serves to emphasize the tenet espoused by Thorne (2014, 2016) that my findings and interpretations (as a proxy for qualitative research more generally) were shaped by the context in which the data collection and analysis occurred. Furthermore, my interpretations and conclusions have immediate relevance for practice (in terms of recommendations outlined above) and set the stage for future inquiry (as I elaborate on below).

### 9.5 Areas for Future Inquiry

One of my motivations to use interpretive description for this study was that this methodology situated me to be able to join an interdisciplinary conversation with published literature in three areas: health care ethics; health care quality and safety; and patient and family experience. In joining this conversation, I contribute an analysis intended to improve the ethics and efficacy of QI, and articulate new questions and approaches. The *Relational Safety Framework* I propose

<sup>&</sup>lt;sup>205</sup> The World Health Organization (2020b) uses the term *pandemic* to characterize an outbreak of a new disease for which people do not have immunity that spreads worldwide beyond expectations.

provides a conceptual starting point for further deliberations and empirical work. I close this dissertation by pointing the way for future inquiry.

## 9.5.1 Conceptual analyses.

**Relationship between relational safety and trust.** My findings focused on the value of positive relational connections for patients and family members with providers and places of care; specifically, in the context of QI initiatives where possible relational mismatches may result from traditional functional/transactional approaches to design. I interpreted these findings as indicating patients' and families' need to have a sense of relational safety in health care settings, and I subsequently generated a *Relational Safety Framework* linking relational interactions, connections, safety, and trust. Future studies could explore how further relational (self, others, context) explorations of relationships between these concepts may shape understandings of ethical concepts such as relational autonomy and executive autonomy.

Relational safety and ethical mechanisms for QI activities. My findings highlighted that applying a relational safety lens to QI revealed complex ethical strengths and tensions, suggesting that further research is needed to identify and evaluate the effectiveness of approaches to appreciate the ethical implications of QI implementation of diverse initiatives in diverse practice contexts. Currently, few quality/safety initiatives conducted in BC and elsewhere routinely undergo any sort of ethical review process. In public health, where ethics review for QI may be more commonly applied, Klingler et al. (2020) note: "effects of ethics review mechanisms on service provision have so far not been studied. Public health organizations should consider implementing evaluations to allow learning about and

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improvement of existing mechanisms" (p. E21). To Klingler et al.'s recommendation, I add that the value of relational safety could offer a complementary measure that health care systems would be able to use to evaluate QI, and thereby generate a distinct contribution to advance high quality health care.

**Relationships between relational, patient, and cultural safety.** During my analysis, I found interesting similarities and differences between relational safety and related constructs such as patient safety and cultural safety. For example, Indigenous literature on cultural safety (First Nations Health Authority, n.d.-e, n.d.-b, n.d.-c) is highly linked to relationality and a holistic world view. Future inquiries may explore how relational constructs fit together in diverse people's lives and communities, and how considering these constructs together might help understand and optimize patient and family experiences of QI and health care more generally.

**Relational safety and physiological safety.** While it is beyond the scope of this dissertation to explore the physiological dimension of safety, future inquiry might study how trauma-informed approaches (e.g., Geller & Porges, 2014; Parnas & Isobel, 2019; Young et al., 2019) based on neurological advances such as Stephen Porges' polyvagal theory and neuroception (2009) might complement Crotty's (1998) "intent of mental phenomena" (perception) to further explain the implications of relational safety in health care interactions and quality of care. For example, future studies could explore patients'/families' capacity to participate in QI interventions according to physiological indicators of relational safety and relational danger.

Ethical impact of QI interventions on patient/families and the precautionary principle. While uncertainty should *not* be a reason not to pursue improvements in the quality of health care (one interpretation of Daniel Steel's (2015) precautionary principle), my fieldwork and discussion raise questions that challenge the typical level of non-inquiry about the ethical impact of QI interventions on patient/families. When proceeding with QI interventions, I have argued that knowledge about how patients/families experience and articulate benefits, harms and burdens should be balanced with other health care system aims such as effectiveness and costeffectiveness. Future research could examine how the precautionary principle applies to health care improvement decision-making in diverse contexts (e.g., QI interventions to improve the hand hygiene of unstably housed patients in hospital emergency departments).

**Relational safety beyond QI context.** Given the prevalence of chronic illness, and the value that patients and families in my study placed on positive relational connections with their care providers and places of care, future research should explore the *Relational Safety Framework* generated in this study beyond the QI context to include (1) people with diverse chronic illnesses (for example, cancer, HIV, mental health), and (2) health care more generally.

## 9.5.2 Empirical analyses.

Link patient/family behaviour and experience. In this study, I gathered some interesting data about patient and family reactions, attitudes, perceptions and behaviours about QI interventions at the point of care. The study themes (valuing positive relational connections, personal hygiene as an important aspect of identity, a desire to be a good patient, and the shared nature of hygiene) reflected these data. An overarching argument of this dissertation is that ethically-oriented

research and evaluation are critical components to assess the impact of QI initiatives on patients' and families' lives. To continue to raise the profile of patient and family perspectives and the credibility of patient/family knowledge in QI, future research could operationalize an axiological (values-based) focus on patient/family subjective experiences and behavioural changes in response to QI interventions. This could include, for example, patient journey mapping and longer-term studies.

**Change fatigue and relational mismatch.** My study's focus on the experiences of patients and their families meant that the perspectives of other moral agents/actors, including care providers, were not fully explored in the dissertation. My data, together with literature about change fatigue (Baxley et al., 2011; Halm & Siu, 2005; The Health Foundation, 2011b) raise important questions about how the context of continuous QI within ongoing resource constraints shapes staff/provider attitudes and behaviour. Further research could explore how relational interactions, relational connections, and relational mismatches between care providers and patients/families in the context of QI interventions (e.g., designed to be flexible and run as short-term pilot projects) are similar to and different from (1) less transient types of innovations (e.g., new clinical practice guidelines and protocols), and (2) routine medical care.

**Cost/value analysis of relational ethical approaches to QI.** Given the emphasis on achieving short-term efficiencies in the health care system, I propose that relational safety is a new, values-added strategy to complement existing concepts about health care system improvement. For example, Semel et al. (2010) characterized the value of the surgical checklist innovation in terms of saving costs and improving quality. Future research could examine the tensions between

short-term and long-term costs and benefits of incorporating relational safety into QI implementation.

**How organizations prioritize relational safety.** In my analysis, patients and families described connecting with and disconnecting from health care organizations (or specific care units within organizations) based on qualities they perceived the organization to emanate. On the premise that organizations have moral agency, future axiological research may explore the differences in how health care organizations prioritize strategies to improve the quality of care if they consider relational safety as one strategy to advance QI, as well as building on Rodney, Buckley et al.'s (2013) among others' work studying the moral climate of the workplace.

#### 9.5.3 Methodological approaches and research team.

#### Honouring different world views.

Over the course of my study, this new conceptualization of QI as an ethical, relational endeavour drew me to consider alternative perspectives where connectedness and relatedness are foundational.<sup>206</sup> As Sherwin (2011a) states, we need "new methods and frameworks that will allow us to contribute effectively to badly needed societal conversations about the big picture" (p. 80). Approaching QI with insight from relational and holistic perspectives may promote connective and collaborative approaches to address some of the challenges inherent in complex

<sup>&</sup>lt;sup>206</sup> One example of a highly relational perspective is the Indigenous world view; a holistic philosophy whereby the interrelated human, natural, and spiritual realms seek harmony and balance (First Nations Health Authority, n.d.-d; Hogan et al., 2014; S. Wilson, 2008; Younging, 2018). Future inquiries to tackle the complexities of patient and family experience and health care system improvement could also benefit from honoring and integrating different world views into relational ethics, for example building on the work of Indigenous scholars Willie Ermine (2007), Jesse Thistle (2017) and Shawn Wilson (2008).

adaptive systems, such as reducing harm caused by health care-associated infections. Within complexity and diversity, I came to see the potential of viewing the relational spaces in health care as produced by sometimes contrasting world views.

**Research team.** Given the emphasis on interpretation and reflexivity in this study, it would be worthwhile for another group of researchers to pursue an axiological inquiry about patient and family experiences of QI interventions. Conducting this research heightened my sensitivity to the power and privilege of my research team (myself, my doctoral committee, research sponsor, and patient partners). We were all white, educated, and highly connected with the health care and education systems, both of which are powerful social institutions. Future inquiry with research team members and patient partners including, for example, people from different disciplinary and ethnocultural backgrounds, and methodology such as community-based participatory action research<sup>207</sup> might distribute power more evenly between research team, study participants, and social institutions. In turn, such research may uncover different enablers and barriers to sustaining QI interventions in health care systems in ways that patients and families value.

## 9.5.4 Methods and study samples.

**Diverse foci.** As I conducted this study on two specialized hospital units, future research might focus on patient/family experiences of QI interventions in different clinical settings such as: (1) general medicine/surgery units (with a more diverse composition of patients and staff); (2)

<sup>&</sup>lt;sup>207</sup> In Given (2008), community-based research methodologies (inclusive of action and participatory aspects, for the purpose of explanation here) are "a form of collective action that a community undertakes as key to its survival, its empowerment, or its continued effectiveness in encouraging social and political change" (p. 97).

emergency departments (because many participants in my study described specific hygiene concerns given the range of people attending with different socioeconomic circumstances together with immunocompromised patients in a small area); (3) longitudinal primary care; and (4) longitudinal home care. In addition, there were indications in my study data that some patient participants who are homeless and marginalized by society in other ways had deeply rooted mistrust of care providers and hospitals (as also described by others such as Bauer, Baggett, Stern, O'Connell, & Shtasel, 2013). For example, future research might further explore constructs of being clean and feeling valued in the context of initiatives to control infection in health care organizations.

**Non-English speaking participants.** As I excluded non-English speaking participants in this study, future research might include more ethnocultural and linguistic diversity in terms of patient and family experience of QI. Different aspects of family, culture, and exposure to health care services in other jurisdictions could play an important role in how patients and families experience QI interventions when they are asked to take on a new role and/or interact with care providers in new ways (for example, see Berkowitz, Phillip, Berry, & Yen, 2018 who write about the need to understand cultural behaviors and interactional styles).

**QI topic.** The QI case studies in this research focused on patient hand hygiene, a relatively noncontroversial topic with widespread agreement as to benefit (OECD, 2018b; World Health Organization (WHO), 2009d). Future research, including ethical analyses, might explore patient/family experience of QI interventions involving topics that have more diverse ethical and medico-legal implications. For example, topics that arose in the context of my study data included boundaries in patient–provider relationships, discharge planning, and medical assistance in dying. Topics could also include highly stigmatized conditions such as psychiatric genetics (Lázaro-Muñoz et al., 2019) and, as Dixon (2017) suggests, end-of-life care, do-not-resuscitate decisions, conformance with advance directives, patient understanding of information given as part of the consent process, health care-related decision-making for patients who lack mental capacity, and care of women who experience a miscarriage or stillbirth (p. 13). All of these areas bring diverse and complex challenges to QI.

## 9.6 Conclusion

I embarked on this interpretive description study because I was aware that engaging patients and families in QI has been the subject of considerable discussion, yet there has been little empirical research on experiences of QI at the point of care. Indeed, my reviews of related literature indicate that ethical judgements about QI tend to be truncated and based on a presumption that QI endeavours are, from an ethical perspective, generally laudable and unproblematic. My research explored what it was like for patients and families when their hospital piloted a care process that gave them a new opportunity to improve the quality and safety of their *own care*. I also explored how significant ethical implications of my empirical findings could be translated into practice. In my study I argued that context in relation to patient/family experience, implementation of quality/safety initiatives, and ethics – in particular the power imbalance borne by patients and families – supported, and indeed require, a value-based framing I refer to as a relational ecological perspective.

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The conclusions drawn in this study are "a product of study findings interpreted in the context of available literature" (Thorne, 2016, p. 225) and are intended to build on current and evolving scholarship and insights in the field of QI overall. In my study, I articulated ways in which the hand hygiene intervention of focus was more complex than originally envisioned by the health care organization. I learned that the new QI intervention created uncertainty for staff and patients/families, and that the way the new care process (whether labelled as QI or not) transpired at the point of care shaped patient/family experiences. There was a disconnect between the way quality leaders imagined the QI intervention was being implemented and how I observed it happening at the point of care. Notably, I observed that after the pilot period, the care process itself dropped off in the absence of consistent monitoring and reinforcement. I also observed a disconnect (what I term a relational mismatch) between the way staff imagined the QI intervention to impact patients and how some patients and families described their experiences. Given the diverse responses in my study, it is my conclusion that QI interventions at the point of care ought not to be automatically presumed to be beneficial extensions of medical care. As my research has shown, QI processes and the small social exchanges between patients and providers that accompany these QI processes can have high relational significance for patients and families and cannot be assumed to always be benign or beneficial.

For patients and families, values such as trust – with their health care providers, with other patients/families, with health care organizations and with institutions in general – came up repeatedly in my research. Patients and families sought a sense of relational safety (feeling safe and valued) when interacting with others in health care settings, connecting community and place. In my discussion, I have aimed to articulate the foundational notion of relational safety in

the context of a QI intervention at the point of care. When people had a sense of relational safety, they described moving towards connections with others, fostering trust and a sense of empowerment. In my study analyses, I have aimed to contribute to a more nuanced understanding of patient and family experience of QI interventions at the point of care (what I term *Work-as-Experienced*). My resulting *Relational Safety Framework* articulates important aspects of relationships between patients, families, care providers, and organizations within layers of context. Furthermore, I argue that for those working in the health care system, understanding and acknowledging the significance of relational safety for patients and families in their health care relationships is part of the moral obligation to do good and to not harm – during QI initiatives and beyond.

Solomon and Bonham (2013) portray system learning as an ethical imperative, one that is critical in the stewardship of public resources because: "systems that do not aim to study what they do and make improvements on the basis of what they learn inadvertently harm patients, maintain disparities, and waste resources" (p. S3). This learning perspective is consistent with my research findings that QI activities are not value free, and draws through ethical concepts that I set out in Chapter 8. In this dissertation I conclude that without an understanding of how relational safety fits into QI at the point of care, we cannot fully understand the impact of QI initiatives. If we conceptualize high quality health care as improving the quality of life of individuals and populations as measured by their own experiences (in addition to improving health outcomes, lowering costs, and improving provider experience), then my study suggests that QI ought to more consistently consider the context of *all* health care relationships – patients, families, care providers, other staff, organizations – in this pursuit. My central recommendation from this study

is that health care leaders ought to more fully appreciate the ethical implications of QI implementation, such that ethical attention to QI, including relational safety, enhances QI by becoming integral aspects of health care improvement. Moving forward, in addition to designing new QI care processes, organizations and care providers ought to emphasize and nurture the relational interactions accompanying these processes at the point of care.

In closing my dissertation, I have suggested areas of future inquiry to challenge and to extend how I have conceptualized relational safety in this study (see Section 9.5). I encourage health care leaders and researchers to explore how relational safety may be a values-added approach to enhance QI and possibly other contexts in health care. Strengthening relational safety in QI is a means to promote ethical principles such as welfare, equity, trust, solidarity, autonomy, patient/family interests and rights, and to offer important insights about strengthening the efficacy of QI initiatives in health care systems especially where resources are scarce. Ultimately, strengthening relational safety can benefit patients, families, populations, the health care workforce and our health care institutions.

# References

- Abelson, J., Humphrey, A., Syrowatka, A., Bidonde, J., & Judd, M. (2018). Evaluating patient, family and public engagement in health services improvement and system redesign. *Healthcare Quarterly*, 21(SP), 31–37. https://doi.org/10.12927/hcq.2018.25636
- Access to Justice BC. (2019). Over 50 justice organizations agree to a common access to justice goal that puts user experience at the centre. https://accesstojusticebc.ca/wpcontent/uploads/2019/06/Cross-sector-justice-agreement.pdf
- Accreditation Canada. (n.d.). *The Qmentum Accreditation Program*. Retrieved January 15, 2020, from https://accreditation.ca/accreditation/qmentum/
- Accreditation Canada. (2018, April 6). 5 tips for creating a culture of quality improvement. https://accreditation.ca/news/5-tips-creating-culture-quality-improvement/
- Agency for Healthcare Research and Quality. (2013). *Guide to patient and family engagement in hospital quality and safety* (AHRQ Publication No. 13-0033). Agency for Healthcare Research and Quality.
- Ahn, H., Bailey, C. S., Rivers, C. S., Noonan, V. K., Tsai, E. C., Fourney, D. R., Attabib, N., Kwon, B. K., Christie, S. D., Fehlings, M. G., Finkelstein, J., Hurlbert, R. J., Townson, A., Parent, S., Drew, B., Chen, J., Dvorak, M. F., & Rick Hansen Spinal Cord Injury Registry Network. (2015). Effect of older age on treatment decisions and outcomes among patients with traumatic spinal cord injury. *Canadian Medical Association Journal*, *187*(12), 873–880. https://doi.org/10.1503/cmaj.150085

Alberta Health Services. (2016). Alberta Health Services Code of Conduct.
www.albertahealthservices.ca/assets/about/policies/ahs-pub-code-of-conduct.pdf
Alberta Innovates. (2010). ARECCI Ethics Screening Tool.
Alberta Innovates. (2017a). ARECCI Ethics Guideline Tool. https://albertainnovates.ca/programs/arecci/
Alberta Innovates. (2017b). ARECCI Ethics Screening Tool. https://albertainnovates.ca/programs/arecci/

- Alberta Research Ethics Community Consensus Initiative (ARECCI). (2005). *Protecting people while increasing knowledge: Recommendations for a province-wide approach to ethics review of knowledge-generating projects (research, program evaluation and quality improvement) in health care*. Alberta Heritage Foundation for Medical Research. www.assembly.ab.ca/lao/library/egovdocs/2005/alhfm/173539.pdf
- Alberta Research Ethics Community Consensus Initiative (ARECCI). (2010). *Project ethics course level 1: Course manual*. Alberta Innovates – Health Solutions.
- Alexander, J. A., & Hearld, L. R. (2009). What can we learn from quality improvement research? A critical review of research methods. *Medical Care Research and Review*, *66*(3), 235–271.
- Alexander, J. A., & Hearld, L. R. (2011). The science of quality improvement implementation: Developing capacity to make a difference. *Medical Care*, 49 Suppl, S6-20. https://doi.org/10.1097/MLR.0b013e3181e1709c
- Aligning Forces for Quality. (2010). Good for health, good for business: The case for measuring patient experience of care. Robert Wood Johnson Foundation.
- Allen, D., Braithwaite, J., Sandall, J., & Waring, J. (2016). Towards a sociology of healthcare safety and quality. *Sociology of Health & Illness*, *38*(2), 181–197. https://doi.org/10.1111/1467-9566.12390
- Allin, S., Guilcher, S., Riley, D., & Zhang, Y. J. (2017). Improving health system efficiency: Perspectives of decision-makers. *Healthcare Quarterly*, 20(1), 10–13.
- Al-Tawfiq, J. A., & Memish, Z. A. (2017). Religion and hand hygiene. In D. Pittet, J. M. Boyce, & B.
  Allegranzi (Eds.), *Hand hygiene: A handbook for medical professionals* (1st ed., pp. 216–220).
  John Wiley & Sons, Inc.
- Alteren, J., Hermstad, M., White, J., & Jordan, S. (2018). Conflicting priorities: Observation of medicine administration. *Journal of Clinical Nursing*, 27(19–20), 3613–3621. https://doi.org/10.1111/jocn.14518

- Ambrose, C. T. (2005). Osler and the infected letter. *Emerging Infectious Diseases*, 11(5), 689–693. https://doi.org/10.3201/eid1105.040616
- American Hospital Association. (2013). Engaging Health Care Users: A framework for healthy individuals and communities. American Hospital Association.
- American Psychological Association. (2003). Guidelines on multicultural education, training, research, practice, and organizational change for psychologists. *American Psychologist*, 58(5), 377–402. https://doi.org/10.1037/0003-066X.58.5.377
- Anderson, J. A. (2010). Clinical Research in Context: Reexamining the Distinction between Research and Practice. *Journal of Medicine and Philosophy*, *35*(1), 46–63. https://doi.org/10.1093/jmp/jhp054
- Anderson, J. A., Sawatzky-Girling, B., McDonald, M., & Willison, D. J. (2011). Research ethics broadly writ: Beyond research ethics review. *Health Law Review*, *19*(3), 12–24.
- Anderson, J. E., Ross, J. R., & Jaye, P. (2017). Modelling resilience and researching the gap between Work-as-Imagined and Work-as-Done. In J. Braithwaite, R. L. Wears, & E. Hollnagel (Eds.), *Reconciling Work-as-Imagined and Work-as-Done* (Vol. 3, pp. 133–141). CRC Press.
- Andersson, A.-C., & Olheden, A. (2012). Patient participation in quality improvement: Managers' opinions of patients as resources. *Journal of Clinical Nursing*, 21(23–24), 3590–3593. https://doi.org/10.1111/j.1365-2702.2012.04254.x
- Angus Reid Institute. (2019, March 18). As government presents election-year budget, Canadians are uneasy about economic fortunes. http://angusreid.org/economy-trudeau-budget-2019/
- Ansen, D. (1991, August 4). A surgeon under the knife. *Newsweek*. https://www.newsweek.com/surgeonunder-knife-202956
- Appleby, J. (2009). Does improving quality of care save money? *BMJ*, *339*(sep11 1), b3678–b3678. https://doi.org/10.1136/bmj.b3678
- Arbour, L., & Cook, D. (2006). DNA on loan: Issues to consider when carrying out genetic research with aboriginal families and communities. *Community Genetics*, *9*(3), 153.

- Armstrong, N., Herbert, G., Aveling, E. L., Dixon-Woods, M., & Martin, G. (2013). Optimizing patient involvement in quality improvement. *Health Expectations*, 16, 36–47. https://doi.org/10.1111/hex.12039
- Arries, E. J. (2014). Patient safety and quality in healthcare: Nursing ethics for ethics quality. Nursing Ethics, 21(1), 3–5. https://doi.org/10.1177/0969733013509042

Ashenburg, K. (2007). The dirt on clean: An unsanitized history (1st American ed.). North Point Press.

- Austin, M., & Derk, J. (2019). Lives lost, lives saved: An updated comparative analysis of avoidable deaths at hospitals graded by the Leapfrog Group. Armstrong Institute for Patient Safety and Quality, Johns Hopkins Medicine. www.hospitalsafetygrade.org/media/file/Lives-Saved-White-Paper-FINAL.pdf
- Ayres, L. (2008). Grand theory. In L. M. Given (Ed.), *The Sage encyclopedia of qualitative research methods* (pp. 373–374). Sage Publications.
- Babalis, K., Harnett, E., & Steinhoff, K. (2011). Implementation of the process of ethical review of improvement activities at the Children's Hospital at Westmead. *BMJ Quality & Safety*, 20(4), 366–371. https://doi.org/10.1136/bmjqs.2010.043869
- Bacha, K., Hanley, T., & Winter, L. A. (2019). 'Like a human being, I was an equal, I wasn't just a patient': Service users' perspectives on their experiences of relationships with staff in mental health services. *Psychology and Psychotherapy: Theory, Research and Practice*. https://doi.org/10.1111/papt.12218
- Baier, A. (1986). Trust and antitrust. Ethics, 96(2), 231-260. https://doi.org/10.1086/292745
- Bailey, S., Blakeman, T., Brisley, A., Howard, S., & Weisshaar, C. (2018). Improvement in context: An ethnographic study of quality improvement programmes for acute kidney Injury. NIHR CLAHRC Greater Manchester. www.clahrc-

gm.nihr.ac.uk/media/Resources/Kidney%20Health/Improvement%20in%20Context%20FINAL% 2020%2006%2018.pdf

Baily, M. A. (2008). Harming through protection? New England Journal of Medicine, 358(8), 768–769.

- Baily, M. A. (2011). Futility, Autonomy, and Cost in End-of-Life Care. *The Journal of Law, Medicine & Ethics*, 39(2), 172–182. https://doi.org/10.1111/j.1748-720X.2011.00586.x
- Baily, M. A., Bottrell, M., Lynn, J., Jennings, B., & Hastings Center. (2006). The ethics of using QI methods to improve health care quality and safety. *Hastings Center Report*, 36(4), S1-40.
- Baker, G. R. (2014). A review of research highlighting how patient engagement contributes to improved care. Canadian Foundation for Healthcare Improvement. www.cfhi-fcass.ca/sf-docs/default-source/reports/evidenceboost-rossbaker-peimprovedcare-e.pdf?sfvrsn=8
- Baker, G. R., & Black, G. (2015). Beyond the quick fix: Strategies for improving patient safety. University of Toronto. http://ihpme.utoronto.ca/wp-content/uploads/2015/11/Beyond-the-Quick-Fix-Baker-2015.pdf
- Baker, G. R., Fancott, C., Judd, M., & O'Connor, P. (2016). Expanding patient engagement in quality improvement and health system redesign: Three Canadian case studies. *Healthcare Management Forum*, 29(5), 176–182. https://doi.org/10.1177/0840470416645601
- Baker, G. R., MacIntosh-Murray, A. P., L., Dionne, K., Stelmacovich, K., & Born, K. (2008). Learning from high-performing systems: Quality by design. Longwoods Publishing.
- Baker, G. R., Norton, P. G., Flintoft, V., Blais, R., Brown, A., Cox, J., Etchells, E., Ghali, W. a, Hébert,
  P., Majumdar, S. R., O'Beirne, M., Palacios-Derflingher, L., Reid, R. J., Sheps, S., & Tamblyn,
  R. (2004). The Canadian adverse events study: The incidence of adverse events among hospital patients in Canada. *Canadian Medical Association Journal*, *170*(11), 1678–86.
- Baker, L., Egan-Lee, E., Martimianakis, M. A. (Tina), & Reeves, S. (2011). Relationships of power: Implications for interprofessional education. *Journal of Interprofessional Care*, 25(2), 98–104. https://doi.org/10.3109/13561820.2010.505350

- Balik, B., Conway, J., Zipperer, L., & Watson, J. (2011). Achieving an exceptional patient and family experience of inpatient hospital care (IHI Innovation Series White Paper, pp. 1–34). Institute for Healthcare Improvement. www.IHI.org
- Ball, J. E., Murrells, T., Rafferty, A. M., Morrow, E., & Griffiths, P. (2014). 'Care left undone' during nursing shifts: Associations with workload and perceived quality of care. *BMJ Quality & Safety*, 23(2), 116–125. https://doi.org/10.1136/bmjqs-2012-001767
- Bar, S., Grant, K., Asuri, S., & Holms, S. (2018). British Columbia Ministry of Health Patients as Partners: A transformational approach. *Healthcare Management Forum*, 31(2), 51–56. https://doi.org/10.1177/0840470417744569
- Barach, P., & Johnson, J. K. (2018). Assessing risk and preventing harm in the clinical microsystem. In J.
  K. Johnson & W. A. Sollecito (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed., pp. 516–557). Jones & Bartlett.
- Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., & Beyrer, C. (2013). Modified social ecological model:
  A tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC Public Health*, *13*(1). https://doi.org/10.1186/1471-2458-13-482
- Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision making—The pinnacle of patient-centered care. New England Journal of Medicine, 366(9), 780–781. https://doi.org/10.1056/NEJMp1109283
- Bastian, H., Glasziou, P., & Chalmers, I. (2010). Seventy-Five Trials and Eleven Systematic Reviews a Day: How Will We Ever Keep Up? *PLoS Medicine*, 7(9), e1000326. https://doi.org/10.1371/journal.pmed.1000326
- Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L., & Hartung, H.
  (2016). Coproduction of healthcare service. *BMJ Quality & Safety*, 25(7), 509–517.
  https://doi.org/10.1136/bmjqs-2015-004315

Batalden, P. B. (2018). Getting more health from healthcare: Quality improvement must acknowledge patient coproduction—an essay by Paul Batalden. *BMJ*, k3617.

https://doi.org/10.1136/bmj.k3617

- Batalden, P. B., & Davidoff, F. (2007). What is "Quality Improvement" and how can it Transform Healthcare? *Quality & Safety in Health Care*, *16*(1), 2–3.
- Bate, P. (2014). Context is everything. In *Perspectives on context: A selection of essays considering the role of context in successful quality improvement* (pp. 1–29). The Health Foundation.
- Bate, P., Mendel, P., & Robert, G. (2008). Organising for quality: The improvement journeys of leading hospitals in Europe and the United States. Radcliffe.
- Bate, P., & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality & Safety in Health Care*, 15(5), 307–310. https://doi.org/10.1136/qshc.2005.016527
- Bate, P., & Robert, G. (2007). Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design. Radcliffe Pub.
- Batt, S. (2017). *Health Advocacy Inc: How pharmaceutical funding changed the breast cancer movement.* UBC Press.
- Bauer, L. K., Baggett, T. P., Stern, T. A., O'Connell, J. J., & Shtasel, D. (2013). Caring for homeless persons with serious mental illness in general hospitals. *Psychosomatics*, 54(1), 14–21. https://doi.org/10.1016/j.psym.2012.10.004
- Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. *BMC Psychology*, 3(32). https://doi.org/10.1186/s40359-015-0089-9
- Baxley, E. G., Bennett, K. J., Pumkam, C., Crutcher, S., & Helms, M. G. (2011). "PDSA-ADHD": A newly reported syndrome. *Journal of the American Board of Family Medicine: JABFM*, 24(6), 752–757. https://doi.org/10.3122/jabfm.2011.06.100244

- Baylis, F. E., Kenny, N. P., & Sherwin, S. B. (2008). A relational account of public health ethics. *Public Health Ethics*, 1(3), 196–209. https://doi.org/10.1093/phe/phn025
- BC Ministry of Environment. (n.d.). *Welcome to the Lower Mainland Region*. Retrieved June 28, 2019, from www.env.gov.bc.ca/lower-mainland/
- BC Ministry of Health. (n.d.-a). *Baby's most chosen names in British Columbia, 2017*. Retrieved June 28, 2019, from www.health.gov.bc.ca/vs/babynames/baby2017.html
- BC Ministry of Health. (n.d.-b). *Health authorities*. Retrieved May 3, 2020, from https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/healthauthorities
- BC Ministry of Health. (2011). Integrated primary and community care patient and public engagement *framework*.
- BC Ministry of Health. (2018). Patient, family, caregiver and public engagement framework.
- BC Patient Safety & Quality Council. (2016). *Inpatient sepsis toolkit*. https://bcpsqc.ca/resource/inpatient-sepsis-toolkit
- BC Patient Safety & Quality Council. (2017). *British Columbia Health Quality Matrix*. BC Patient Safety & Quality Council. https://bcpsqc.ca/resource/bc-health-quality-matrix/

BC Patient Safety & Quality Council. (2018, January 25). *What matters to you?* https://bcpsqc.ca/advance-the-patient-voice/what-matters-to-you/

- BC Patient Safety & Quality Council. (2019). Summary of ethical review and oversight requirements for quality improvement projects in BC. https://bcpsqc.ca/wp-content/uploads/2019/09/Ethics-Processes-in-BC-Health-Authorities-Sep-26-2019-Updates.pdf
- BC Patient Safety & Quality Council. (2020). British Columbia Health Quality Matrix. BC Patient Safety & Quality Council. https://bcpsqc.ca/wp-content/uploads/2020/02/BC-Health-Quality-Matrix-January-2020.pdf

- BC Patient Safety & Quality Council, & Patient Voices Network. (2017). Conversations that matter: A report on "What Matters to You?" Day. https://bcpsqc.ca/wp-content/uploads/2018/03/WMTYReport digital.pdf
- BC Renal Agency. (n.d.). *Kidney services in BC*. BC Renal. Retrieved June 28, 2019, from www.bcrenalagency.ca/kidney-services
- Beach, M. C., Inui, T., & and the Relationship-Centered Care Research Network. (2006). Relationshipcentered care: A constructive reframing. *Journal of General Internal Medicine*, 21(S1), S3–S8. https://doi.org/10.1111/j.1525-1497.2006.00302.x
- Beauchamp, T. L., & Childress, J. E. (1979). Principles of biomedical ethics. Oxford University Press.
- Beauchamp, T. L., & Childress, J. E. (1994). Principles of biomedical ethics (4th ed.). Oxford University Press.
- Beauchamp, T. L., & Childress, J. F. (2019). *Principles of biomedical ethics* (8th ed.). Oxford University Press.
- Beecher, H. (1966). Ethics and clinical research. The New England Journal of Medicine, 274(24), 1354.
- Beitat, K. (2015). *Trust and incidents: The dynamic of interpersonal trust between patients and practitioners*. Springer Fachmedien Wiesbaden.
- Bélanger, E., Towers, A., Wright, D. K., Chen, Y., Tradounsky, G., & Macdonald, M. E. (2019). Of dilemmas and tensions: A qualitative study of palliative care physicians' positions regarding voluntary active euthanasia in Quebec, Canada. *Journal of Medical Ethics*, 45(1), 48–53. https://doi.org/10.1136/medethics-2017-104339
- Bellin, E., & Dubler, N. N. (2001). The quality improvement-research divide and the need for external oversight. *American Journal of Public Health*, 91(9), 1512–1517.
- Bellissimo-Rodrigues, F., Pires, D., Zingg, W., & Pittet, D. (2016). Role of parents in the promotion of hand hygiene in the paediatric setting: A systematic literature review. *Journal of Hospital Infection*, 93(2), 159–163. https://doi.org/10.1016/j.jhin.2016.02.001

- Benessaiah, K., & Sengupta, R. (2014). How is shrimp aquaculture transforming coastal livelihoods and lagoons in Estero Real, Nicaragua?: The need to integrate social–ecological research and ecosystem-based approaches. *Environmental Management*, 54(2), 162–179. https://doi.org/10.1007/s00267-014-0295-x
- Berg, L., & Danielson, E. (2007). Patients' and nurses' experiences of the caring relationship in hospital: An aware striving for trust. *Scand J Caring Sci*, 21, 500–506.
- Berg, S. (2017, July 7). Better communication with patients linked to less burnout. *AMA Wire*. https://wire.ama-assn.org/life-career/better-communication-patients-linked-less-burnout
- Berger, Z., Flickinger, T. E., Pfoh, E., Martinez, K. A., & Dy, S. M. (2014). Promoting engagement by patients and families to reduce adverse events in acute care settings: A systematic review. *BMJ Quality & Safety*, 23(7), 548–555.
- Bergerum, C., Thor, J., Josefsson, K., & Wolmesjö, M. (2019). How might patient involvement in healthcare quality improvement efforts work—A realist literature review. *Health Expectations*, 22(5), 952–964. https://doi.org/10.1111/hex.12900
- Bergum, V. (2013). Relational ethics for health care. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.),
   *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 127–142).
   Pearson.
- Bergum, V., & Dossetor, J. B. (2005). *Relational ethics: The full meaning of respect*. University Pub. Group.
- Berkhof, M., van Rijssen, H. J., Schellart, A. J. M., Anema, J. R., & van der Beek, A. J. (2011). Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews. *Patient Education and Counseling*, 84(2), 152–162. https://doi.org/10.1016/j.pec.2010.06.010

- Berkowitz, R. L., Phillip, N., Berry, L., & Yen, I. H. (2018). Patient experiences in a linguistically diverse safety net primary care setting: Qualitative study. *Journal of Participatory Medicine*, 10(1), e4. https://doi.org/10.2196/jopm.9229
- Bernabeo, E., & Holmboe, E. (2013). Patients, providers, and systems need to acquire a specific set of competencies to achieve truly patient-centered care. *Health Affairs*, *32*(2), 250–258.
- Berwick, D. (1996). A primer on leading the improvement of systems. *BMJ*, *312*(7031), 619–622. https://doi.org/10.1136/bmj.312.7031.619
- Berwick, D. (1998). Developing and testing changes in delivery of care. *Annals of Internal Medicine*, *128*(8), 651–656. https://doi.org/10.7326/0003-4819-128-8-199804150-00009
- Berwick, D. (2009). What "patient-centered" should mean: Confessions of an extremist. *Health Affairs*, 28(4), w555-65.
- Berwick, D. (2012). The question of improvement. *JAMA: The Journal of the American Medical Association*, 307(19), 2093–2094. https://doi.org/10.1001/jama.2012.4146
- Berwick, D., & Fox, D. M. (2016). "Evaluating the Quality of Medical Care": Donabedian's classic article 50 years later. *The Milbank Quarterly*, 94(2), 237–241. https://doi.org/10.1111/1468-0009.12189
- Berwick, D., Nolan, T. W., & Whittington, J. (2008). The Triple Aim: Care, health, and cost. *Health Affairs*, *27*(3), 759–769.
- Bhavnani, K.-K., Chua, P., & Collins, D. (2014). Critical approaches to qualitative research. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 164–178). Oxford University Press.
- Birtwhistle, R., Morissette, K., Dickinson, J. A., Reynolds, D. L., Avey, M. T., Domingo, F. R., Rodin,
  R., & Thombs, B. D. (2019). Recommendation on screening adults for asymptomatic thyroid dysfunction in primary care. *Canadian Medical Association Journal*, *191*(46), E1274–E1280. https://doi.org/10.1503/cmaj.190395

- Bishop, L. J., Cherry, M. N., & Darragh, M. (1999). Organizational ethics and health care: Expanding bioethics to the institutional arena (Scope Note 36). Bioethics Research Library. https://pdfs.semanticscholar.org/93ca/6ebcfb90cc5f3bbae007bd5aed346f7d4f52.pdf
- Blair, A. (2017). The intersection of conflict, substance use, trauma, and HIV: Exploring their complex interplay among conflict affected populations in a rapidly changing northern Uganda. University of British Columbia.
- Bodenheimer, T., & Sinsky, C. (2014). From Triple to Quadruple Aim: Care of the patient requires care of the provider. *The Annals of Family Medicine*, *12*(6), 573–576. https://doi.org/10.1370/afm.1713
- Bodolica, V., & Spraggon, M. (2014). Clinical governance infrastructures and relational mechanisms of control in healthcare organizations. *Journal of Health Management*, 16(2), 183–198. https://doi.org/10.1177/0972063414526126
- Boehmer, K., Gionfriddo, M. R., Rodriguez-Gutierrez, R., Dabrh, A. M. A., Leppin, A. L., Hargraves, I., May, C., Shippee, N. D., Castaneda-Guarderas, A., Palacios, C. Z., Bora, P., Erwin, P., & Montori, V. M. (2016). Patient capacity and constraints in the experience of chronic disease: A qualitative systematic review and thematic synthesis. *BMC Family Practice*, *17*(1), 127. https://doi.org/10.1186/s12875-016-0525-9
- Boilevin, L., Chapman, J., Deane, L., Doerksen, C., Fresz, G., Joe, D., Leech-Crier, N., Marsh, S.,
  McLeod, J., Neufeld, S. D., Pham, S., Shaver, L., Smith, P., Steward, M., Wilson, D., & Winter,
  P. (2019). *Research 101: A Manifesto for Ethical Research in the Downtown Eastside*.
  http://bit.ly/R101Manifesto
- Boissy, A., & Gilligan, T. (2016). *Communication the Cleveland Clinic way: How to drive a relationshipcentered strategy for superior patient experience.*

- Bollig, G., Gjengedal, E., & Rosland, J. H. (2016). Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing Ethics*, 23(2), 142–153. https://doi.org/10.1177/0969733014557719
- Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J.-L., & Pomey, M.-P. (2018). Engaging patients to improve quality of care: A systematic review. *Implementation Science*, 13(1), 98. https://doi.org/10.1186/s13012-018-0784-z
- Boothe, K. (2019). "Getting to the table": Changing ideas about public and patient involvement in Canadian drug assessment. *Journal of Health Politics, Policy and Law, 44*(4), 631–663. https://doi.org/10.1215/03616878-7530825
- Boulet, L.-P. (2016). The expert patient and chronic respiratory diseases. *Canadian Respiratory Journal*, 2016, 1–6. https://doi.org/10.1155/2016/9454506
- Boulton, R., Sandall, J., & Sevdalis, N. (2020). The cultural politics of 'implementation science.' *Journal* of Medical Humanities, 1–16. https://doi.org/10.1007/s10912-020-09607-9
- Braithwaite, J., Herkes, J., Ludlow, K., Testa, L., & Lamprell, G. (2017). Association between organisational and workplace cultures, and patient outcomes: Systematic review. *BMJ Open*, 7(11), e017708. https://doi.org/10.1136/bmjopen-2017-017708
- Braithwaite, J., Wears, R. L., & Hollnagel, E. (2015). Resilient health care: Turning patient safety on its head. *International Journal for Quality in Health Care*, 27(5), 418–420. https://doi.org/10.1093/intqhc/mzv063
- Braithwaite, J., Wears, R. L., & Hollnagel, E. (2017). *Reconciling Work-As-Imagined and Work-as-Done* (J. Braithwaite, R. L. Wears, & E. Hollnagel, Eds.; Vol. 3). CRC Press.
- Brody, B. A. (1998). *The ethics of biomedical research: An international perspective*. Oxford University Press.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.

- Bronfenbrenner, U. (1993). Ecological models of human development. In M. Gauvain & M. Cole (Eds.), *Readings on the development of children* (2nd ed., pp. 37–43). Scientific American Books.
- Broughton, E. I., & Marquez, L. (2016). Why economic analysis of health system improvement interventions matters. *Frontiers in Public Health*, 4, 1–4. https://doi.org/10.3389/fpubh.2016.00218
- Brown, A., Baker, G. R., Closson, T., & Sullivan, T. (2012). The journey toward high performance and excellent quality. *Healthcare Quarterly*, *15*, 6–9.
- Brown, B. (2012). *Daring greatly: How the courage to be vulnerable transforms the way we live, love, parent, and lead*. Gotham Books.
- Browne, A. J., Ford-Gilboe, M., Varcoe, C. M., & Wathen, N. (2018). EQUIP healthcare: Project summary. https://equiphealthcare.ca/equip/wp-content/uploads/2018/01/EQUIP-Healthcare-Research-Overview-updated-January-15-2018.pdf
- Browne, A. J., Varcoe, C. M., Smye, V., Reimer-Kirkham, S., Lynam, M. J., & Wong, S. (2009). Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nursing Philosophy*, 10(3), 167–179. https://doi.org/10.1111/j.1466-769X.2009.00406.x
- Browne, A. J., Varcoe, C. M., Wong, S., Smye, V., & Khan, K. B. (2014). Can ethnicity data collected at an organizational level be useful in addressing health and healthcare inequities? *Ethnicity & Health*, 19(2), 240–254. https://doi.org/10.1080/13557858.2013.814766
- Browne, K., Roseman, D., Shaller, D., & Edgman-Levitan, S. (2010). Measuring patient experience as a strategy for improving primary care. *Health Affairs*, 29(5), 921–925. https://doi.org/10.1377/hlthaff.2010.0238
- Browning, D. M., Meyer, E. C., Truog, R. D., & Solomon, M. Z. (2007). Difficult conversations in health care: Cultivating relational learning to address the hidden curriculum. *Academic Medicine*, 82(9), 905–913.

- Broyles, L. M., Binswanger, I. A., Jenkins, J. A., Finnell, D. S., Faseru, B., Cavaiola, A., Pugatch, M., & Gordon, A. J. (2014). Confronting inadvertent stigma and pejorative language in addiction scholarship: A recognition and response. *Substance Abuse*, *35*(3), 217–221. https://doi.org/10.1080/08897077.2014.930372
- Buckwalter, J. G. (2007). The good patient. New England Journal of Medicine, 357, 2534-2535.
- Burkitt, I. (2016). Relational agency: Relational sociology, agency and interaction. *European Journal of Social Theory*, 19(3), 322–339. https://doi.org/10.1177/1368431015591426

Burr, V. (2015). Social constructionism (3rd ed.). Routledge.

Burton, C. R., Rycroft Malone, J., Robert, G., Willson, A., & Hopkins, A. (2014). Investigating the organisational impacts of quality improvement: A protocol for a realist evaluation of improvement approaches drawing on the Resource Based View of the Firm. *BMJ Open*, 4, e005650. https://doi.org/10.1136/bmjopen-2014-005650

Butler, R. N. (1975). Why survive?: Being old in America (1st ed.). Harper & Row.

- Bykova, M. F. (2011). Tolstoy and Chekhov: Philosophy invested in literature. *Russian Studies in Philosophy*, *50*(2), 3–7. https://doi.org/10.2753/RSP1061-1967500200
- Calabrese, J. D. (2013). Ethnographic approaches to health experiences research. In S. Ziebland, A.
   Coulter, J. D. Calabrese, & L. Locock (Eds.), *Understanding and using health experiences: Improving patient care* (pp. 16–26). Oxford University Press.
- Canadian Association of Social Workers. (2005). *Code of ethics*. Canadian Association of Social Workers. www.casw-acts.ca/sites/default/files/attachements/casw code of ethics 0.pdf
- Canadian Institute for Health Information. (n.d.). *Patient-reported outcome measures (PROMs)*. www.cihi.ca/en/patient-reported-outcome-measures-proms
- Canadian Institute for Health Information. (2019a). *National health expenditure trends, 1975 to 2019*. Canadian Institute for Health Information. www.cihi.ca/en/national-health-expenditure-trends-1975-to-2019

- Canadian Institute for Health Information. (2019b, April). Patient experience in Canadian hospitals. www.cihi.ca/en/patient-experience/patient-experience-in-canadian-hospitals
- Canadian Institutes of Health Research. (2014). *Ethics in research: A science lifecycle approach*. www.cihr-irsc.gc.ca/e/48635.html
- Canadian Institutes of Health Research. (2018). *Ethics in research: A science lifecycle approach*. Canadian Institutes of Health Research. www.cihr-irsc.gc.ca/e/48832.html
- Canadian Institutes of Health Research (CIHR). (2017, August 31). *Antimicrobial resistance*. Canadian Institutes of Health Research. www.cihr-irsc.gc.ca/e/46057.html

Canadian Institutes of Health Research (CIHR). (2019, January 4). *Strategy for Patient-Oriented Research (SPOR)*. Canadian Institutes of Health Research. www.cihr-irsc.gc.ca/e/41204.html

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2014). *Tri-council policy statement: Ethical conduct for research involving humans*. www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS 2 FINAL Web.pdf

 Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada,
 & Social Sciences and Humanities Research Council of Canada. (2018). *Tri-council policy* statement: Ethical conduct for research involving humans (TCPS2 2018).
 www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS 2 FINAL Web.pdf

Canadian Interprofessional Health Collaborative. (2010). A national interprofessional competency framework. www.cihc-cpis.com/publications1.html

- Canadian Medical Association. (2018). *CMA code of ethics and professionalism*. Canadian Medical Association. https://policybase.cma.ca/documents/Policypdf/PD19-03.pdf
- Canadian Nurses Association. (2010). *Ethics, relationships and quality practice environments* (Ethics in Practice for Registered Nurses). Canadian Nurses Association. https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/ethics in practice jan 2010 e.pdf

Canadian Nurses Association. (2012). *Staff mix decision-making framework for quality nursing care*. www.cna-aiic.ca/-/media/cna/page-content/pdfen/staff mix framework 2012 e.pdf?la=en&hash=6714249BFE851724178917E918E2411843D

21BB6

- Canadian Nurses Association. (2015). CNA/CFNU evidence-based safe nurse staffing toolkit. www.cnaaiic.ca/en/nursing-practice/tools-for-practice/safe-staffing-toolkit
- Canadian Nurses Association. (2017). Code of ethics for registered nurses. Canadian Nurses Association. www.cna-aiic.ca/~/media/cna/page-content/pdf-en/code-of-ethics-2017-edition-secure-interactive
- Canadian Nurses Association, & Canadian Federation of Nurses Union. (2019). Patient safety: Joint position statement. www.cna-aiic.ca/-/media/cna/page-content/pdf-en/2019-joint-position-statement-\_patient-

safety.pdf?la=en&hash=4688BDFCF9B9D3FC6D0B210C89DBB5C757D6F7AC

- Canadian Patient Safety Institute. (n.d.-a). *Conquer silence*. Retrieved February 8, 2020, from https://conquersilence.ca/about
- Canadian Patient Safety Institute. (n.d.-b). *Hand hygiene*. Retrieved June 28, 2019, from www.patientsafetyinstitute.ca/en/Topic/Pages/Hand-Hygiene.aspx
- Canadian Patient Safety Institute. (n.d.-c). *Hand hygiene observation tools*. Retrieved February 26, 2020, from www.patientsafetyinstitute.ca/en/toolsResources/pages/hand-hygiene-observation-tools.aspx
- Canadian Patient Safety Institute. (n.d.-d). *Infection Prevention and Control (IPAC)*. Retrieved June 28, 2019, from www.patientsafetyinstitute.ca/en/topic/pages/infection-prevention-and-control.aspx
- Canadian Patient Safety Institute. (n.d.-e). *Patient safety forward with four*. Retrieved June 28, 2019, from www.patientsafetyinstitute.ca/en/about/patientsafetyforwardwith4/pages/default.aspx
- Canadian Patient Safety Institute. (2019, May 6). *Clean care conversations*. STOP! Clean Your Hands Day. www.patientsafetyinstitute.ca/en/Events/StopCleanYourHandsDay/Pages/default.aspx

- Canadian Physiotherapy Association (CPA). (2017). *CPA code of ethics*. Canadian Physiotherapy Association. https://physiotherapy.ca/cpa-code-ethics
- Canfield, C. (2017). Recovery to resilience: A patient perspective. In J. Braithwaite, R. L. Wears, & E. Hollnagel (Eds.), *Reconciling Work-As-Imagined and Work-as-Done* (Vol. 3, pp. 27–36). CRC Press.
- Canfield, C. (2018). The capacity for patient engagement: What patient experiences tell us about what's ahead. *Healthcare Quarterly*, *21*(SP), 68–72. https://doi.org/10.12927/hcq.2018.25635
- Cao, J., Min, L., Lansing, B., Foxman, B., & Mody, L. (2016). Multidrug-resistant organisms on patients' hands: A missed opportunity. *JAMA Internal Medicine*, 176(5), 705. https://doi.org/10.1001/jamainternmed.2016.0142
- Carayon, P., Wetterneck, T. B., Rivera-Rodriguez, A. J., Hundt, A. S., Hoonakker, P., Holden, R., & Gurses, A. P. (2014). Human factors systems approach to healthcare quality and patient safety. *Applied Ergonomics*, 45(1), 14–25. https://doi.org/10.1016/j.apergo.2013.04.023
- Carinci, F., Van Gool, K., Mainz, J., Veillard, J., Pichora, C., Januel, J. M., Arispe, I., Kim, S. M., & Klazinga, N. S. (2015). Towards actionable international comparisons of health system performance: Expert revision of the OECD framework and quality indicators. *International Journal for Quality in Health Care*, 27(2), 137–146. https://doi.org/10.1093/intqhc/mzv004
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32, 223–231. https://doi.org/10.1377/hlthaff.2012.1133
- Casarett, D., Karlawish, J., & Sugarman, J. (2000). Should patients in quality-improvement activities have the same protections as participants in research studies? *JAMA: The Journal of the American Medical Association*, 283, 2275–2280.

- Cascio, M. A., & Racine, E. (2018). Person-oriented research ethics: Integrating relational and everyday ethics in research. *Accountability in Research*, 25(3), 170–197. https://doi.org/10.1080/08989621.2018.1442218
- Cené, C. W., Johnson, B. H., Wells, N., Baker, B., Davis, R., & Turchi, R. (2016). A narrative review of patient and family engagement: The "foundation" of the medical "home." *Medical Care*, 54(7), 697–705. https://doi.org/10.1097/MLR.00000000000548
- Center for Practical Bioethics. (n.d.). *Case Studies*. Retrieved June 28, 2019, from www.practicalbioethics.org/resources/case-studies.html
- Centers for Disease Control and Prevention. (2017). *Talking about fall prevention with your patients*. www.cdc.gov/steadi/pdf/Talking about Fall Prevention with Your Patients-print.pdf
- Chan, B., & Cochrane, D. (2016). Measuring patient harm in Canadian hospitals. What can be done to improve patient safety? Canadian Institute for Health Information, Canadian Patient Safety Institute. https://secure.cihi.ca/free\_products/cihi\_cpsi\_hospital\_harm\_en.pdf
- Charles, G., & Anderson-Nathe, B. (2019). Disconnection and mattering. *Child & Youth Services*, 40(2), 117–119. https://doi.org/10.1080/0145935X.2019.1629567
- Chavan, P. (2013, June 6). 5 ways to "humanize" process improvement. *Process Excellent Network*. www.processexcellencenetwork.com/lean-six-sigma-business-performance/articles/5-ways-tohumanize-process-improvement
- Chenail, R. J. (2011). How to conduct clinical qualitative research on the patient's experience. *The Qualitative Report*, *16*(4), 1173–1190.

Chew, E. (2014). Music interaction with others as conveyor of relational intent: A response to Cross (2014). *Psychology of Music*, *42*(6), 826–838. https://doi.org/10.1177/0305735614549407

Child and Youth Mental Health and Substance Use Collaborative. (2017, August 1). *ER protocol training video*. www.youtube.com/watch?v=8W9DwSLSk4E&feature=youtu.be

- Chou, C. L. (2018). Communication Rx: Transforming healthcare through relationship-centered communication. McGraw-Hill.
- Chung, G. H., Choi, J. N., & Du, J. (2017). Tired of innovations? Learned helplessness and fatigue in the context of continuous streams of innovation implementation: Innovation Fatigue. *Journal of Organizational Behavior*, 38(7), 1130–1148. https://doi.org/10.1002/job.2191
- Clancy, C., & Berwick, D. (2011). The science of safety improvement: Learning while doing. *Annals of Internal Medicine*, *154*(10), 699–701. https://doi.org/10.7326/0003-4819-154-10-201105170-00013
- Clark, B., & Preto, N. (2018). Exploring the concept of vulnerability in health care. *Canadian Medical Association Journal*, *190*(11), E308–E309. https://doi.org/10.1503/cmaj.180242
- Clay-Williams, R., Hounsgaard, J., & Hollnagel, E. (2015). Where the rubber meets the road: Using FRAM to align work-as-imagined with work-as-done when implementing clinical guidelines. *Implementation Science*, *10*(1). https://doi.org/10.1186/s13012-015-0317-y
- Cleveland Clinic. (n.d.). Communicate with H.E.A.R.T®.

https://my.clevelandclinic.org/departments/patient-experience/depts/experience-

partners/training/communicate-with-heart

- Cohen, D., & Crabtree, B. (2006). Reflexivity. In *Qualitative Research Guidelines Project*. www.qualres.org/HomeRefl-3703.html
- Cohn, S. (2015). 'Trust my doctor, trust my pancreas': Trust as an emergent quality of social practice. *Philosophy, Ethics, and Humanities in Medicine, 10*(1), 1–9. https://doi.org/10.1186/s13010-015-0029-6
- Cole, M. (2014). Social construction of hand hygiene as a simple measure to prevent health care associated infection [University of Nottingham]. http://eprints.nottingham.ac.uk/14426/1/Final PhD revision.pdf

- Collen, A. (2006). An application of experiential method in psychology: What is it like to be a stranger in a foreign land? In C. T. Fischer (Ed.), *Qualitative research methods for psychologists: Introduction through empirical studies* (pp. 331–376). Academic Press.
- Cooper, J. A., & McNair, L. (2015). How to distinguish research from quality improvement. Journal of Empirical Research on Human Research Ethics, 10(2), 209–210. https://doi.org/10.1177/1556264615575513
- Coulter, A. (2013). Understanding the experience of illness and treatment. In S. Ziebland, A. Coulter, J.
   D. Calabrese, & L. Locock (Eds.), *Understanding and using health experiences: Improving patient care* (pp. 6–15). Oxford University Press.
- Coulter, A. (2016). Patient feedback for quality improvement in general practice. *BMJ*, 352, i913. https://doi.org/10.1136/bmj.i913
- Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *BMJ*, *335*(7609), 24–27. https://doi.org/10.1136/bmj.39246.581169.80
- Coulter, A., Locock, L., Ziebland, S., & Calabrese, J. D. (2014). Collecting data on patient experience is not enough: They must be used to improve care. *BMJ*, 348(mar26 1), g2225–g2225. https://doi.org/10.1136/bmj.g2225
- Council for International Organizations of Medical Sciences (CIOMS). (2016). *International ethical guidelines for health-related research involving humans*. https://cioms.ch/shop/product/international-ethical-guidelines-for-health-related-research-involving-humans
- Council of Canadian Academies. (2015). Accessing health and health-related data in Canada: The expert panel on timely access to health and social data for health research and health system innovation. Council of Canadian Academies.

Coutre, L. (2016). Medical improv putting physicians to the test. Crain's Cleveland Business, 37(18), 6.

- Cox, S. M., & McDonald, M. (2013). Ethics is for human subjects too: Participant perspectives on responsibility in health research. *Social Science and Medicine*, 98, 224–231. https://doi.org/10.1016/j.socscimed.2013.09.015
- Cox, S. M., McDonald, M., & Townsend, A. (2019). Epistemic strategies in ethical review: REB members' experiences of assessing probable impacts of research for human subjects. *Journal of Empirical Research on Human Research Ethics*. https://doi.org/10.1177/1556264619872369
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2013). Developing and evaluating complex interventions: The new Medical Research Council guidance. *International Journal of Nursing Studies*, 50(5), 587–592. https://doi.org/10.1016/j.ijnurstu.2012.09.010

Creswell, J. W. (2013). Qualitative inquiry and research design (3rd ed.). Sage.

- Cribb, A., Entwistle, V., & Mitchell, P. (2019). What does 'quality' add? Towards an ethics of healthcare improvement. *Journal of Medical Ethics*, medethics-2019-105635. https://doi.org/10.1136/medethics-2019-105635
- Crooke, A. H. D. (2015). Music therapy, social policy and ecological models: A located example of music in Australian schools. *Voices: A World Forum for Music Therapy*, 15(2). https://doi.org/10.15845/voices.v15i2.829
- Cross, I. (2014). Music and communication in music psychology. *Psychology of Music*, 42(6), 809–819. https://doi.org/10.1177/0305735614543968

Crotty, M. (1998). The foundations of social research. Sage.

Cunha, D. (2018, January 12). The important lesson new moms should learn from Serena Williams's scary childbirth experience. *The Washington Post*. www.washingtonpost.com/news/parenting/wp/2018/01/12/the-important-lesson-new-moms-should-learn-from-serena-williamss-scary-childbirth-experience/?utm\_term=.5d3f69ab2438

Dalton, R. (2002). Tribe blasts "exploitation" of blood samples. *Nature*, 420(6912), 111–111. https://doi.org/10.1038/420111a

- Damschroder, L., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science: IS*, *4*, 50. https://doi.org/10.1186/1748-5908-4-50
- D'Andreamatteo, A., Ianni, L., Lega, F., & Sargiacomo, M. (2015). Lean in healthcare: A comprehensive review. *Health Policy*, *119*(9), 1197–1209. https://doi.org/10.1016/j.healthpol.2015.02.002
- Danholt, P. (2010). The sociotechnical configuration of the problem of patient safety. *Studies in Health Technology and Informatics*, 157, 31–37.
- Daniels, J. P., Hunc, K., Cochrane, D., Carr, R., Shaw, N. T., Taylor, A., Heathcote, S., Brant, R., Lim, J., & Ansermino, J. M. (2012). Identification by families of pediatric adverse events and near misses overlooked by health care providers. *Canadian Medical Association Journal*, 184(1), 29–34.
- Davidoff, F. (2011). Systems of service: Reflections on the moral foundations of improvement. *BMJ Quality & Safety, 20 Suppl 1*(Suppl 1), i5–10.
- Davis, C. (2015). *When the nurse becomes a patient: A story in words and images.* The Kent State University Press.
- Davis, R. E., Parand, A., Pinto, A., & Buetow, S. (2015). Systematic review of the effectiveness of strategies to encourage patients to remind healthcare professionals about their hand hygiene. *Journal of Hospital Infection*, 89(3), 141–162. https://doi.org/10.1016/j.jhin.2014.11.010
- Davis, R. E., Sevdalis, N., & Vincent, C. (2011). Patient involvement in patient safety: How willing are patients to participate? *BMJ Quality & Safety*, 20(1), 108–14.
- Davis, S., Berkson, S., Gaines, M. E., Prajapati, P., Schwab, W., Pandhi, N., & Edgman-Levitan, S.
  (2016). Implementation science workshop: Engaging patients in team-based practice redesign critical reflections on program design. *Journal of General Internal Medicine*, *31*(6), 688–695. https://doi.org/10.1007/s11606-016-3656-8

- Dawson, A., Lignou, S., Siriwardhana, C., & O'Mathúna, D. P. (2019). Why research ethics should add retrospective review. *BMC Medical Ethics*, *20*(1), 68. https://doi.org/10.1186/s12910-019-0399-1
- Debono, D. S., & Braithwaite, J. (2015). Workarounds in nursing practice in acute care: A case of a health care arms race? In R. L. Wears & J. Braithwaite (Eds.), *The resilience of everyday clinical* work. Ashgate.
- Debono, D. S., Greenfield, D., Travaglia, J. F., Long, J. C., Black, D., Johnson, J., & Braithwaite, J. (2013). Nurses' workarounds in acute healthcare settings: A scoping review. *BMC Health Services Research*, 13(1). https://doi.org/10.1186/1472-6963-13-175
- Dekker, S. (2011). Drift into failure: From hunting broken components to understanding complex systems. Ashgate Publishing, Ltd.
- Dekker, S. (2014). *The field guide to understanding "human error"* (3rd ed.). CRC Press. https://doi.org/10.1201/9781317031833
- Delbanco, T. L., Berwick, D., Boufford, J. I., Edgman-Levitan, S., Ollenschläger, G., Plamping, D., & Rockefeller, R. G. (2001). Healthcare in a land called PeoplePower: Nothing about me without me: Healthcare in a land called PeoplePower. *Health Expectations*, 4(3), 144–150. https://doi.org/10.1046/j.1369-6513.2001.00145.x
- Deming, W. E. (1986). *Out of the crisis*. Massachusetts Institute of Technology, Center for Advanced Engineering Study.
- Deming, W. E. (1993). *The new economics for industry, government, education*. Massachusetts Institute of Technology, Center for Advanced Engineering Study.
- Department of Health & Human Services. (1979). *Protection of human subjects: The Belmont Report*. US Department of Health & Human Services.

www.hhs.gov/ohrp/humansubjects/guidance/belmont.html
- Detsky, J., & Shaul, R. Z. (2013). Incentives to increase patient satisfaction: Are we doing more harm than good? *Canadian Medical Association Journal*, 185(14), 1199–1200. https://doi.org/10.1503/cmaj.130366
- Dhalla, I. A., & Tepper, J. (2018). Improving the quality of health care in Canada. *Canadian Medical Association Journal*, *190*(39), E1162–E1167. https://doi.org/10.1503/cmaj.171045

 DiGioia, A. M., & Shapiro, E. (2012). Go shadow: View and co-design exceptional care experiences, your guide to patient and family shadowing with patients, families and care givers. Patient and Family Centered Care Innovation Centre of UPMC. https://static1.squarespace.com/static/59a2f24de3df28ce22791378/t/59c01175be42d644772cc1b7

/1505759609058/shadow-guide%5B1%5D.pdf

- Dixon, N. (2017). Guide to managing ethical issues in quality improvement or clinical audit projects. Healthcare Quality Improvement Partnership (HQIP). www.hqip.org.uk/resource/guide-tomanaging-ethical-issues-in-quality-improvement-or-clinical-audit-projects/
- Dixon-Woods, M., Baker, R., Charles, K., Dawson, J., Jerzembek, G., Martin, G., McCarthy, I., McKee, L., Minion, J., Ozieranski, P., Willars, J., Wilkie, P., & West, M. (2014). Culture and behaviour in the English National Health Service: Overview of lessons from a large multimethod study. *BMJ Quality & Safety*, 23(2), 106–115. https://doi.org/10.1136/bmjqs-2013-001947
- Dixon-Woods, M., & Martin, G. P. (2016). Does quality improvement improve quality? *Future Hospital Journal*, *3*(3), 191–194. https://doi.org/10.7861/futurehosp.3-3-191
- Dixon-Woods, M., McNicol, S., & Martin, G. (2012). Ten challenges in improving quality in healthcare:
   Lessons from the Health Foundation's programme evaluations and relevant literature: Table 1.
   *BMJ Quality & Safety*, 21(10), 876–884. https://doi.org/10.1136/bmjqs-2011-000760
- Doan, M. D., & Sherwin, S. B. (2016). Relational solidarity and climate change in Western nations. In C.
   C. Macpherson (Ed.), *Bioethical Insights into Values and Policy* (pp. 79–88). Springer
   International Publishing.

- Doane, G. H., & Varcoe, C. M. (2013). Relational practice and nursing obligations. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 143–159). Pearson.
- Doane, G. H., & Varcoe, C. M. (2015). *How to nurse: Relational inquiry with individuals and families in changing health and health care contexts.* Wolters Kluwer.
- Donabedian, A. (1966). Evaluating the quality of medical care. *The Milbank Memorial Fund Quarterly*, *44*(3), Suppl:166-206.
- Donabedian, Avedis. (1980). *The definition of quality and approaches to its assessment*. Health Administration Press.
- Donabedian, Avedis. (2005). Evaluating the quality of medical care. Milbank Quarterly, 83(4), 691–729.
- Dotolo, D. (2017). "It's always in the back of your mind": LGBTQ partners' experiences of discrimination in health care for serious illnesses. University of Washington.
- Dougherty, S., & Allen, S. (2017). Nuremberg betrayed: Human experimentation and the CIA torture program. Physicians for Human Rights. https://phr.org/resources/nuremberg-betrayed-human-experimentation-and-the-cia-torture-program
- Douglas, H. E., Raban, M. Z., Walter, S. R., & Westbrook, J. I. (2017). Improving our understanding of multi-tasking in healthcare: Drawing together the cognitive psychology and healthcare literature. *Applied Ergonomics*, 59, 45–55. https://doi.org/10.1016/j.apergo.2016.08.021
- Dresser, R. (2016). *Silent partners: Human subjects and research ethics* (Vol. 1). Oxford University Press.
- Dubbin, L. A., Chang, J. S., & Shim, J. K. (2013). Cultural health capital and the interactional dynamics of patient-centered care. *Social Science & Medicine*, 93, 113–120. https://doi.org/10.1016/j.socscimed.2013.06.014
- Duhn, L., & Medves, J. (2018). A 5-facet framework to describe patient engagement in patient safety. *Health Expectations*, 21(6), 1122–1133. https://doi.org/10.1111/hex.12815

- Duncan, S., Rodney, P., & Thorne, S. (2014). Forging a strong nursing future: Insights from the Canadian context. *Journal of Research in Nursing*, 19(7–8), 621–633.
- Dwyer, S. C., & Buckle, J. L. (2009). The space between: On being an insider-outsider in qualitative research. *International Journal of Qualitative Methods*, 8(1), 54–63. https://doi.org/10.1177/160940690900800105
- Eccles, M. P., & Mittman, B. S. (2006). Welcome to implementation science. *Implementation Science*, *I*(1), 1. https://doi.org/10.1186/1748-5908-1-1
- Edwards, A. (2005). Relational agency: Learning to be a resourceful practitioner. *International Journal of Educational Research*, 43(3), 168–182. https://doi.org/10.1016/j.ijer.2006.06.010
- Edwards, K. J., Walker, K., & Duff, J. (2015). Instruments to measure the inpatient hospital experience: A literature review. *Patient Experience Journal*, *2*(2), 77–85. https://doi.org/10.35680/2372-0247.1088
- Ells, C., Hunt, M., & Chambers-Evans, J. (2011). Relational autonomy as an essential component of patient-centered care. *IJFAB: International Journal of Feminist Approaches to Bioethics*, 4(2), 79–101. https://doi.org/10.3138/ijfab.4.2.79
- Emanuel, E. J. (Ed.). (2008). The Oxford textbook of clinical research ethics. Oxford University Press.
- Emanuel, E. J., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *JAMA: The Journal of the American Medical Association*, *283*(20), 2701–2711.
- Entwistle, V., Carter, S. M., Cribb, A., & McCaffery, K. (2010). Supporting patient autonomy: The importance of clinician-patient relationships. *Journal of General Internal Medicine*, 25(7), 741– 745. https://doi.org/10.1007/s11606-010-1292-2
- Entwistle, V., Cribb, A., & Owens, J. (2018). Why health and social care support for people with longterm conditions should be oriented towards enabling them to live well. *Health Care Analysis*, 26, 48–65. https://doi.org/10.1007/s10728-016-0335-1

 Entwistle, V., Firnigl, D., Ryan, M., Francis, J., & Kinghorn, P. (2012). Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. *Journal of Health Services Research & Policy*, *17*(2), 70–78. https://doi.org/10.1258/jhsrp.2011.011029

Entwistle, V., & Watt, I. S. (2013). Treating patients as persons: A capabilities approach to support delivery of person-centered care. *The American Journal of Bioethics*, *13*(8), 29–39. https://doi.org/10.1080/15265161.2013.802060

Epstein, R. (2017). Attending: Medicine, mindfulness and humanity. Scribner.

- Epstein, R., Fiscella, K., Lesser, C., & Stange, K. (2010). Why the nation needs a policy push on patientcentered health care. *Health Affairs*, *29*(8), 1489–1495.
- Ermine, W. (2007). The ethical space of engagement. Indigenous Law Journal, 6(1), 193-203.
- Ezzat, H., Ross, S., Dadelszen, P. V., Morris, T., Liston, R., & Magee, L. A. (2010). Ethics review as a component of institutional approval for a multicentre continuous quality improvement project: The investigator's perspective. *BMC Health Services Research*, 10(1), 223.
- Faden, R. R., Kass, N. E., Goodman, S. N., Pronovost, P. J., Tunis, S., & Beauchamp, T. L. (2013). An ethics framework for a learning health care system: A departure from traditional research ethics and clinical ethics. *The Hastings Center Report, Spec*(Jan-Feb), S16–27.
- Fan, E., Laupacis, A., Pronovost, P. J., Guyatt, G. H., & Needham, D. M. (2010). How to Use an Article About Quality Improvement. JAMA: The Journal of the American Medical Association, 304(20), 2279–2287.
- Farmanova, E., Kirvan, C., Verma, J., Mukerji, G., Akunov, N., Phillips, K., & Samis, S. (2016). Triple Aim in Canada: Developing capacity to lead to better health, care and cost. *International Journal* for Quality in Health Care. https://doi.org/10.1093/intqhc/mzw118
- Fine, P., Eames, K., & Heymann, D. L. (2011). "Herd immunity": A rough guide. *Clinical Infectious Diseases*, 52(7), 911–916. https://doi.org/10.1093/cid/cir007

- First Nations Health Authority. (n.d.-a). 7 *Directives*. Retrieved June 28, 2019, from www.fnha.ca/about/fnha-overview/directives
- First Nations Health Authority. (n.d.-b). Creating a climate for change: Cultural safety and humility in health services delivery for First Nations and Aboriginal Peoples in British Columbia. Retrieved June 28, 2019, from www.fnha.ca/Documents/FNHA-Creating-a-Climate-For-Change-Cultural-Humility-Resource-Booklet.pdf
- First Nations Health Authority. (n.d.-c). *Cultural safety and humility: Key drivers and ideas for change*. Retrieved June 28, 2019, from www.fnha.ca/Documents/FNHA-Cultural-Safety-and-Humility-Key-Drivers-and-Ideas-for-Change.pdf
- First Nations Health Authority. (n.d.-d). *First Nations perspective on health and wellness*. Retrieved June 28, 2019, from www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/first-nations-perspective-on-wellness
- First Nations Health Authority. (n.d.-e). *Policy statement on cultural safety and humility*. Retrieved June 28, 2019, from www.fnha.ca/Documents/FNHA-Policy-Statement-Cultural-Safety-and-Humility.pdf
- First Nations Health Authority. (n.d.-f). *Research, knowledge exchange, and evaluation*. Retrieved July 7, 2019, from www.fnha.ca/what-we-do/research-knowledge-exchange-and-evaluation
- Fiscella, K., Tobin, J. N., Carroll, J. K., He, H., & Ogedegbe, G. (2015). Ethical oversight in quality improvement and quality improvement research: New approaches to promote a learning health care system. *BMC Medical Ethics*, *16*(1), 63. https://doi.org/10.1186/s12910-015-0056-2
- Flaming, D. (2017). Appropriate ethics review is required. *Healthcare Management Forum*, *30*(1), 46–48. https://doi.org/10.1177/0840470416669926
- Flannigan, K. (2015). Asking for hand hygiene: Are patients comfortable asking, and, are healthcare providers comfortable being asked? *The Canadian Journal of Infection Control, Summer 2015*, 105–109.

Fond, M., Volmert, A., Levay, K., L'Hôte, E., & Kendall-Taylor, N. (2017). Safety is more than caring: Mapping the gaps between expert, public, and health care professionals understandings of patient safety. FrameWorks Institute.

www.betsylehmancenterma.gov/assets/uploads/FW\_MapTheGaps\_Final.pdf

- Ford, J. D., & Russo, E. (2006). Trauma-focused, present-centered, emotional self-regulation approach to integrated treatment for posttraumatic stress and addiction: Trauma Adaptive Recovery Group Education and Therapy (TARGET). *American Journal of Psychotherapy*, 60(4), 335–355. https://doi.org/10.1176/appi.psychotherapy.2006.60.4.335
- Frampton, S., Guastello, S., Brady, C., Hale, M., Horowitz, S., Bennett Smith, S., & Stone, S. (2008). *Patient-centred care improvement guide*. Planetree, Inc. and Picker Institute.
- Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive summary*. The Stationery Office. www.gov.uk/government/publications/report-of-the-mid-staffordshire-nhs-foundation-trust-public-inquiry
- Frosch, D. L., May, S. G., Rendle, K. A. S., Tietbohl, C., & Elwyn, G. (2012). Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Affairs*, 31(5), 1030–1038. https://doi.org/10.1377/hlthaff.2011.0576
- Fry, S. T., Veatch, R. M., & Taylor, C. R. (2011). Case studies in nursing ethics (4th ed.). Jones and Bartlett Learning.
- Gallacher, K., May, C., Langhorne, P., & Mair, F. S. (2018). A conceptual model of treatment burden and patient capacity in stroke. *BMC Family Practice*, 19(1), 9. https://doi.org/10.1186/s12875-017-0691-4
- Gandhi, T. K., Feeley, D., & Schummers, D. (2020). Zero Harm in Health Care. *NEJM Catalyst*, 1(2). https://doi.org/10.1056/CAT.19.1137
- Garfat, T. (2016). Nudging the development of relational safety. *CYC-Online: E-Journal of the International Child and Youth Network*, 213, 2–4.

- Gawande, A. (2007a, December 10). The checklist: If something so simple can transform intensive care, what else can it do? *The New Yorker*. www.newyorker.com/magazine/2007/12/10/the-checklist
- Gawande, A. (2007b, December 30). A lifesaving checklist. *The New York Times*. www.nytimes.com/2007/12/30/opinion/30gawande.html?mcubz=1
- Geller, S. M., & Porges, S. W. (2014). Therapeutic presence: Neurophysiological mechanisms mediating feeling safe in therapeutic relationships. *Journal of Psychotherapy Integration*, 24(3), 178–192. https://doi.org/10.1037/a0037511
- Gerlach, A. J. (2012). A critical reflection on the concept of cultural safety. *Canadian Journal of Occupational Therapy*, 79(3), 151–158. https://doi.org/10.2182/cjot.2012.79.3.4
- Gerteis, M., Edgman-Levitan, S., Daley, J., & Delbanco, T. L. (Eds.). (1993). *Through the patient's eyes: Understanding and promoting patient-centered care*. Jossey-Bass Publishers.
- Gill, R., Barbour, J., & Dean, M. (2014). Shadowing in/as work: Ten recommendations for shadowing fieldwork practice. *Qualitative Research in Organizations and Management: An International Journal*, 9(1), 69–89. https://doi.org/10.1108/QROM-09-2012-1100
- Gillon, R. (2015). Defending the four principles approach as a good basis for good medical practice and therefore for good medical ethics. *Journal of Medical Ethics*, 41(1), 111–116. https://doi.org/10.1136/medethics-2014-102282
- Ginter, A. C., & Braun, B. (2014). Single mothers with breast cancer: Relationships with their children. In
   J. H. McCormick & S. L. Blair (Eds.), *Family relationships and familial responses to health issues* (pp. 163–182). Emerald. http://site.ebrary.com/id/10978421

Given, L. M. (Ed.). (2008). The Sage encyclopedia of qualitative research methods. Sage Publications.

- Gladwell, M. (2013). Blink: The power of thinking without thinking. Back Bay Books.
- Glasby, J. (2019). The short guide to health and social care. Policy Press.
- Glickman, S., Boulding, W., Manary, M., Staelin, R., Roe, M., Wolosin, R., Ohman, E., Peterson, E., & Schulman, K. (2010). Patient satisfaction and its relationship with clinical Saskatchewan quality

and inpatient mortality in acute myocardial infarction. *Circulation Cardiovascular Quality and Outcomes*, *3*, 188–195.

- Goderis, G., Borgermans, L., Mathieu, C., Van Den Broeke, C., Hannes, K., Heyrman, J., & Grol, R. P.
  (2009). Barriers and facilitators to evidence based care of type 2 diabetes patients: Experiences of general practitioners participating to a quality improvement program. *Implementation Science: IS*, *4*, 41. https://doi.org/10.1186/1748-5908-4-41
- Goldenberg, M. (2012). Defining "quality of care" persuasively. *Theoretical Medicine and Bioethics*, 33(4), 243–61.
- Goldman, B. (2015, July 6). Ageism still rampant in health care [CBC Radio]. *White Coat, Black Art.* www.cbc.ca/radio/whitecoat/blog/ageism-still-rampant-in-health-care-1.3139864
- Goldman, B. (2018a, September 21). How Alan Alda went from playing a doctor on TV to teaching doctors about empathy. In *White Coat Black Art*. Canadian Broadcasting Corporation. www.cbc.ca/listen/shows/white-coat-black-art/episode/15602298
- Goldman, B. (2018b, October 10). An ER doctor sees the health care system through a patient's eyes. *Chatelaine*. www.chatelaine.com/living/features-living/behind-the-curtain-hospital-code-fromcanadian-patient-perspective/
- Goldstein, C. E., Weijer, C., Brehaut, J. C., Campbell, M., Fergusson, D. A., Grimshaw, J. M., Hemming, K., Horn, A. R., & Taljaard, M. (2018). Accommodating quality and service improvement research within existing ethical principles. *Trials*, *19*(1). https://doi.org/10.1186/s13063-018-2724-2
- Goldstein, H., & Olswang, L. (2017). Is there a science to facilitate implementation of evidence-based practices and programs? *Evidence-Based Communication Assessment and Intervention*, 11(3–4), 55–60. https://doi.org/10.1080/17489539.2017.1416768
- Goodman, D., Ogrinc, G., Davies, L., Baker, G. R., Barnsteiner, J., Foster, T. C., Gali, K., Hilden, J., Horwitz, L., Kaplan, H. C., Leis, J., Matulis, J. C., Michie, S., Miltner, R., Neily, J., Nelson, W.

A., Niedner, M., Oliver, B., Rutman, L., ... Thor, J. (2016). Explanation and elaboration of the SQUIRE (Standards for QUality Improvement Reporting Excellence) Guidelines, V.2.0:
Examples of SQUIRE elements in the healthcare improvement literature. *BMJ Quality & Safety*, 25(12), e7–e7. https://doi.org/10.1136/bmjqs-2015-004480

- Goodman, J., McElligott, A., & Marks, L. (Eds.). (2003). Useful bodies: Humans in the service of medical science in the twentieth century. Johns Hopkins University Press.
- Gordon, S., Hayes, L., & Reeves, S. (2013). *Bedside manners: Play and workbook.* ILR Press, an imprint of Cornell University Press.
- Gould, D. J., Moralejo, D., Drey, N., Chudleigh, J. H., & Taljaard, M. (2017). Interventions to improve hand hygiene compliance in patient care. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD005186.pub4
- Canada Health Act, R.S.C., c. C-6 (1985). http://laws-lois.justice.gc.ca
- Food and Drugs Act, R.S.C., c. F-27 (1985). https://laws.justice.gc.ca/eng/acts/F-27/
- Grady, C. (2007). Quality improvement and ethical oversight. *Annals of Internal Medicine*, *146*(9), 680–681.
- Graham, B., Endacott, R., Smith, J. E., & Latour, J. M. (2019). 'They do not care how much you know until they know how much you care': A qualitative meta-synthesis of patient experience in the emergency department. *Emergency Medicine Journal*, *36*(6), 355–363. https://doi.org/10.1136/emermed-2018-208156
- Graham, C., Käsbauer, S., Cooper, R., King, J., Sizmur, S., Jenkinson, C., & Kelly, L. (2018). An evaluation of a near real-time survey for improving patients' experiences of the relational aspects of care: A mixed-methods evaluation. *Health Services and Delivery Research*, 6(15), 1–174. https://doi.org/10.3310/hsdr06150

Grainger, K., & Pointon, C. (2017). Hello My Name Is ... https://hellomynameis.org.uk

- Grant, S., & Collier, A. (2018). Safety and wellbeing as spatial capacities: An analysis from two ethnographic studies in primary care and palliative care contexts. *Health & Place*, 54, 244–252. https://doi.org/10.1016/j.healthplace.2018.08.020
- Grant, V. J. (2002). Everyday ethics in an acute psychiatric unit. *Journal of Medical Ethics*, 28(3), 173–176. https://doi.org/10.1136/jme.28.3.173
- Greene, J., Farley, D., Amy, C., & Hutcheson, K. (2018). How patient partners influence quality improvement efforts. *The Joint Commission Journal on Quality and Patient Safety*, 44(4), 186– 195. https://doi.org/10.1016/j.jcjq.2017.09.006
- Greenhalgh, T. (2009). Patient and public involvement in chronic illness: Beyond the expert patient. *BMJ*, 338(feb17 1), b49–b49. https://doi.org/10.1136/bmj.b49
- Greenhalgh, T, Annandale, E., Ashcroft, R., Barlow, J., Black, N., Bleakley, A., Boaden, R., Braithwaite, J., Britten, N., Carnevale, F., Checkland, K., Cheek, J., Clark, A., Cohn, S., Coulehan, J., Crabtree, B., Cummins, S., Davidoff, F., Davies, H., ... Ziebland, S. (2016). An open letter to The BMJ editors on qualitative research. *BMJ*, i563. https://doi.org/10.1136/bmj.i563
- Greenhalgh, T, & Papoutsi, C. (2018). Studying complexity in health services research: Desperately seeking an overdue paradigm shift. *BMC Medicine*, *16*(1). https://doi.org/10.1186/s12916-018-1089-4
- Greenhalgh, T, Robert, G., Bate, P., MacFarlane, F., & Kyriakidou, O. (2005). *Diffusion of innovations in health service organisations: A systematic literature review*. Blackwell.
- Greenhalgh, T, Robert, G., MacFarlane, F., Bate, P., & Kyriakidou, O. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *The Milbank Quarterly*, 82(4), 581–629.
- Greenhalgh, T., & Papoutsi, C. (2019). Spreading and scaling up innovation and improvement. *BMJ* (*Clinical Research Ed.*), 365, 12068. https://doi.org/10.1136/bmj.12068

- Griffin, G. (2017). Othering. In *Dictionary of Gender Studies*. Oxford University Press. www.oxfordreference.com.ezproxy.library.ubc.ca/view/10.1093/acref/9780191834837.001.0001/ acref-9780191834837-e-283.
- Groene, O., Lombarts, M. J. M. H., Klazinga, N. S., Alonso, J., Thompson, A., & Suñol, R. (2009). Is patient-centredness in European hospitals related to existing quality improvement strategies?
  Analysis of a cross-sectional survey (MARQuIS study). *Quality & Safety in Health Care*, *18*(Suppl I), i44–i50. https://doi.org/10.1136/qshc.2008.029397
- Grol, R. P., Bosch, M. C., Hulscher, M. E. J. L., Eccles, M. P., & Wensing, M. (2007). Planning and studying improvement in patient care: The use of theoretical perspectives. *The Milbank Quarterly*, 85(1), 93–138.
- Grol, R. P., Wensing, M., Eccles, M. P., & Davis, D. (Eds.). (2013). Improving patient care: The implementation of change in health care (2nd.). Wiley Blackwell.
- Guba, E. G. (1990). The alternative paradigm dialog. In E. G. Guba (Ed.), *The paradigm dialog* (pp. 17–30). Sage.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications.
- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (3rd ed., pp. 191–215). Sage.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry*, *10*, 261–280. https://doi.org/10.1177/1077800403262360
- Hadibhai, S., Lacroix, J., & Leeb, K. (2018). Developing the first pan-Canadian acute care patient experiences survey. *Patient Experience Journal*, 5(3), 25–33. https://doi.org/10.35680/2372-0247.1227

- Hagen, B., O'Beirne, M., Desai, S., Stingl, M., Pachnowski, C. A., & Hayward, S. (2007). Innovations in the Ethical Review of Health-Related Quality Improvement and Research: The Alberta Research Ethics Community Consensus Initiative (ARECCI). *Healthcare Policy*, 4(2), e164–e177.
- Hakanson, C., & Ohlen, J. (2016). Illness narratives of people who are homeless. *International Journal of Qualitative Studies on Health and Well-Being*, 11(1), 32924. https://doi.org/10.3402/ghw.v11.32924
- Hall, S., Lee, V., & Haase, K. (2020). Exploring the challenges of ethical conduct in quality improvement projects. *Canadian Oncology Nursing Journal*, 30(1), 64–68.
- Halm, E. A., & Siu, A. L. (2005). Are quality improvement messages registering? *Health Services Research*, 40(2), 311–315. https://doi.org/10.1111/j.1475-6773.2005.00357.x
- Hammersley, M., & Atkinson, P. (2007). Ethnography: Principles in practice (3rd ed.). Routledge.
- Harrigan, M. (2000). Quest for quality in Canadian health care: Continuous quality improvement. Health Canada.
- Harris, R., Sims, S., Leamy, M., Levenson, R., Davies, N., Brearley, S., Grant, R., Gourlay, S., Favato,
  G., & Ross, F. (2019). *Intentional rounding in hospital wards to improve regular interaction and engagement between nurses and patients: A realist evaluation*. NIHR Journals Library.
  www.ncbi.nlm.nih.gov/books/NBK547460/
- Hart, S., Dixon, A., Drummond, M. J., & McIntyre, D. (2004). *Learning without limits*. Open University Press.
- Havens, D. S., Gittell, J. H., & Vasey, J. (2018). Impact of Relational Coordination on Nurse Job Satisfaction, Work Engagement and Burnout: Achieving the Quadruple Aim. *The Journal of Nursing Administration*, 48(3), 132–140. https://doi.org/10.1097/NNA.00000000000587
- Hawkins, M. (2013). *A precarious journey: Experiences of nurses from the Philippines seeking RN licensure and employment in Canada*. University of British Columbia.

Hayes, C. W., & Goldmann, D. (2018). Highly Adoptable Improvement: A Practical Model and Toolkit to Address Adoptability and Sustainability of Quality Improvement Initiatives. *The Joint Commission Journal on Quality and Patient Safety*, 44(3), 155–163.
https://doi.org/10.1016/j.jcjq.2017.09.005

- Haynes, A. B., Weiser, T. G., Berry, W. R., Lipsitz, S. R., Breizat, A.-H. S., Dellinger, E. P., Herbosa, T., Joseph, S., Kibatala, P. L., Lapitan, M. C. M., Merry, A. F., Moorthy, K., Reznick, R. K., Taylor, B., & Gawande, A. A. (2009). A surgical safety checklist to reduce morbidity and mortality in a global population. *New England Journal of Medicine*, *360*(5), 491–499. https://doi.org/10.1056/NEJMsa0810119
- Heale, R., & Twycross, A. (2018). What is a case study? *Evidence Based Nursing*, 21(1), 7–8. https://doi.org/10.1136/eb-2017-102845
- Health Council of Canada. (2013). Which way to quality? Key perspectives on quality improvement in Canadian health care systems. Health Council of Canada.
- Health Quality Ontario. (2016). Ontario patient experience measurement strategy. https://hqontario.ca/Portals/0/documents/system-performance/patient-experience-measurementstrategy-1608-en.pdf
- Health Quality Ontario. (2017). *Quality matters: Realizing excellent care for all.* www.hqontario.ca/Portals/0/documents/health-quality/realizing-excellent-care-for-all-1704en.pdf
- Health Quality Ontario (HQO). (2012). *Quality improvement guide*. Queen's Printer for Ontario. www.hqontario.ca/portals/0/Documents/qi/qi-quality-improve-guide-2012-en.pdf

Health Research Council Act, Sections 24 and 25, (1990). www.legislation.govt.nz

Heller, J. (1972, July 26). Syphilis victims in U.S. study went untreated for 40 years. New York Times. www.nytimes.com/1972/07/26/archives/syphilis-victims-in-us-study-went-untreated-for-40years-syphilis.html Hendricks, R., O'Neil, M., & Volmert, A. (2019). How to talk about patient safety: A FrameWorks MessageMemo. FrameWorks Institute. www.betsylehmancenterma.gov/assets/uploads/Patient-Safety-MessageMemo-2019.pdf

Henriques, G. (2011). A new unified theory of psychology. Springer.

- Henriques, G. (2017). Character adaptation systems theory: A new big five for personality and psychotherapy. *Review of General Psychology*, 21(1), 9–22. https://doi.org/10.1037/gpr0000097
- Henry, B. (2009). Soap and water & common sense: The definitive guide to viruses, bacteria, parasites, and disease. House of Anansi Press.
- Henry, R., Tait, C., & STR8 UP. (2017). Creating ethical research partnerships: Relational accountability in action. *Engaged Scholar Journal: Community-Engaged Research, Teaching, and Learning*, 2(1), 183–204.
- Hernández, P. (2008). The cultural context model in clinical supervision. *Training and Education in Professional Psychology*, 2(1), 10–17. https://doi.org/10.1037/1931-3918.2.1.10
- Hernández, P., & McDowell, T. (2010). Intersectionality, power, and relational safety in context: Key concepts in clinical supervision. *Training and Education in Professional Psychology*, 4(1), 29– 35. https://doi.org/10.1037/a0017064
- Hernández, P., & Rankin, P. (2008). Relational safety and liberating training spaces: An application with a focus on sexual orientation issues. *Journal of Marital and Family Therapy*, 34(2), 251–264. https://doi.org/10.1111/j.1752-0606.2008.00067.x
- Heron, J., & Reason, P. (1997). A participatory inquiry paradigm. *Qualitative Inquiry*, 3, 274–294.
- Hickerson, K. A. (2017). Checklists for New Graduates. *The Journal of Continuing Education in Nursing*, 48(11), 494–495. https://doi.org/10.3928/00220124-20171017-05
- Hilton, K., & Anderson, A. (2018). IHI Psychology of Change Framework to advance and sustain improvement. Institute for Healthcare Improvement. www.ihi.org

- Hoffmaster, B. (2018). From applied ethics to empirical ethics to contextual ethics. *Bioethics*, *32*(2), 119–125. https://doi.org/10.1111/bioe.12419
- Hogan, L., Bengoechea, E. G., Salsberg, J., Jacobs, J., King, M., & Macaulay, A. C. (2014). Using a participatory approach to the development of a school-based physical activity policy in an Indigenous Community. *Journal of School Health*, 84(12), 786–792.
  https://doi.org/10.1111/josh.12214
- Hollnagel, E. (2012). FRAM, the functional resonance analysis method: Modelling complex sociotechnical systems. Ashgate. www.crcnetbase.com/isbn/

Hollnagel, E. (2014). Safety-I and Safety-II: the past and future of safety management. Ashgate.

- Hollnagel, E. (2015). Why is Work-as-Imagined different from Work-as-Done? In R. L. Wears, E.
  Hollnagel, & J. Braithwaite (Eds.), *The resilience of everyday clinical work* (Vol. 2, pp. 249–264). Ashgate Publishing, Ltd.
- Hor, S., Godbold, N., Collier, A., & Iedema, R. (2013). Finding the patient in patient safety. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 17(6), 567–583. https://doi.org/10.1177/1363459312472082
- Howe, L. C., Leibowitz, K. A., & Crum, A. J. (2019). When Your doctor "Gets It" and "Gets You": The critical role of competence and warmth in the patient–provider interaction. *Frontiers in Psychiatry*, 10, 475. https://doi.org/10.3389/fpsyt.2019.00475

Hradcová, D. (2017). Relational approach to ethics and quality improvement in institutional care for people with dementia. *Annals of Palliative Medicine*, 6(4), 319–326. https://doi.org/10.21037/apm.2017.06.20

Hrisos, S., & Thomson, R. (2013). Seeing it from both sides: Do approaches to involving patients in improving their safety risk damaging the trust between patients and healthcare professionals? An interview study. *PLoS ONE*, 8(11), 1–11. https://doi.org/10.1371/journal.pone.0080759

- Huminuik, K. (2017). Vulnerability in the Canadian refugee determination arena: An interpretive description study. The University of British Columbia.
- Humphrey Beebe, L., & Smith, K. (2010). Informed consent to research in persons with schizophrenia spectrum disorders. *Nursing Ethics*, *17*(4), 425–434. https://doi.org/10.1177/0969733010364581

Hunt, M. (2008). Ethics of health care practice in humanitarian crises. McGill University.

- Hunt, M., Tansey, C. M., Anderson, J., Boulanger, R. F., Eckenwiler, L., Pringle, J., & Schwartz, L. (2016). The challenge of timely, responsive and rigorous ethics review of disaster research: Views of research ethics committee members. *PLOS ONE*, *11*(6), e0157142. https://doi.org/10.1371/journal.pone.0157142
- Huq, J.-L., & Woiceshyn, J. (2018). Relational connecting in complex quality improvement initiatives (abstract). Academy of Management Proceedings, 2018(1), 15161. https://doi.org/10.5465/AMBPP.2018.15161abstract
- Hutchison, B., Abelson, J., & Lavis, J. (2001). Primary care in Canada: So much innovation, so little change. *Health Affairs*, 20(3), 116–131. https://doi.org/10.1377/hlthaff.20.3.116
- Iedema, R., & Angell, B. (2015). What are patients' care experience priorities? *BMJ Quality & Safety*, 24(6), 356–359. https://doi.org/10.1136/bmjqs-2015-004298

Illich, I. (1974). Medical nemesis. Lancet, 303(7863), 919–922.

Illingworth, J. (2015). *Continuous improvement of patient safety: The case for change in the NHS*. The Health Foundation.

www.health.org.uk/sites/default/files/ContinuousImprovementPatientSafety.pdf

Institute for Family-Centered Care and Institute for Healthcare Improvement. (2008). Partnering with patients and families to design a patient-and family-centered health care system: Recommendations and promising practices.

https://psnet.ahrq.gov/resources/resource/7362/partnering-with-patients-and-families-to-design-a-patient--and-family-centered-health-care-system-recommendations-and-promising-practices

Institute for Healthcare Improvement. (2017). *QI essentials toolkit*. Institute for Healthcare Improvement. Institute for Healthcare Improvement. (2018). *Quality Improvement Project Charter*.

www.ihi.org/resources/Pages/Tools/QI-Project-Charter.aspx

- Institute for Healthcare Improvement. (2019). Patient safety essentials toolkit. Institute for Healthcare Improvement. www.ihi.org
- Institute for Patient- and Family-Centered Care. (n.d.). *Patient- and family-centered care*. Retrieved June 28, 2019, from www.ipfcc.org/about/pfcc.html
- Institute of Medicine (IOM). (1990). *Medicare: A strategy for quality assurance, vol. 1*. National Academy Press.
- Institute of Medicine (US) Committee on Quality of Health Care in America. (2000). *To err is human: Building a safer health system* (L. T. Kohn, J. M. Corrigan, & M. S. Donaldson, Eds.). National Academies Press.
- Institute of Medicine (US) Committee on Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century*. National Academies Press.

Interior Health. (2014). AL1600—Project Ethics Policy.

www.interiorhealth.ca/AboutUs/Policies/Documents/Project%20Ethics.pdf

- International Association for Public Participation. (2007). *IAP2 spectrum of public participation*. www.iap2.org
- International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use. (2016). *ICH Harmonised Tripartite Guideline – Guideline for Good Clinical Practice* (E6(R2)).

https://database.ich.org/sites/default/files/E6\_R2\_Addendum.pdf

Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report*, *17*(42), 1–10.

- Jamieson, M., Chen, S.-P., Murphy, S., Maracle, L., Mofina, A., & Hill, J. (2017). Pilot testing an intervention on cultural safety and Indigenous health in a Canadian occupational therapy curriculum. *Journal of Allied Health*, 46(1), E1.
- Jardine, C. G. (2008). Considerations in planning for successful risk communication. In E. L. Melnick & B. S. Everitt (Eds.), *Encyclopedia of Quantitative Risk Analysis and Assessment* (pp. 362–365). John Wiley & Sons, Ltd. https://doi.org/10.1002/9780470061596.risk0009
- Jeffrey, P., Harris, R., & Sherman, J. (2019). Quality improvement: A practical nursing program's admission test. *Nurse Education Today*, *73*, 65–70. https://doi.org/10.1016/j.nedt.2018.11.016
- Jennings, B., Baily, M. A., Bottrell, M., & Lynn, J. (Eds.). (2007). *Health care quality improvement: Ethical and regulatory issues*. The Hastings Center.
- John Hopkins Berman Institute of Bioethics. (n.d.). *What is bioethics?* Retrieved January 2, 2020, from https://bioethics.jhu.edu/about/what-is-bioethics/
- Johnson, J. K., & Sollecito, W. A. (2018a). Future trends and challenges for continuous quality improvement in health care. In J. K. Johnson & W. A. Sollecito (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed., pp. 701–753). Jones & Bartlett.
- Johnson, J. K., & Sollecito, W. A. (Eds.). (2018b). *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed.). Jones & Bartlett.
- Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and being othered in the context of health care services. *Health Communication*, 16(2), 255–271. https://doi.org/10.1207/S15327027HC1602\_7
- Jones, B., Vaux, E., & Olsson-Brown, A. (2019). How to get started in quality improvement. *BMJ*, k5408. https://doi.org/10.1136/bmj.k5437

- Jones, E. L., Lees, N., Martin, G., & Dixon-Woods, M. (2016). How Well Is Quality Improvement Described in the Perioperative Care Literature? A Systematic Review. *Joint Commission Journal* on Quality and Patient Safety, 42(5), 196–206. https://doi.org/10.1016/s1553-7250(16)42025-8
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, *19*(11), 1632–1641.
- Kalanithi, P., & Verghese, A. (2016). When breath becomes air. Random House.
- Kalengayi, F. K. N., Hurtig, A.-K., Ahlm, C., & Ahlberg, B. M. (2012). "It is a challenge to do it the right way": An interpretive description of caregivers' experiences in caring for migrant patients in Northern Sweden. *BMC Health Services Research*, 12(1), 433–433.
- Kaplan, H. C., Brady, P. W., Dritz, M. C., Hooper, D. K., Linam, W. M., Froehle, C. M., & Margolis, P. (2010). The influence of context on quality improvement success in health care: A systematic review of the literature: quality improvement success in health care. *Milbank Quarterly*, 88(4), 500–559. https://doi.org/10.1111/j.1468-0009.2010.00611.x
- Kaplan, H. C., Provost, L. P., Froehle, C. M., & Margolis, P. A. (2012). The Model for Understanding Success in Quality (MUSIQ): Building a theory of context in healthcare quality improvement. *BMJ Quality & Safety*, 21(1), 13–20. https://doi.org/10.1136/bmjqs-2011-000010
- Kass, N. E., Faden, R. R., Goodman, S. N., Pronovost, P. J., Tunis, S., & Beauchamp, T. L. (2013). The research-treatment distinction: A problematic approach for determining which activities should have ethical oversight. *The Hastings Center Report, Spec No*(February), S4–S15.
- Kass, N. E., Pronovost, P. J., Sugarman, J., Goeschel, C. A., Lubomski, L. H., & Faden, R. R. (2008). Controversy and quality improvement: Lingering questions about ethics, oversight, and patient safety research. *Joint Commission Journal of Quality and Patient Safety*, 34(6), 349–353.
- Katzan, I. L., & Lapin, B. (2018). PROMIS GH (Patient-Reported Outcomes Measurement Information System Global Health) Scale in Stroke: A Validation Study. *Stroke*, 49(1), 147–154. https://doi.org/10.1161/STROKEAHA.117.018766

- Kean, S. (2018, July 30). Why doctors should read fiction: Could a simple literary exercise make physicians more caring? *The Atlantic*. www.theatlantic.com/health/archive/2018/07/medicinedoctors-fiction/566342/
- Kelleher, D., Gabe, J., & Williams, G. (Eds.). (2006). Challenging medicine (Second). Routledge.
- Kelly, L., Sizmur, S., Käsbauer, S., King, J., Cooper, R., Jenkinson, C., & Graham, C. (2018). The Relational Aspects of Care Questionnaire: Item reduction and scoring using inpatient and accident and emergency data in England. *Patient Related Outcome Measures, Volume 9*, 173– 181. https://doi.org/10.2147/PROM.S157213
- Kemp, K. A., Santana, M. J., Southern, D. A., McCormack, B., & Quan, H. (2016). Association of inpatient hospital experience with patient safety indicators: A cross-sectional, Canadian study. *BMJ Open*, 6(7), e011242. https://doi.org/10.1136/bmjopen-2016-011242
- Kenny, N. P., Sherwin, S. B., & Baylis, F. E. (2010). Re-visioning public health ethics: A relational perspective. *Canadian Journal of Public Health*, 101(1), 9–11.
- Kim, M.-K., Nam, E. Y., Na, S. H., Shin, M., Lee, H. S., Kim, N.-H., Kim, C.-J., Song, K.-H., Choe, P. G., Park, W. B., Bang, J.-H., Kim, E. S., Park, S. W., Kim, N. J., Oh, M., & Kim, H. B. (2015). Discrepancy in perceptions regarding patient participation in hand hygiene between patients and health care workers. *American Journal of Infection Control*, *43*(5), 510–515. https://doi.org/10.1016/j.ajic.2015.01.018
- Kimble, L., & Massoud, M. R. (2017). What do we mean by innovation in healthcare? *European Medical Journal Innovation*, *1*(1), 89–91.

Kish, L. (2012, August 28). The blockbuster drug of the century: An engaged patient. *Health Standards: Expanding Conversation on Healthcare Technology*. http://healthstandards.com/blog/2012/08/28/drug-of-the-century/

- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4–15. https://doi.org/10.1111/j.1365-2648.2012.06064.x
- Kitson, A., Muntlin Athlin, Å., & Conroy, T. (2014). Anything but basic: Nursing's challenge in meeting patients' fundamental care needs. *Journal of Nursing Scholarship*, 46(5), 331–339. https://doi.org/10.1111/jnu.12081
- Kitto, S., Bell, M., Peller, J., Sargeant, J., Etchells, E., Reeves, S., & Silver, I. (2013). Positioning Continuing Education: Boundaries and Intersections Between the Domains Continuing Education, Knowledge Translation, Patient Safety and Quality Improvement. *Advances in Health Sciences Education*, 18(1), 141–56.

Kleinman, S., & Copp, M. A. (1993). Emotions and fieldwork. Sage.

- Klingler, C., Barrett, D. H., Ondrusek, N., Johnson, B. R., Saxena, A., & Reis, A. A. (2020). Beyond research ethics: Novel approaches of 3 major public health institutions to provide ethics input on public health practice activities. *Journal of Public Health Management and Practice*, 26(2), E12– E22. https://doi.org/10.1097/PHH.000000000000734
- Knudson-Martin, C., Huenergardt, D., Lafontant, K., Bishop, L., Schaepper, J., & Wells, M. (2015).
  Competencies for Addressing Gender and Power in Couple Therapy: A Socio Emotional
  Approach. *Journal of Marital and Family Therapy*, *41*(2), 205–220.
  https://doi.org/10.1111/jmft.12068
- Koczwara, B., Stover, A. M., Davies, L., Davis, M. M., Fleisher, L., Ramanadhan, S., Schroeck, F. R., Zullig, L. L., Chambers, D. A., & Proctor, E. (2018). Harnessing the synergy between improvement science and implementation science in cancer: A call to action. *Journal of Oncology Practice*, 14(6), 335–340. https://doi.org/10.1200/JOP.17.00083

- Kofke, W. A., & Rie, M. A. (2003). Research ethics and law of healthcare system quality improvement: The conflict of cost containment and quality: *Critical Care Medicine*, *31*(Supplement), S143– S152. https://doi.org/10.1097/01.CCM.0000054902.85329.50
- Kornhaber, R., Walsh, K., Duff, J., & Walker, K. (2016). Enhancing adult therapeutic interpersonal relationships in the acute health care setting: An integrative review. *Journal of Multidisciplinary Healthcare*, *9*, 537–546.
- Kouzes, J. M., & Posner, B. Z. (2017). The leadership challenge (6th ed.). John Wiley & Sons Inc.
- Koven, S. (2016). The doctor's new dilemma. *New England Journal of Medicine*, 374(7), 608–609. https://doi.org/10.1056/NEJMp1513708
- Krever, H. (1997). Final report: Commission of Inquiry on the Blood System in Canada. The Commission.
- Kringos, D. S., Sunol, R., Wagner, C., Mannion, R., Michel, P., Klazinga, N. S., Groene, O., & on behalf of the DUQuE Consortium. (2015). The influence of context on the effectiveness of hospital quality improvement strategies: A review of systematic reviews. *BMC Health Services Research*, *15*(1), 277. https://doi.org/10.1186/s12913-015-0906-0
- Kuehn, B. M. (2008). DHHS halts quality improvement study: Policy may hamper tests of methods to improve care. JAMA, 299(9), 1005–1006. https://doi.org/10.1001/jama.299.9.1005
- Kuhl, D., Appleby, A., Pearson, H., MacNutt, L., & Lotherington, K. (2017). What we know, cures; Who we are, heals. *Transplantation*, 101, S77. https://doi.org/10.1097/01.tp.0000525100.01718.ad
- Kulhan, B. (2013, April 10). Why "Yes, and..." might be the most valuable phrase in business. *Big Think*. http://bigthink.com/experts-corner/why-yes-and-might-be-the-most-valuable-phrase-in-business
- Kuzel, A. J. (2004). Patient reports of preventable problems and harms in primary health care. *The Annals of Family Medicine*, 2(4), 333–340. https://doi.org/10.1370/afm.220
- Kvale, S. (2009). InterViews: Learning the craft of qualitative research interviewing (2nd ed.). Sage.

- Kwok, E. S. H., Perry, J. J., Mondoux, S., & Chartier, L. B. (2019). An environmental scan of quality improvement and patient safety activities in emergency medicine in Canada. *CJEM*, 21(4), 535– 541. https://doi.org/10.1017/cem.2019.16
- Lally, K. M., McCutcheon Adams, K., Zambeaux, A., Joshi, C., & Sokol-Hessner, L. (2019). *How to talk to your patients about end-of-life care: A conversation ready toolkit for clinicians*. Institute for Healthcare Improvement. www.ihi.org
- Landers, T., Abusalem, S., Coty, M.-B., & Bingham, J. (2012). Patient-centered hand hygiene: The next step in infection prevention. *American Journal of Infection Control*, 40(4), S11–S17. https://doi.org/10.1016/j.ajic.2012.02.006
- Langley, G. J., Moen, R., & Nolan, K. M. (2009). Changes that result in improvement. In *The improvement guide: A practical approach to enhancing organizational performance* (2nd ed., pp. 15–25). Jossey-Bass.
- Lawton, R., O'Hara, J. K., Sheard, L., Armitage, G., Cocks, K., Buckley, H., Corbacho, B., Reynolds, C., Marsh, C., Moore, S., Watt, I., & Wright, J. (2017). Can patient involvement improve patient safety? A cluster randomised control trial of the Patient Reporting and Action for a Safe Environment (PRASE) intervention. *BMJ Quality & Safety*, *26*(8), 622–631. https://doi.org/10.1136/bmjqs-2016-005570
- Lázaro-Muñoz, G., Sabatello, M., Huckins, L., Peay, H., Degenhardt, F., Meiser, B., Lencz, T., Soda, T., Docherty, A., Crepaz-Keay, D., Austin, J., Peterson, R. E., Davis, L. K., & on behalf of the ISPG Ethics Committee. (2019). International Society of Psychiatric Genetics Ethics Committee: Issues facing us. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, *180*(8), 543–554. https://doi.org/10.1002/ajmg.b.32736
- Leape, L., Berwick, D., Clancy, C., Conway, J., Gluck, P., Guest, J., Lawrence, D., Morath, J., O'Leary, D., O'Neill, P., Pinakiewicz, D., & Isaac, T. (2009). Transforming healthcare: A safety

imperative. Quality & Safety in Health Care, 18(6), 424-8.

https://doi.org/10.1136/qshc.2009.036954

- Lemov, R. (2011). Brainwashing's avatar: The curious career of Dr. Ewen Cameron. *Grey Room*, 45, 61– 87.
- Leslie, M., Paradis, E., Gropper, M. A., Reeves, S., & Kitto, S. (2014). Applying ethnography to the study of context in healthcare quality and safety. *BMJ Quality & Safety*, 23(2), 99–105. https://doi.org/10.1136/bmjqs-2013-002335
- Liang, L., Cako, A., Urquhart, R., Straus, S. E., Wodchis, W. P., Baker, G. R., & Gagliardi, A. R. (2018).
   Patient engagement in hospital health service planning and improvement: A scoping review. *BMJ Open*, 8(1), e018263. https://doi.org/10.1136/bmjopen-2017-018263
- Lincoln, Y. S., & Guba, E. G. (1985). Naturalistic inquiry. Sage.
- Lincoln, Y. S., & Guba, E. G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 163–188). Sage.
- Lincoln, Y. S., & Guba, E. G. (2003). Ethics: The failure of positivist science. In Y. S. Lincoln & N. K. Denzin (Eds.), *Turning points in qualitative research* (pp. 219–237). AltaMira Press.
- Liska, C. M., Morash, R., Paquet, L., & Stacey, D. (2018). Empowering cancer survivors to meet their physical and psychosocial needs: An implementation evaluation. *Canadian Oncology Nursing Journal*, 28(2), 76–81. https://doi.org/10.5737/236880762827681
- Longtin, Y., Sax, H., Hugonnet, S., Pittet, D., & Allegranzi, B. (2009). Patients' beliefs and perceptions of their participation to increase healthcare worker compliance with hand hygiene. *Infection Control and Hospital Epidemiology*, *30*(9), 830–839.
- Longtin, Y., Sax, H., Leape, L., Sheridan, S. E., Donaldson, L., & Pittet, D. (2010). Patient participation: Current knowledge and applicability to patient safety. *Mayo Clinic Proceedings*, *85*(1), 53–62.

- Longtin, Y., Sheridan, S. E., & McGuckin, M. (2017). Patient participation and empowerment. In D.
  Pittet, J. M. Boyce, & B. Allegranzi (Eds.), *Hand hygiene: A handbook for medical professionals*(1st ed., pp. 206–215). John Wiley & Sons, Inc.
- Lu, A., Koenig, A., & Borries, C. (2008). Formal submission, tolerance and socioecological models: A test with female Hanuman langurs. *Animal Behaviour*, 76(2), 415–428. https://doi.org/10.1016/j.anbehav.2008.04.006
- Lynn, J., Baily, M. A., Bottrell, M., Jennings, B., Levine, R., Davidoff, F., Casarett, D., Corrigan, J., Fox,
  E., Wynia, M., & Agich, G. J. (2007). The ethics of using quality improvement methods in health
  care. *Annals of Internal Medicine*, 146(9), 666–73.

MacIntyre, A. C. (2007). After virtue: A study in moral theory (3rd ed.). University of Notre Dame Press.

- Mack, N., Woodsong, C., MacQueen, K. M., Guest, G., & Namey, E. (2005). Qualitative research methods: A data collector's field guide. Family Health International. www.fhi360.org/resource/qualitative-research-methods-data-collectors-field-guide
- Mackintosh, N. J., Davis, R. E., Easter, A., Rayment-Jones, H., Sevdalis, N., Wilson, S., Adams, M., & Sandall, J. (2017). Interventions to increase patient and family involvement in escalation of care for acute life-threatening illness in community health and hospital settings. *Cochrane Database of Systematic Reviews*. https://doi.org/10.1002/14651858.CD012829
- Maher, L. (2017, November 28). Co designing Health and Care Services for the Partners In Care Programme. Understanding Experience & Co-designing Solutions, Richmond, BC. www.hqsc.govt.nz/assets/Consumer-Engagement/Resources/Dr\_Lynne\_Maher\_-\_Codesigning\_Health\_and\_Care\_Services\_May\_2017.pdf
- Mair, F. S., & May, C. (2014). Thinking about the burden of treatment: Should it be regarded as an indicator of the quality of care? *BMJ*, *349*, g6680. https://doi.org/10.1136/bmj.g6680

- Manafo, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada:
  A scoping review of the 'how' and 'what' of patient engagement in health research. *Health Research Policy and Systems*, 16(1), 5. https://doi.org/10.1186/s12961-018-0282-4
- Marck, P. (2013). Building moral community: Fostering place ethics in twenty-first century health care systems for a healthier world. In *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 215–235). Pearson.
- Marcus, A., & Oransky, I. (n.d.). *Retraction Watch*. Retrieved April 13, 2020, from https://retractionwatch.com
- Marshall, M., Pronovost, P. J., & Dixon-Woods, M. (2013). Promotion of improvement as a science. *The Lancet*, *381*(9864), 419–421. https://doi.org/10.1016/S0140-6736(12)61850-9
- Martin, D. (2017). *Better now: Six big ideas to improve health care for all Canadians*. Penguin Random House.
- Matthews, D. A., Suchman, A. L., & Branch, J. (1993). Making "connexions": Enhancing the therapeutic potential of patient-clinician relationships. *Annals of Internal Medicine*, *118*(12), 973–977.
- Maxwell, J. A. (2013). Qualitative research design: An interactive approach (3rd ed.). Sage Publications.
- May, C. (2007). The clinical encounter and the problem of context. *Sociology*, *41*(1), 29–45. https://doi.org/10.1177/0038038507072282
- May, C. (2013). Agency and implementation: Understanding the embedding of healthcare innovations in practice. *Social Science & Medicine*, 78, 26–33. https://doi.org/10.1016/j.socscimed.2012.11.021
- May, C., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., MacDonald, S., Mair, F. S., May, C. M.,
  Montori, V. M., & Richardson, A. (2014). Rethinking the patient: Using Burden of Treatment
  Theory to understand the changing dynamics of illness. *BMC Health Services Research*, 14(1), 281–281.

- May, C., & Finch, T. (2009). Implementing, embedding, and integrating practices: An outline of Normalization Process Theory. *Sociology*, 43(3), 535–554. https://doi.org/10.1177/0038038509103208
- May, C., Johnson, M., & Finch, T. (2016). Implementation, context and complexity. *Implementation Science: IS*, 11(1), 141. https://doi.org/10.1186/s13012-016-0506-3
- May, C., Mair, F. S., Finch, T., MacFarlane, A., Dowrick, C., Treweek, S., Rapley, T., Ballini, L., Ong,
  B. N., Rogers, A., Murray, E., Elwyn, G., Légaré, F., Gunn, J., & Montori, V. M. (2009).
  Development of a theory of implementation and integration: Normalization Process Theory. *Implementation Science*, 4(1). https://doi.org/10.1186/1748-5908-4-29
- McBride, H. L., Kwee, J. L., & Buchanan, M. J. (2017). Women's healthy body image and the motherdaughter dyad. *Canadian Journal of Counselling and Psychotherapy (Online)*, *51*(2), 97–113.
- McCabe, C. (2004). Nurse-patient communication: An exploration of patients' experiences. *Journal of Clinical Nursing*, *13*(1), 41–49. https://doi.org/10.1111/j.1365-2702.2004.00817.x
- McCarron, T. L., Noseworthy, T., Moffat, K., Wilkinson, G., Zelinsky, S., White, D., Hassay, D., Lorenzetti, D. L., & Marlett, N. J. (2019). Understanding the motivations of patients: A codesigned project to understand the factors behind patient engagement. *Health Expectations*, 22(4), 709–720. https://doi.org/10.1111/hex.12942
- McClimans, Leah. M., Dunn, M., & Slowther, A.-M. (2011). Health policy, patient-centred care and clinical ethics: Policy, patient-centred care and ethics. *Journal of Evaluation in Clinical Practice*, *17*(5), 913–919. https://doi.org/10.1111/j.1365-2753.2011.01726.x
- McDonald, F. (2010). *Patient safety law: Regulatory change in Britain and Canada*. Dalhousie University.
- McDonald, M. (2000). *The governance of health research involving human subjects (HRIHS)*. Law Commission of Canada. www.publications.gc.ca/site/eng/325188/publication.html

- McDonald, M. (2001). Canadian governance of health research involving human subjects: Is anybody minding the store? *Health Law Journal*, *9*, 1–21.
- McDonald, M. (2009). From code to policy statement: Creating Canadian policy for ethical research involving humans. *Health Law Review*, *17*(2–3), 12–25.
- McDonald, M., & Cox, S. M. (2009). Moving toward evidence-based human participant protection. Journal of Academic Ethics, 7(1–2), 1–16.
- McDonald, M., Cox, S. M., & Townsend, A. (2014). Toward human research protection that is evidence based and participant centered. In I. Cohen & H. Fernandez Lynch (Eds.), *Human subjects research regulation: Perspectives on the future* (pp. 113–126). MIT Press.
- McDonald, M., & Meslin, E. M. (2003). Research ethics as social policy: Some lessons from experiences in Canada and the United States. *The Tocqueville Review*, *24*(2), 61–85.
- McDonald, M., Pullman, D., Anderson, J. A., Preto, N., & Sampson, H. (2011). Research ethics in 2020: Strengths, weaknesses, opportunities, and threats. *Health Law Review*, *19*(3), 36–55.
- McDonald, M., Townsend, A., Cox, S. M., Paterson, N. D., & Lafrenière, D. (2008). Trust in health research relationships: Accounts of human subjects. *Journal of Empirical Research on Human Research Ethics*, 3(4), 35–47. https://doi.org/10.1525/jer.2008.3.4.35
- McGavin, C., & Holmes, B. (2014, November). Patient engagement: How can research help us get it right? Northern Health Research Days, BC. www.msfhr.org/sites/default/files/McGavin Holmes Nov10 FINAL.pdf
- McGinnis, M. D., & Ostrom, E. (2014). Social-ecological system framework: Initial changes and continuing challenges. *Ecology and Society*, 19(2). https://doi.org/10.5751/ES-06387-190230
- McGuckin, M., & Govednik, J. (2013). Patient empowerment and hand hygiene, 1997-2012. *Journal of Hospital Infection*, 84(3), 191–199. https://doi.org/10.1016/j.jhin.2013.01.014
- McLaren, L., & Hawe, P. (2005). Ecological perspectives in health research. *Journal of Epidemiology* and Community Health, 59(1), 6–14. https://doi.org/10.1136/jech.2003.018044

- McLeod, C. (2015). Trust. In E. N. Zalta (Ed.), *Stanford Encyclopedia of Philosophy*. Stanford University. https://plato.stanford.edu/archives/fall2015/entries/trust
- McMillan, K., & Perron, A. (2013). Nurses Amidst Change: The Concept of Change Fatigue Offers an Alternative Perspective on Organizational Change. *Policy, Politics, & Nursing Practice, 14*(1), 26–32. https://doi.org/10.1177/1527154413481811
- Melnychuk, R. M., & Kenny, N. P. (2006). Pandemic triage: The ethical challenge. *Canadian Medical* Association Journal, 175(11), 1393–1393. https://doi.org/10.1503/cmaj.061322
- Mentor, D. (2019). Micro to macro social connectedness through mobile phone engagement. In M. Khosrow-Pour (Ed.), Advanced methodologies and technologies in network architecture, mobile computing, and data analytics. IGI Global.
- Mery, G., Majumder, S., Brown, A., & Dobrow, M. J. (2017). What do we mean when we talk about the Triple Aim? A systematic review of evolving definitions and adaptations of the framework at the health system level. *Health Policy*, *121*(6), 629–636. https://doi.org/10.1016/j.healthpol.2017.03.014
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Sage Publications.
- Miller, F. G., & Emanuel, E. J. (2008). Quality-improvement research and informed consent. New England Journal of Medicine, 358(8), 765–767.
- Mitchell, E. A., & McCance, T. (2012). Nurse-patient encounters in the hospital ward, from the perspectives of older persons: An analysis using the Authentic Consciousness Framework.
   *International Journal of Older People Nursing*, 7(2), 95–104. https://doi.org/10.1111/j.1748-3743.2010.00233.x
- Moezzi, M., Janda, K. B., & Rotmann, S. (2017). Using stories, narratives, and storytelling in energy and climate change research. *Energy Research & Social Science*, 31, 1–10. https://doi.org/10.1016/j.erss.2017.06.034

- Moll, S. E. (2014). The web of silence: A qualitative case study of early intervention and support for healthcare workers with mental ill-health. *BMC Public Health*, 14(1). https://doi.org/10.1186/1471-2458-14-138
- Moraros, J., Lemstra, M., & Nwankwo, C. (2016). Lean interventions in healthcare: Do they actually work? A systematic literature review. *International Journal for Quality in Health Care*, *28*(2), 150–165. https://doi.org/10.1093/intqhc/mzv123
- Moreno, J. D., Schmidt, U., & Joffe, S. (2017). The Nuremberg Code 70 years later. *JAMA: The Journal* of the American Medical Association, 318(9), 795–796. https://doi.org/10.1001/jama.2017.10265
- Mormer, E., & Stevans, J. (2019). Clinical quality improvement and quality improvement research. *Perspectives of the ASHA Special Interest Groups*, 4(1), 27–37. https://doi.org/10.1044/2018 PERS-ST-2018-0003
- Mosby, I. (2013). Administering colonial science: Nutrition research and human biomedical experimentation in Aboriginal communities and residential schools, 1942-1952. *Social History*, 46(1), 145–172.
- Murray, M. (2012). Patient experiences with acute inpatient hospital care in British Columbia, 2011/12 (Report). www.health.gov.bc.ca/library/publications/year/2012/patient-experiences-acuteinpatient.pdf
- Murrells, T., Robert, G., Adams, M., Morrow, E., & Maben, J. (2013). Measuring relational aspects of hospital care in England with the 'Patient Evaluation of Emotional Care during Hospitalisation' (PEECH) survey questionnaire. *BMJ Open*, *3*(1), e002211. https://doi.org/10.1136/bmjopen-2012-002211
- Nagle, L. (2019). Being a Nurse More Than Just Tasks. Canadian Journal of Nursing Leadership, 32(1), 1–2. https://doi.org/10.12927/cjnl.2019.25853

Naik, A. D., Dyer, C. B., Kunik, M. E., & McCullough, L. B. (2009). Patient autonomy for the management of chronic conditions: A two-component re-conceptualization. *American Journal of Bioethics*, 9(2), 23–30. https://doi.org/10.1080/15265160802654111

National Advisory Group on the Safety of Patients in England. (2013). A promise to learn – a commitment to act. Improving the safety of patients in England. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/ 226703/Berwick\_Report.pdf

- National Health and Medical Research Council. (2018). *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.* Commonwealth of Australia. www.nhmrc.gov.au/guidelines-publications/ind2
- National Patient Safety Foundation. (2015). Free from harm: Accelerating patient safety improvement fifteen years after To Err Is Human. National Patient Safety Foundation. www.ihi.org/resources/Pages/Publications/Free-from-Harm-Accelerating-Patient-Safety-Improvement.aspx
- Nelson, G., Ochocka, J., Griffin, K., & Lord, J. (1998). "Nothing about me, without me": Participatory action research with self-help/mutual aid organizations for psychiatric consumer/survivors. *American Journal of Community Psychology*, 26(6), 881–912. https://doi.org/10.1023/A:1022298129812
- Nelson, W. A., Gardent, P. B., Shulman, E., & Splaine, M. E. (2010). Preventing ethics conflicts and improving healthcare quality through system redesign. *Quality and Safety in Health Care*, 19, 526–530.
- Nerenz, D. R. (2009). Ethical issues in using data from quality management programs. *European Spine Journal*, *18 Suppl 3*, 321–30. https://doi.org/10.1007/s00586-009-0972-2
- Nicholls, S. G., Carroll, K., Zwarenstein, M., Brehaut, J. C., Weijer, C., Hey, S. P., Goldstein, C. E., Graham, I. D., Grimshaw, J. M., McKenzie, J. E., Fergusson, D. A., Taljaard, M., & Ethics of

Pragmatic Trials project. (2019). The ethical challenges raised in the design and conduct of pragmatic trials: An interview study with key stakeholders. *Trials*, *20*(1), 765. https://doi.org/10.1186/s13063-019-3899-x

- Nicholls, S. G., Hayes, T. P., Brehaut, J. C., McDonald, M., Weijer, C., Saginur, R., & Fergusson, D. (2015). A scoping review of empirical research relating to quality and effectiveness of research ethics review. *PLOS ONE*, *10*(7), e0133639. https://doi.org/10.1371/journal.pone.0133639
- Nicholls, S. G., Morin, K., Evans, L., & Longstaff, H. (2018). Call for a pan-Canadian approach to ethics review in Canada. *Canadian Medical Association Journal*, 190(18), E553–E555. https://doi.org/10.1503/cmaj.171088
- Nicklin, W., & Williams, G. (2011). What's on the quality agenda? Acknowledging progress, respecting the challenges. *Healthcare Papers*, 11(3), 30–35.
- Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges (NCRM/012; ESRC National Centre for Research Methods Review Paper). ESRC National Centre for Research Methods. http://eprints.ncrm.ac.uk/491/
- Nisker, J. (2013). Narrative ethics in health promotion and care. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 107–126). Pearson.
- Nolte, E., & McKee, M. (Eds.). (2008). *Caring for people with chronic conditions: A health system perspective*. McGraw-Hill, Open University Press.

Nuu-chah-nulth Tribal Council Research Ethics Committee. (2008). Protocols and principles for conducting research in a Nuu-chah-nulth context. https://icwrn.uvic.ca/wpcontent/uploads/2013/08/NTC-Protocols-and-Principles.pdf

Obama, M. (2018). Becoming. Crown Publishing.

- Oberle, K., & Storch, J. L. (2013). Research ethics and nursing. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 282–301). Pearson.
- Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: Progressing patient and public involvement in healthcare improvement. *BMJ Quality & Safety*, 25(8), 626–632. https://doi.org/10.1136/bmjqs-2015-004839
- OECD. (2018a). Stemming the superbug tide in Canada (OECD Health Policy Studies). OECD Publishing. www.oecd.org/canada/Stemming-the-Superbug-Tide-in-Canada.pdf
- OECD. (2018b). Stemming the superbug tide: Just a few dollars more. OECD Publishing. https://doi.org/10.1787/9789264307599-en
- OECD. (2019). *Health at a glance 2019: OECD indicators*. OECD Publishing. https://doi.org/10.1787/4dd50c09-en
- OED Online. (n.d.). Initiative, n. In *OED Online*. Oxford University Press. Retrieved April 4, 2017, from www.oed.com.ezproxy.library.ubc.ca/view/Entry/96070?rskey=jiII9T&result=1
- OED Online. (2017a). Axiology, n. In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/7367?rskey=mEaOe8&result=1&isAdvanced=f alse
- OED Online. (2017b). Clean, adj. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/34053?rskey=QFiCrK&result=2
- OED Online. (2017c). Relational, adj. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/161811?redirectedFrom=relational
- OED Online. (2017d). Ecosystem, n. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/59402?redirectedFrom=ecosystem
- OED Online. (2018a). Ethos, n. In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/64840?redirectedFrom=ethos

- OED Online. (2018b). Vulnerable, adj. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/224872?rskey=Vwqe1n&result=1&isAdvanced =false
- OED Online. (2018c). Catch, n.1. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/28813?redirectedFrom=catch-22

OED Online. (2018d). Hand, n. In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/83801?redirectedFrom=in+good+hands

- OED Online. (2018e). Pest-house, n. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/141756?redirectedFrom=pest+house
- OED Online. (2018f). Workaround, n. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/419283?rskey=rw0fYV&result=2&isAdvanced =false
- OED Online. (2018g). Liminal, adj.". In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/108471?redirectedFrom=liminal
- OED Online. (2018h). Linch-pin, n. In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/108578?redirectedFrom=linchpin
- OED Online. (2018i). Safety, n. In *OED Online*. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/169687?rskey=wEr3uR&result=1
- OED Online. (2018j). Situational, adj. In OED Online. Oxford University Press. www.oed.com.ezproxy.library.ubc.ca/view/Entry/180521?redirectedFrom=situational
- OED Online. (2019a). patient, adj. and n. In *OED Online*. Oxford University Press. www-oedcom.ezproxy.library.ubc.ca/view/Entry/138820?rskey=1Ousnw&result=1&isAdvanced=false (accessed February 02, 2020)
- OED Online. (2019b). *pilot, n. And adj.* Oxford University Press. www-oedcom.ezproxy.library.ubc.ca/view/Entry/143950?rskey=QeQ0IC&result=1

- Office for Human Research Protections. (2020). *International compilation of human research standards*. US Department of Health & Human Services. www.hhs.gov/ohrp/sites/default/files/2020international-compilation-of-human-research-standards.pdf
- Office of the Auditor General of British Columbia. (2008). *Public participation: Principles and best practices for British Columbia* (Report 11 No. 9780772660756). www.bcauditor.com/online/pubs/394/394
- Ogrinc, G., Davies, L., Goodman, D., Batalden, P. B., Davidoff, F., & Stevens, D. (2016). Standards for QUality Improvement Reporting Excellence 2.0: Revised publication guidelines from a detailed consensus process. *Journal of Surgical Research*, 200(2), 676–682. https://doi.org/10.1016/j.jss.2015.09.015
- Ogrinc, G., Mooney, S. E., Estrada, C., Foster, T., Goldmann, D., Hall, L. W., Liu, S. K., Mills, P., Neily, J., Nelson, W., Pronovost, P. J., Provost, L. P., Speroff, T., Splaine, M., Thomson, R., Tomolo, A. M., Watts, B., Huizinga, M. M., & Rubenstein, L. V. (2008). The SQUIRE (Standards for QUality Improvement Reporting Excellence) guidelines for quality improvement reporting: Explanation and elaboration. *Quality and Safety in Health Care, October 2009*. https://doi.org/10.1136/qshc.2008.029058
- Ogrinc, G., Nelson, W. A., Adams, S. A., & O'Hara, A. E. (2013). An instrument to differentiate between clinical research and quality improvement. *IRB: Ethics & Human Research*, *35*(5), 1–8.
- Ondrusek, N. K., Willison, D. J., Haroun, V., Bell, J. A. H., & Bornbaum, C. C. (2015). A risk screening tool for ethical appraisal of evidence-generating initiatives. *BMC Medical Ethics*, 16(1). https://doi.org/10.1186/s12910-015-0039-3
- O'Neill, P. (2016). Assessing risk in psychological research. In W. Van den Hoonaard & A. Hamilton (Eds.), *The ethics rupture: Exploring alternatives to formal research-ethics review* (pp. 119–132). University of Toronto Press.

- Ono, S. (2017, March 6). The Learning Exchange: Engaging UBC with the Downtown Eastside. *Office of the President*. https://president.ubc.ca/blog/2017/03/06/learning\_exchange
- O'Shea, A., Boaz, A. L., & Chambers, M. (2019). A Hierarchy of Power: The Place of Patient and Public Involvement in Healthcare Service Development. *Frontiers in Sociology*, *4*, 38. https://doi.org/10.3389/fsoc.2019.00038
- Osler, W. (1904). *The principles and practice of medicine: Designed for the use of practitioners and students of medicine* (5th ed.). Appleton.

https://babel.hathitrust.org/cgi/pt?id=nnc2.ark:/13960/t1bk24v14;view=2up;seq=130;size=125

- Östman, L., Näsman, Y., Eriksson, K., & Nyström, L. (2017). Ethos: The heart of ethics and health. *Nursing Ethics*, 096973301769565. https://doi.org/10.1177/0969733017695655
- Ostwald, K. (2014). Ebola, SARS, and the economies of Southeast Asia. ISEAS Perspective, 63, 1-8.
- Ovretveit, J. (2009). Does improving quality save money? A review of the evidence of which improvements to quality reduce costs to health service providers. The Health Foundation.
- Ovretveit, J. (2011). Understanding the conditions for improvement: Research to discover which context influences affect improvement success. *BMJ Quality & Safety*, *20*(Suppl 1), i18–i23. https://doi.org/10.1136/bmjqs.2010.045955
- Ovretveit, J. (2014). How does context affect quality improvement? In *Perspectives on context: A* selection of essays considering the role of context in successful quality improvement (pp. 59–85). The Health Foundation.
- Ozkan, J. (2019). Piero Anversa and cardiomyocyte regeneration. *European Heart Journal*, 40(13), 1036– 1037. https://doi.org/10.1093/eurheartj/ehz096
- Page, S. A., & Nyeboer, J. (2017). Improving the process of research ethics review. *Research Integrity* and Peer Review, 2(1). https://doi.org/10.1186/s41073-017-0038-7
- Paley, J. R. (2014). Cognition and the compassion deficit: The social psychology of helping behaviour in nursing. *Nursing Philosophy*, 15(4), 274–287.
- Panel on Research Ethics. (2017, October 12). *TCPS 2 (2018) Introduction*. https://ethics.gc.ca/eng/tcps2-eptc2 2018 introduction.html
- Pannick, S., Sevdalis, N., & Athanasiou, T. (2016). Beyond clinical engagement: A pragmatic model for quality improvement interventions, aligning clinical and managerial priorities. *BMJ Quality & Safety*, 25(9), 716–725. https://doi.org/10.1136/bmjqs-2015-004453
- Paré, G., & Kitsiou, S. (2016). Methods for literature reviews. In F. Lau & C. Kuziemsky (Eds.), Handbook of eHealth Evaluation: An Evidence-based Approach (pp. 157–180). University of Victoria. www.ncbi.nlm.nih.gov/books/NBK48158
- Park, M. M., Lencucha, R., Mattingly, C., Zafran, H., & Kirmayer, L. J. (2015). A qualitative study on the ethics of transforming care: Examining the development and implementation of Canada's first mental health strategy. *Implementation Science*, 10(1). https://doi.org/10.1186/s13012-015-0297y
- Parnas, S., & Isobel, S. (2019). Using relational mindfulness to facilitate safety in the clinical encounter. *Australasian Psychiatry*, 27(6), 596–599. https://doi.org/10.1177/1039856219866318
- Parry, G. J. (2014). A brief history of quality improvement. *Journal of Oncology Practice*, *10*(3), 196–199.
- Patel, D. I., Stevens, K. R., & Puga, F. (2013). Variations in institutional review board approval in the implementation of an improvement research study. *Nursing Research and Practice*, 2013, 1–6. https://doi.org/10.1155/2013/548591
- Patenaude, J., Grant, A. M., Xhignesse, M., Leblanc, F., & Courteau, J. (2008). Evaluation of clinical innovation: A gray zone in the ethics of modern clinical practice? *Journal of General Internal Medicine*, 23 Suppl 1(Suppl 1), 27–31. https://doi.org/10.1007/s11606-007-0410-2
- Patient Engagement Action Team. (2017). *Engaging patients in patient safety: A Canadian guide*. Canadian Patient Safety Institute. www.patientsafetyinstitute.ca/en/toolsResources/Patient-

Engagement-in-Patient-Safety-

Guide/Documents/Engaging%20Patients%20in%20Patient%20Safety.pdf

Patient Voices Network. (n.d.-a). *Patient Voices Network*. Retrieved February 20, 2020, from https://patientvoicesbc.ca

Patient Voices Network. (n.d.-b). Ten questions to ask when planning a patient engagement.

- Patient-Centered Outcomes Research Institute. (n.d.). Patient-Centered Outcomes Research Institute. Retrieved March 21, 2019, from www.pcori.org
- Pauly, B. M. (2013). Challenging health inequities: Enacting social justice in nursing practice. In J. L.
  Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 430–447). Pearson.
- Pauly, B. M., McCall, J., Browne, A. J., Parker, J., & Mollison, A. (2015). Toward cultural safety: Nurse and patient perceptions of illicit substance use in a hospitalized setting. *Advances in Nursing Science*, 38(2), 121–135. https://doi.org/10.1097/ANS.0000000000000070
- Pavli, A., Maltezou, H. C., Papadakis, A., Katerelos, P., Saroglou, G., Tsakris, A., & Tsiodras, S. (2016).
   Respiratory infections and gastrointestinal illness on a cruise ship: A three-year prospective study. *Travel Medicine and Infectious Disease*, *14*(4), 389–397.
   https://doi.org/10.1016/j.tmaid.2016.05.019
- Peat, M., Entwistle, V., Hall, J., Birks, Y., Golder, S., & PIPS Group. (2010). Scoping review and approach to appraisal of interventions intended to involve patients in patient safety. *Journal of Health Services Research & Policy*, *15 Suppl 1*, 17–25. https://doi.org/10.1258/jhsrp.2009.009040
- Peplau, H. E. (1952). Interpersonal relations in nursing: A conceptual frame of reference for psychodynamic nursing. Putnam.

Perla, R., Provost, L. P., & Parry, G. J. (2013). Seven propositions of the science of improvement: Exploring foundations. *Quality Management in Health Care*, 22(3), 170–86. https://doi.org/10.1097/QMH.0b013e31829a6a15

Pimple, K. D. (Ed.). (2017). Research ethics. Ashgate Publishing, Ltd.

Pittet, D., Boyce, J. M., & Allegranzi, B. (2017). Hand hygiene: A handbook for medical professionals.

Pittet, D., Panesar, S. S., Wilson, K., Longtin, Y., Morris, T., Allan, V., Storr, J., Cleary, K., & Donaldson, L. (2011). Involving the patient to ask about hospital hand hygiene: A National Patient Safety Agency feasibility study. *Journal of Hospital Infection*, 77(4), 299–303. https://doi.org/10.1016/j.jhin.2010.10.013

- Polit, D. F., & Beck, C. T. (2012). Nursing research: Generating and assessing evidence for nursing practice (9th ed.). Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Pomey, M.-P., Clavel, N., Aho-Glele, U., Ferré, N., & Fernandez-McAuley, P. (2018). How patients view their contribution as partners in the enhancement of patient safety in clinical care. *Patient Experience Journal*, 5(1).
- Pomey, M.-P., Hihat, H., Khalifa, M., Lebel, P., Néron, A., & Dumez, V. (2015). Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced. *Patient Experience Journal*, 2(1), 29–42. https://doi.org/10.35680/2372-0247.1064
- Poniewozik, J. (2017, November 12). On 'The Good Doctor,' the anti-antihero is in. *The New York Times*. www.nytimes.com/2017/11/12/arts/television/the-good-doctor-freddie-highmore-abc.html

Pope Francis [Pontifex]. (2017, June 15). Everyone's existence is tied to that of others: Life is not time merely passing by, life is about interactions. [Tweet]. https://twitter.com/Pontifex/status/875314447497252866

Population Data BC. (2019, July 9). Patient centered measurement data—The Acute Inpatient 2016/17 Survey. www.popdata.bc.ca/data/health/pcm/AIS 2016-17

- Porges, S. W. (2009). The polyvagal theory: New insights into adaptive reactions of the autonomic nervous system. *Cleveland Clinic Journal of Medicine*, 76(Suppl\_2), S86–S90. https://doi.org/10.3949/ccjm.76.s2.17
- Powell, A. E., Rushmer, R. K., & Davies, H. T. O. (2009). *A Systematic Narrative Review of Quality Improvement Models in Health Care*. National Health Services Quality Improvement Scotland.
- Prisbell, M., & Andersen, J. F. (1980). The importance of perceived homophily, level of uncertainty, feeling good, safety, and self-disclosure in interpersonal relationships. *Communication Quarterly*, 28(3), 22–33. https://doi.org/10.1080/01463378009369372
- Pritchard, I. (2011). How do IRB members make decisions? A review and research agenda. *Journal of Empirical Research on Human Research Ethics*, 6(2), 31–46.
- Proctor, S. L., & Rogers, M. R. (2013). Making the invisible visible: Understanding social processes within multicultural internship supervision. *School Psychology Forum: Research in Practice*, 7(1), 1–12.
- Pronovost, P. J., Needham, D. M., Berenholtz, S., Sinopoli, D. J., Chu, H., Cosgrove, S., Sexton, J. B., Hyzy, R. C., Welsh, R., Roth, G., Bander, J., Kepros, J., & Goeschel, C. (2006). An intervention to decrease catheter-related bloodstream infections in the ICU. *The New England Journal of Medicine*, 355(26), 2725–2732. https://doi.org/10.1056/NEJMoa061115
- Pronovost, P. J., Ravitz, A. D., Stoll, R. A., & Kennedy, S. B. (2015). Transforming patient safety: A sector-wide systems approach: Report of the WISH Patient Safety Forum 2015. World Innovation Summit for Health. www.wish.org.qa/wp-

content/uploads/2018/01/WISH\_PatientSafety\_Forum\_08.01.15\_WEB-1.pdf

Provincial Hand Hygiene Working Group of British Columbia (PHHWG), & Provincial Infection Control Network of BC (PICNet). (2019). *Hand cleaning compliance in healthcare facilities, Q1 of* 2019/20. www.picnet.ca/surveillance/hand-hygiene

- Provincial Health Services Authority. (2019). *Provincial Health Services Authority Code of Ethics*. http://shop.healthcarebc.ca/phsa/PHSAPOD/Human%20Resources/C-99-11-20200.pdf
- Punch, K. F. (2014). Introduction to social research: Qualitative and quantitative approaches (3rd ed.). Sage Publications.
- Radnor, Z. J., Holweg, M., & Waring, J. (2012). Lean in healthcare: The unfilled promise? Social Science and Medicine, 74, 364–371.
- Rainey, H., Ehrich, K., Mackintosh, N., & Sandall, J. (2015). The role of patients and their relatives in 'speaking up' about their own safety—A qualitative study of acute illness. *Health Expectations*, 18(3), 392–405. https://doi.org/10.1111/hex.12044
- Ramsden, I. (1993). Cultural safety in nursing education in Aotearoa (New Zealand). Nursing Praxis in New Zealand, 8(3), 4–10.
- Rathert, C., Brandt, J., & Williams, E. S. (2012). Putting the 'patient' in patient safety: A qualitative study of consumer experiences: Putting the 'patient' in patient safety. *Health Expectations*, 15(3), 327–336. https://doi.org/10.1111/j.1369-7625.2011.00685.x
- Rathert, C., Williams, E. S., Lawrence, E. R., & Halbesleben, J. R. B. (2012). Emotional exhaustion and workarounds in acute care: Cross sectional tests of a theoretical framework. *International Journal* of Nursing Studies, 49(8), 969–977. https://doi.org/10.1016/j.ijnurstu.2012.02.011
- Rathert, C., Williams, E. S., & Linhart, H. (2018). Evidence for the Quadruple Aim: A Systematic
  Review of the Literature on Physician Burnout and Patient Outcomes. *Medical Care*, 56(12),
  976–984. https://doi.org/10.1097/MLR.00000000000999
- Reader, T. W., Gillespie, A., & Roberts, J. (2014). Patient complaints in healthcare systems: A systematic review and coding taxonomy. *BMJ Quality & Safety*, 23(8), 678–689. https://doi.org/10.1136/bmjqs-2013-002437
- Reed, J. E., & Card, A. J. (2016). The problem with Plan-Do-Study-Act cycles. *BMJ Quality & Safety*, 25(3), 147–152. https://doi.org/10.1136/bmjqs-2015-005076

- Reeves, S., Albert, M., Kuper, A., & Hodges, B. D. (2008). Why use theories in qualitative research? BMJ, 337(aug07 3), a949–a949. https://doi.org/10.1136/bmj.a949
- Reeves, S., Macmillan, K., & Van Soeren, M. (2010). Leadership of interprofessional health and social care teams: A socio-historical analysis: Interprofessional health and social care teams. *Journal of Nursing Management*, 18(3), 258–264. https://doi.org/10.1111/j.1365-2834.2010.01077.x
- Registered Nurses' Association of Ontario. (2004). *Position statement: Patient safety*. Registered Nurses Association of Ontario. https://rnao.ca/policy/position-statements/patient-safety
- Reid, N., Moghaddas, J., Loftus, M., Stuart, R. L., Kotsanas, D., Scott, C., & Dendle, C. (2012). Can we expect patients to question health care workers' hand hygiene compliance? *Infection Control and Hospital Epidemiology*, 33(5), 531–532.
- Reilly, J., Currie, K., & Madeo, M. (2016). Are you serious? From fist bumping to hand hygiene:
   Considering culture, context and complexity in infection prevention intervention research.
   *Journal of Infection Prevention*, 17(1), 29–33. https://doi.org/10.1177/1757177415605659
- Reimer-Kirkham, S., & Anderson, J. M. (2010). The advocate-analyst dialectic in critical and postcolonial feminist research: Reconciling tensions around scientific integrity. ANS. Advances in Nursing Science, 33(3), 196–205. https://doi.org/10.1097/ANS.0b013e3181e4a7d3
- Renedo, A., Marston, C. A., Spyridonidis, D., & Barlow, J. (2015). Patient and Public Involvement in Healthcare Quality Improvement: How organizations can help patients and professionals to collaborate. *Public Management Review*, 17(1), 17–34.

https://doi.org/10.1080/14719037.2014.881535

- Resar, R. K., Haraden, C., & Nolan, T. W. (2012). Using care bundles to improve health care quality [Series white paper]. Institute for Healthcare Improvement. www.ihi.org/resources/Pages/IHIWhitePapers/UsingCareBundles.aspx
- Resnick, D. B. (2018). *The ethics of research with human subjects: Protecting people, advancing science, promoting trust.* Springer International Publishing.

Revised Standards for Quality Improvement Reporting Excellence. (n.d.). SQUIRE 2.0 Glossary. Retrieved June 28, 2019, from http://squire-

statement.org/index.cfm?fuseaction=page.viewpage&pageid=485

- Reynolds, J., DiLiberto, D., Mangham-Jefferies, L., Ansah, E. K., Lal, S., Mbakilwa, H., Bruxvoort, K.,
  Webster, J., Vestergaard, L. S., Yeung, S., Leslie, T., Hutchinson, E., Reyburn, H., Lalloo, D. G.,
  Schellenberg, D., Cundill, B., Staedke, S. G., Wiseman, V., Goodman, C., & Chandler, C. I.
  (2014). The practice of 'doing' evaluation: Lessons learned from nine complex intervention trials
  in action. *Implementation Science*, 9(1), 75. https://doi.org/10.1186/1748-5908-9-75
- Rhodes, P., McDonald, R., Campbell, S., Daker-White, G., & Sanders, C. (2016). Sensemaking and the co-production of safety: A qualitative study of primary medical care patients. *Sociology of Health* & *Illness*, 38(2), 270–285. https://doi.org/10.1111/1467-9566.12368
- Richard, L., Gauvin, L., & Raine, K. (2011). Ecological models revisited: Their uses and evolution in health promotion over two decades. *Annual Review of Public Health*, 32(1), 307–326. https://doi.org/10.1146/annurev-publhealth-031210-101141
- Ringdal, M., Chaboyer, W., Ulin, K., Bucknall, T., & Oxelmark, L. (2017). Patient preferences for participation in patient care and safety activities in hospitals. *BMC Nursing*, 16(1). https://doi.org/10.1186/s12912-017-0266-7
- Rober, P. (1998). Reflections on Ways to Create a Safe Therapeutic Culture for Children in Family Therapy. *Family Process*, *37*(2), 201–213. https://doi.org/10.1111/j.1545-5300.1998.00201.x
- Robert, G., Cornwell, J., Brearley, S., Foot, C., Goodrich, J., Joule, N., Levenson, R., Maben, J., Murrells,
  T., Tsianakas, V., & Waite, D. (2011). 'What matters to patients'?: Developing the evidence base for measuring and improving patient experience. King's College London and The King's Fund.
- Robert, G., & Fulop, N. (2014). The role of context in successful improvement. In *Perspectives on context: A selection of essays considering the role of context in successful quality improvement* (pp. 31–57). The Health Foundation.

- Rodney, P. (1997). Towards connectedness and trust: Nurses' enactment of their moral agency within an organizational context. University of British Columbia.
- Rodney, P. (2013). Seeing ourselves as moral agents in relation to our organizational and sociopolitical contexts: Commentary on "a reflection on moral distress in nursing together with a current application of the concept" by Andrew Jameton. *Journal of Bioethical Inquiry*, *10*(3), 313–315. https://doi.org/10.1007/s11673-013-9461-8
- Rodney, P., Buckley, B., Street, A., Serrano, E., & Martin, L. A. (2013). The moral climate of nursing practice: Inquiry and action. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 188–214). Pearson.
- Rodney, P., Burgess, M., Pauly, B. M., & Phillips, J. C. (2013). Our theoretical landscape:
  Complementary approaches to health care ethics. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 84–106). Pearson.
- Rodney, P., Burgess, M., Phillips, J. C., McPherson, G., & Brown, H. (2013). Our theoretical landscape:
  A brief history of health care ethics. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 59–83). Pearson.
- Rodney, P., Harrigan, M., Jiwani, B., & Phillips, J. C. (2013). A further landscape: Ethics in health care organizations and health/health care policy. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 358–383). Pearson.
- Rodney, P., Kadyschuk, S., Liaschenko, J., Brown, H., Musto, L. C., & Snyder, N. (2013). Moral agency:
   Relational connections and support. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 160–187). Pearson.
- Rodney, P., Varcoe, C. M., Storch, J. L., McPherson, G., Mahoney, K., Brown, H., Pauly, B. M., Hartrick, G., & Starzomski, R. (2009). Navigating towards a moral horizon: A multisite

qualitative study of ethical practice in nursing. *The Canadian Journal of Nursing Research*, 41(1), 292–319.

- Rolnick, J., Downing, N. L., Shieh, L., Heidenreich, P., & Cho, M. (2017). Ethical oversight of quality improvement and the research-QI boundary: A new Common Rule changes little. *IRB: Ethics & Human Research*, *39*(3), 1–10.
- Romanow, R. J. (2002). *Building on values: The future of health care in Canada: Final report.* Commission on the Future of Health Care in Canada.

Rorty, R. (1999). Philosophy and social hope. Penguin Books.

- Rose, N. (1993). Government, authority and expertise in advanced liberalism. *Economy and Society*, 22(3), 283–299.
- Rostam, H. (2013). Substance use counsellors' understanding and incorporation of ethnocultural diversity factors: An interpretive description. The University of British Columbia.
- Rothman, D. J. (1991). Strangers at the bedside: A history of how law and bioethics transformed medical decision making. Basic Books.
- Rowland, P. (2013). Power/knowledge, identity and patient safety: Intersections of patient safety and professional practice discourses in a Canadian acute care hospital. Fielding Graduate University.
- Royal College of Physicians. (2012). *The patient shadowing framework: Guidance for completing a patient–centred service review*. www.networks.nhs.uk/nhs-networks/inflammatory-bowel-disease-quality-

improvement/documents/Framework%20for%20patient%20centred%20service%20review.pdf

Rubenstein, L. V., Khodyakov, D., Hempel, S., Danz, M., Salem-Schatz, S., Foy, R., O'Neill, S., Dalal,
 S., & Shekelle, P. (2014). How can we recognize continuous quality improvement? *International Journal for Quality in Health Care*, *26*(1), 6–15. https://doi.org/10.1093/intqhc/mzt085

- Russ, A. L., Fairbanks, R. J., Karsh, B.-T., Militello, L. G., Saleem, J. J., & Wears, R. L. (2013). The science of human factors: Separating fact from fiction. *BMJ Quality & Safety*, 22(10), 802–808. https://doi.org/10.1136/bmjqs-2012-001450
- Sadler, J. Z., & Hulgus, Y. F. (1992). Clinical problem solving and the biopsychosocial model. *American Journal of Psychiatry*, *149*(10), 1315–1323. https://doi.org/10.1176/ajp.149.10.1315
- Safran, D. G., Miller, W., & Beckman, H. (2006). Organizational Dimensions of Relationship-centered Care. Theory, Evidence, and Practice. *Journal of General Internal Medicine*, 21(S1), S9–S15. https://doi.org/10.1111/j.1525-1497.2006.00303.x
- Saint, S., Kowalski, C. P., Banaszak-Holl, J., Forman, J., Damschroder, L., & Krein, S. L. (2009). How Active Resisters and Organizational Constipators Affect Health Care–Acquired Infection Prevention Efforts. *The Joint Commission Journal on Quality and Patient Safety*, 35(5), 239–246. https://doi.org/10.1016/S1553-7250(09)35032-1
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, 8(3), 27–37.
- Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing & Health*, 18(2), 179–183.
- Sandelowski, M. (2015). A matter of taste: Evaluating the quality of qualitative research. *Nursing Inquiry*, 22(2), 86–94. https://doi.org/10.1111/nin.12080
- Sanders, J., Munford, R., & Liebenberg, L. (2016). The role of teachers in building resilience of at risk youth. *International Journal of Educational Research*, 80, 111–123. https://doi.org/10.1016/j.ijer.2016.10.002
- Sari, O., Sidhu, N., & Wohlgemuth, N. (2011). Patients' experiences with emergency care in Saskatchewan hospitals. Saskatchewan Health Quality Council. http://hqc.sk.ca/Portals/0/documents/ed-survey-2011.pdf

- Saunders, B., Kitzinger, J., & Kitzinger, C. (2014). Anonymising interview data: Challenges and compromise in practice. *Qualitative Research*, 1–17.
- Savel, R. H., Goldstein, E. B., & Gropper, M. A. (2009). Critical care checklists, the Keystone Project, and the Office for Human Research Protections: A case for streamlining the approval process in quality-improvement research. *Critical Care Medicine*, *37*(2), 725–728. https://doi.org/10.1097/CCM.0b013e31819541f8
- Scoville, R., & Little, K. (2014). *Comparing Lean and quality improvement* [White Paper]. Institute for Healthcare Improvement. www.ihi.org
- Semel, M. E., Resch, S., Haynes, A. B., Funk, L. M., Bader, A., Berry, W. R., Weiser, T. G., & Gawande, A. (2010). Adopting A Surgical Safety Checklist Could Save Money And Improve The Quality Of Care In U.S. Hospitals. *Health Affairs*, 29(9), 1593–1599.
  https://doi.org/10.1377/hlthaff.2009.0709
- Senge, P. M. (1990). *The fifth discipline: The art and practice of the learning organization* (1st ed.). Doubleday/Currency.
- Senge, P. M. (2006). The fifth discipline: The art and practice of the learning organization (2nd ed.). Doubleday/Currency.
- Sewell, W. H. (1992). A theory of structure: Duality, agency, and transformation. American Journal of Sociology, 98(1), 1–29. https://doi.org/10.1086/229967
- Shanahan, M. J. (2000). Pathways to Adulthood in Changing Societies: Variability and Mechanisms in Life Course Perspective. *Annual Review of Sociology*, 26(1), 667–692. https://doi.org/10.1146/annurev.soc.26.1.667
- Sheps, S., & Cardiff, K. (2011). Patient safety: A wake-up call. *Clinical Governance: An International Journal*, 16(2), 148–158. https://doi.org/10.1108/14777271111124509

- Sheps, S., & Cardiff, K. (2017). The Jack Spratt problem: The potential downside of Lean application in health care—A threat to Safety II. In J. Braithwaite, R. L. Wears, & E. Hollnagel (Eds.), *Reconciling Work-As-Imagined and Work-as-Done* (Vol. 3, pp. 19–26). CRC Press.
- Sherwin, S. B. (1989). Feminist and Medical Ethics: Two Different Approaches to Contextual Ethics. *Hypatia*, 4(2), 57–72. https://doi.org/10.1111/j.1527-2001.1989.tb00573.x
- Sherwin, S. B. (1992). No longer patient: Feminist ethics and health care. Temple University Press.
- Sherwin, S. B. (2011a). Relational autonomy and global threats. In J. Downie & J. J. Llewellyn (Eds.), *Being relational: Reflections on relational theory and health law* (pp. 13–34). UBC Press.
- Sherwin, S. B. (2011b). Looking backwards, looking forward: Hopes for bioethics' next twenty-five years. *Bioethics*, *25*(2), 75–82. https://doi.org/10.1111/j.1467-8519.2010.01866.x
- Sherwin, S. B., & Feminist Health Care Ethics Research Network (Eds.). (1998). *The politics of women's health: Exploring agency and autonomy*. Temple University Press.
- Sherwin, S. B., & Stockdale, K. (2017). Whither bioethics now? The promise of relational theory. *IJFAB: International Journal of Feminist Approaches to Bioethics*, 10(1), 7–29. https://doi.org/10.3138/ijfab.10.1.7
- Sherwood, G., & Jones, C. B. (2013). Quality improvement in nursing. In W. A. Sollecito & J. K. Johnson (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (4th ed., pp. 485–512). Jones & Bartlett.
- Shevell, M. I. (2009). What do we call 'them'?: The 'patient' versus 'client' dichotomy. *Developmental Medicine & Child Neurology*, *51*(10), 770–772. https://doi.org/10.1111/j.1469-8749.2009.03304.x
- Shimmin, C., Wittmeier, K. D. M., Lavoie, J. G., Wicklund, E. D., & Sibley, K. M. (2017). Moving towards a more inclusive patient and public involvement in health research paradigm: The incorporation of a trauma-informed intersectional analysis. *BMC Health Services Research*, *17*(1). https://doi.org/10.1186/s12913-017-2463-1

- Shippee, N. D., Shah, N. D., May, C., Mair, F. S., & Montori, V. M. (2012). Cumulative complexity: A functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology*, 65, 1041–1051.
- Sikka, R., Morath, J. M., & Leape, L. (2015). The Quadruple Aim: Care, health, cost and meaning in work. *BMJ Quality & Safety*, 24(10), 608–610. https://doi.org/10.1136/bmjqs-2015-004160
- Silver, S. A., McQuillan, R., Harel, Z., Weizman, A. V., Thomas, A., Nesrallah, G., Bell, C. M., Chan, C. T., & Chertow, G. M. (2016). How to sustain change and support continuous quality improvement. *Clinical Journal of the American Society of Nephrology: CJASN*, *11*(5), 916–924. https://doi.org/10.2215/CJN.11501015
- Sinclair, C. M. (1998). The Report of the Manitoba Pediatric Cardiac Surgery Inquest: An inquiry into twelve deaths at the Winnipeg Health Sciences Centre in 1994. Provincial Court of Manitoba.
- Singer, S. J., & Vogus, T. J. (2013). Reducing hospital errors: Interventions that build safety culture. *Annual Review of Public Health*, *34*, 373–396. https://doi.org/10.1146/annurev-publhealth-031912-114439
- Slovic, P. (1999). Trust, emotion, sex, politics, and science: Surveying the risk-assessment battlefield. *Risk Analysis*, *19*(4), 689–704.
- Sokol-Hessner, L., Kane, G. J., Annas, C. L., Coletti, M., Sarnoff Lee, B., Thomas, E. J., Bell, S., & Folcarelli, P. H. (2018). Development of a framework to describe patient and family harm from disrespect and promote improvements in quality and safety: A scoping review. *International Journal for Quality in Health Care*, 1–12. https://doi.org/10.1093/intqhc/mzy231
- Sollecito, W. A., & Johnson, J. K. (2013). *McLaughlin and Kaluzny's continuous quality improvement in health care* (4th ed.). Jones & Bartlett.
- Sollecito, W. A., & Johnson, J. K. (2018). Factors influencing the application and diffusion of CQI in health care. In J. K. Johnson & W. A. Sollecito (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed., pp. 104–150). Jones & Bartlett.

- Solomon, M. Z. (2010). The ethical urgency of advancing implementation science. *The American Journal of Bioethics*, *10*(8), 31–32. https://doi.org/10.1080/15265161.2010.494230
- Solomon, M. Z., & Bonham, A. C. (2013). Ethical oversight of research on patient care. *Hastings Center Report*, 43(s1), S2–S3. https://doi.org/10.1002/hast.132
- Stafford, M., Steventon, A., Thorlby, R., Fisher, R., Turton, C., & Deeny, S. (2018). Briefing: Understanding the health care needs of people with multiple health conditions. The Health Foundation.

www.health.org.uk/sites/default/files/upload/publications/2018/Understanding%20the%20health%20care%20needs%20of%20people%20with%20multiple%20health%20conditions.pdf

Stake, R. E. (1995). The art of case study research. Sage Publications.

- Starfield, B. (2011). Is patient-centered care the same as person-focused care? *The Permanente Journal*, *15*(2), 63–69. https://doi.org/10.7812/tpp/10-148
- Stark, L. (2011). Behind Closed Doors: IRBs and the making of ethical research. University of Chicago Press.
- Statistics Canada. (2018, July 25). *Immigration and ethnocultural diversity in Canada*. www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-010-x/99-010-x2011001-eng.cfm
- Steel, D. (2015). Philosophy and the precautionary principle: Science, evidence, and environmental policy. Cambridge University Press.

Stein, J. G. (2002). The cult of efficiency. House of Anansi Press.

Stevens, P., Matlow, A., & Laxer, R. (2005). Building from the blueprint for patient safety at the Hospital for Sick Children. *Healthcare Quarterly*, 8(sp), 132–139. https://doi.org/10.12927/hcq..17679

Stevenson, F. (2013). Observing interaction as an approach to understanding patients' experiences. In S. Ziebland, A. Coulter, J. D. Calabrese, & L. Locock (Eds.), Understanding and using health experiences: Improving patient care (pp. 27–37). Oxford University Press.

- Stewart, M. (Ed.). (1995). *Patient-centered medicine: Transforming the clinical method*. Sage Publications.
- Stewart, M., Brown, J. B., Weston, W. W., McWhinney, I. R., McWilliam, C. L., & Freeman, T. R. (2013). Patient-centered medicine: Transforming the clinical method (3rd.). CRC Press. https://doi.org/10.1201/b20740
- Storch, J. L. (2013). Nursing ethics: The moral terrain. In J. L. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed., pp. 1–19). Pearson.
- Storkholm, M. H., Mazzocato, P., Savage, M., & Savage, C. (2017). Money's (not) on my mind: A qualitative study of how staff and managers understand health care's triple aim. *BMC Health Services Research*, 17(1), 98. https://doi.org/10.1186/s12913-017-2052-3
- Strathdee, S. (2019, March 1). Why Canada should revive a forgotten cure to combat the global superbug crisis. *The Globe and Mail*. www.theglobeandmail.com/opinion/article-why-canada-should-revive-a-forgotten-cure-to-combat-the-global/

StuderGroup. (n.d.). AIDET Patient Communication. www.studergroup.com/aidet

- Sullivan, T., Ashbury, F., Pun, J., Pitt, B., Stipich, N., & Neeson, J. (2011). Responsibility for Canada's healthcare quality agenda: Interviews with Canadian health leaders. *Healthcare Papers*, 11(3), 10–12.
- Sutherland, K., Leatherman, S., Law, S., Verma, J., & Petersen, S. (2012). Chartbook: Shining a light on the quality of healthcare in Canada. *HealthcarePapers*, 12(1), 10–24. https://doi.org/10.12927/hcpap.2013.22860

Sweeney, B. A. (2008). The ecology of the patient experience: Physician environments, patient-staff interactions, staff behaviours, and quality of care. Cornell University. http://iwsp.human.cornell.edu/files/2013/09/The-ecology-of-the-patient-experiencePhysicalenvironments-patient-staff-interactions-staff-behavior-and-quality-of-care-1jk4fvp.pdf

- Talja, S., Tuominen, K., & Savolainen, R. (2005). "Isms" in information science: Constructivism, collectivism and constructionism. *Journal of Documentation*, 61(1), 79–101. https://doi.org/10.1108/00220410510578023
- Taplin, S. H., Anhang Price, R., Edwards, H. M., Foster, M. K., Breslau, E. S., & Chollette, V. (2012). Introduction: Understanding and influencing multilevel factors across the cancer care continuum. *Journal of the National Cancer Institute*, 44, 2–10. https://doi.org/10.1093/jncimonographs/lgs008
- Tattersall, C., Powell, J., Stroud, J., & Pringle, J. (2011). Mind mapping in qualitative research. *Nursing Times*, *107*(18), 20–22.
- Taylor, D. C. (2015). Residents' interpretation of their experience of care in relation to particular workplace culture social interaction patterns. University of Calgary.
- Taylor, H. A., Chandros Hull, S., & Kass, N. E. (2010). Qualitative methods. In J. Sugarman & D. P. Sulmasy (Eds.), *Methods in medical ethics* (2nd ed., pp. 193–214). Georgetown University Press.
- Taylor, H. A., Pronovost, P. J., Faden, R. R., Kass, N. E., & Sugarman, J. (2010). The ethical review of health care quality improvement initiatives: Findings from the field. *Issue Brief (The Commonwealth Fund)*, 95, 1–12.
- Taylor, H. A., Pronovost, P. J., & Sugarman, J. (2010). Ethics, oversight and quality improvement initiatives. *Quality & Safety in Health Care*, 19(4), 271–4. https://doi.org/10.1136/qshc.2009.038034
- Taylor, M. J., McNicholas, C., Nicolay, C., Darzi, A., Bell, D., & Reed, J. E. (2014). Systematic review of the application of the plan–do–study–act method to improve quality in healthcare. *BMJ Quality* & Safety, 23(4), 290–298. https://doi.org/10.1136/bmjqs-2013-001862
- Taylor, S. L., Dy, S., Foy, R., Hempel, S., McDonald, K. M., Ovretveit, J., Pronovost, P. J., Rubenstein, L. V., Wachter, R. M., & Shekelle, P. G. (2011). What context features might be important

determinants of the effectiveness of patient safety practice interventions? *BMJ Quality & Safety*, 20(7), 611–617. https://doi.org/10.1136/bmjqs.2010.049379

The Beryl Institute. (n.d.). Defining patient experience. www.theberylinstitute.org/DefiningPatientExp

- The Fifth Estate. (2017, December 15). *Brainwashed: The secret CIA experiments in Canada*. Canadian Broadcasting Corporation.
- The Health Foundation. (2010). *How do you get clinicians involved in quality improvement? An evaluation of the Health Foundation's Engaging with Quality Initiative: A programme of work to support clinicians to drive forward quality* (Evidence). The Health Foundation.

The Health Foundation. (2011a). Improvement science (Evidence Scan). The Health Foundation.

The Health Foundation. (2011b). *Are clinicians engaged in quality improvement?* (Evidence). The Health Foundation.

The Health Foundation. (2011c). Levels of harm (Evidence Scan). The Health Foundation.

- The Health Foundation. (2013a). *The puzzle of changing relationships: Does changing relationships between healthcare service users and providers improve the quality of care?* [Evidence Review]. The Health Foundation.
- The Health Foundation. (2013b). *Involving patients in improving safety* (Evidence Scan). The Health Foundation.
- The Health Foundation. (2013c). *Measuring patient experience* (No. 18; Evidence Scan). The Health Foundation.
- The Health Foundation. (2014a). *Helping measure person-centred care* (Evidence Review). The Health Foundation.

The Health Foundation. (2014b). *Perspectives on context* (Original Research). The Health Foundation. The Joint Commission. (2018). *Speak Up<sup>TM</sup> about your care*. www.jointcommission.org/speakup.aspx The University of British Columbia. (n.d.). *CIRcle*. Retrieved June 28, 2019, from https://circle.ubc.ca/

- Thistle, J. (2017). *Definition of Indigenous homelessness in Canada*. Canadian Observatory on Homelessness Press.
- Thistle, J., & Smylie, J. (2020). Pekiwewin (coming home): Advancing good relations with Indigenous people experiencing homelessness. *Canadian Medical Association Journal*, 192(10), E257–E259. https://doi.org/10.1503/cmaj.200199
- Thompson, T., & Kreuter, M. W. (2014). Using written narratives in public health practice: A creative writing perspective. *Preventing Chronic Disease*, *11*, E94. https://doi.org/10.5888/pcd11.130402
- Thorne, S. (2008). Interpretive description. Left Coast Press.
- Thorne, S. (2012). What's in a case? Nursing Inquiry, 19(4), 281-282. https://doi.org/10.1111/nin.12009
- Thorne, S. (2014). Applied interpretive approaches. In P. Leavy (Ed.), *The Oxford handbook of qualitative research* (pp. 99–115). Oxford University Press.
- Thorne, S. (2016). *Interpretive description: Qualitative research for applied practice* (2nd ed.). Routledge.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169–177. https://doi.org/10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I
- Thorne, S., Kirkham, S. R., & O'Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–11. https://doi.org/10.1177/160940690400300101
- Tobiano, G., Marshall, A., Bucknall, T., & Chaboyer, W. (2015). Patient participation in nursing care on medical wards: An integrative review. *International Journal of Nursing Studies*, 52(6), 1107– 1120. https://doi.org/10.1016/j.ijnurstu.2015.02.010
- Towle, A., Godolphin, W., Manklow, J., & Wiesinger, H. (2003). Patient perceptions that limit a community-based intervention to promote participation. *Patient Education and Counseling*, 50(3), 231–233. https://doi.org/10.1016/S0738-3991(03)00042-9

- Townsend, A., & Cox, S. M. (2013). Accessing health services through the back door: A qualitative interview study investigating reasons why people participate in health research in Canada. BMC Medical Ethics, 14(1), 40. https://doi.org/10.1186/1472-6939-14-40
- Townsend, A., Taylor, K., & Cox, S. M. (2014). Conceptions of risk regarding a chronic illness survey: Perspectives of participants, researchers, and ethics review board members. *IRB: Ethics & Human Research*, 36(5), 13–20.

Translink. (n.d.). HandyDART. www.translink.ca/Rider-Guide/Accessible-Transit/HandyDART.aspx

- Travaglia, J. F., & Robertson, H. (2013). The role of the patient in continuous quality improvement. In W.A. Sollecito & J. K. Johnson (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (4th ed., pp. 199–223). Jones & Bartlett.
- Travaglia, J. F., & Robertson, H. (2018). The role of the patient in continuous quality improvement. In J.K. Johnson & W. A. Sollecito (Eds.), *McLaughlin and Kaluzny's continuous quality improvement in health care* (5th ed., pp. 201–218). Jones & Bartlett.
- Treise, D., Weigold, M. F., Birnbrauer, K., & Schain, D. (2016). The best of intentions: Patients' intentions to request health care workers cleanse hands before examinations. *Health Communication*, 31(4), 425–433. https://doi.org/10.1080/10410236.2014.965380
- Trochim, W. (2006). Introduction to validity. In *Research Methods Knowledge Base*. https://socialresearchmethods.net/kb/introval.php
- Tsianakas, V., Maben, J., Wiseman, T., Robert, G., Richardson, A., Madden, P., Griffin, M., & Davies, E.
  A. (2012). Using patients' experiences to identify priorities for quality improvement in breast cancer care: Patient narratives, surveys or both? *BMC Health Services Research*, *12*(1), 271. https://doi.org/10.1186/1472-6963-12-271
- Tuohy, C. H. (2018). *Remaking policy: Scale, pace, and political strategy in health care reform*.University of Toronto Press.

- Turnbull, J., & Adams, O. (2011). The healthcare quality agenda in Canada. *Healthcare Papers*, 11(3),
  24–29. https://doi.org/10.12927/hcpap.2011.22555
- UBC Behavioural Research Ethics Board. (2011). *Checklist for quality improvement/quality assurance/program evaluation/curriculum development studies requiring ethical review* [Guidance Notes]. The University of British Columbia. https://ethics.research.ubc.ca/sites/ore.ubc.ca/files/documents/BREB\_ChecklistForResearchRequi

ringEthicsReview.pdf

UBC Behavioural Research Ethics Board. (2012). Behavioural consent form guidelines.

- UBC Behavioural Research Ethics Board. (2018). *Behavioural consent form guidelines* (BREB Guidance Notes). The University of British Columbia. https://ethics.research.ubc.ca/behavioural-research-ethics/breb-guidance-notes
- UBC Health, Patient and Community Partnership for Education. (n.d.). *Talk to your doc: Community workshops*. Retrieved June 28, 2019, from https://pcpe.health.ubc.ca/ourwork/ttyd/community
- Unger, D. (2011). The Canadian bioethics companion: An online textbook for Canadian ethicists and health care workers. http://canadianbioethicscompanion.ca
- U.S. Department of Health and Human Services. (2016, February 16). *Human subject regulations decision charts*. Office for Human Research Protections. www.hhs.gov/ohrp/regulations-andpolicy/decision-charts/index.html
- U.S. Department of Health and Human Services. (2018). *Revised Common Rule (45 CFR 46, Subparts A, B, C, D, and E)*. Office for Human Research Protections.
   www.hhs.gov/ohrp/sites/default/files/revised-common-rule-reg-text-unofficial-2018-requirements.pdf
- U.S. Food and Drug Administration. (2016, September 2). *Antibacterial soap? You can skip it, use plain soap and water*. Consumer Updates.

www.fda.gov/ForConsumers/ConsumerUpdates/ucm378393.htm

- van Achterberg, T. (2012). Call for papers: Examination of basic nursing care. *Journal of Nursing Scholarship*, 44(4), 313–314. https://doi.org/10.1111/j.1547-5069.2012.01481.x
- Van den Hoonaard, W., & Hamilton, A. (Eds.). (2016). *The ethics rupture: Exploring alternatives to formal research-ethics review*. University of Toronto Press.
- Varcoe, C. M., Pauly, B. M., Webster, G., & Storch, J. L. (2012). Moral distress: Tensions as springboards for action. *HEC Forum*, 24(1), 51–62. https://doi.org/10.1007/s10730-012-9180-2
- Veillard, J., Gula, C., Huynh, T., & Klazinga, N. S. (2012). Measuring and reporting on quality of care and patient safety in Canada: Focusing on what matters. *Healthcare Papers*, 12, 32–37.
- Verghese, A. (2018, May 18). How tech can turn doctors into clerical workers: The threat that electronic health records and machine learning pose to physicians' clinical judgment—And their well-being. *The New York Times*. www.nytimes.com/interactive/2018/05/16/magazine/health-issue-what-welose-with-data-driven-medicine.html
- Vermeil, T., Peters, A., Kilpatrick, C., Pires, D., Allegranzi, B., & Pittet, D. (2019). Hand hygiene in hospitals: Anatomy of a revolution. *Journal of Hospital Infection*, 101(4), 383–392. https://doi.org/10.1016/j.jhin.2018.09.003
- Vincent, C., & Coulter, A. (2002). Patient safety: What about the patient? *Quality & Safety in Health Care*, 11(1), 76–80.
- Visser, M. (1991). The rituals of dinner: The origins, evolution, eccentricities, and meaning of table manners. HarperCollins.
- Vodicka, E., Kim, K., Devine, E. B., Gnanasakthy, A., Scoggins, J. F., & Patrick, D. L. (2015). Inclusion of patient-reported outcome measures in registered clinical trials: Evidence from ClinicalTrials.gov (2007-2013). *Contemporary Clinical Trials*, 43, 1–9. https://doi.org/10.1016/j.cct.2015.04.004

Von Stamm, B. (2008). Managing innovation, design and creativity (2nd ed). John Wiley & Sons Inc.

- Wachter, R. M. (2010). Patient safety at ten: Unmistakable progress, troubling gaps. *Health Affairs*, 29(1), 165–173. https://doi.org/10.1377/hlthaff.2009.0785
- Wachter, R. M., & Pronovost, P. J. (2009). Balancing "no blame" with accountability in patient safety. *New England Journal of Medicine*, 361(14), 1401–1406. https://doi.org/10.1056/NEJMsb0903885
- Wade, D. T. (2005). Ethics, audit, and research: All shades of grey. *BMJ*, *330*(7489), 468–471. https://doi.org/10.1136/bmj.330.7489.468
- Waring, J., & Bishop, S. (2010). Lean healthcare: Rhetoric, ritual and resistance. Social Science & Medicine, 71(7), 1332–1340. https://doi.org/10.1016/j.socscimed.2010.06.028

Watson, C. (2018). The language of kindness: A nurse's story. Doubleday Canada.

- Watson, J. (n.d.). *Caring science theory*. Watson Caring Science Institute. Retrieved June 28, 2019, from www.watsoncaringscience.org
- Watson, K., & Fu, B. (2016). Medical improv: A novel approach to teaching communication and professionalism skills. *Annals of Internal Medicine*, 165(8), 591. https://doi.org/10.7326/M15-2239
- Weaver, L., Bossé, I., Sinclair, D., Blais, B., & Pereira, J. (2016). Making quality improvement stick and stay: Two lines of insurance. *Healthcare Management Forum*, 29(1), 28–32. https://doi.org/10.1177/0840470415616318

Weiste, E. (2018). Relational interaction in occupational therapy: Conversation analysis of positive feedback. *Scandinavian Journal of Occupational Therapy*, 25(1), 44–51. https://doi.org/10.1080/11038128.2017.1282040

Wells, M. A., Lobo, E., Galick, A., Knudson-Martin, C., Huenergardt, D., & Schaepper, H. (2017).
Fostering trust through relational safety: Applying socio-emotional relationship therapy's focus on gender and power with heterosexual adult-survivor couples. *Journal of Couple & Relationship Therapy*, *16*(2), 122–145. https://doi.org/10.1080/15332691.2016.1238795

- West, E. M. (2016). *Parents' perceptions of young children's social interest experiences: An interpretive description*. Kent State University College.
- Westbrook, J. I. (2010). Association of Interruptions With an Increased Risk and Severity of Medication Administration Errors. *Archives of Internal Medicine*, *170*(8), 683.

https://doi.org/10.1001/archinternmed.2010.65

- Whicher, D. M., Kass, N. E., Audera-Lopez, C., Butt, M., Jauregui, I. L., Harris, K., Knoche, J., & Saxena, A. (2014). Ethical issues in patient safety research: A systematic review of the literature. *Journal of Patient Safety, May 10*(00), 1–11. https://doi.org/10.1097/PTS.00000000000064
- Whitfield, D. W. (2018). Conditions for social change: Theorizing critical communication pedagogy with/in the classroom using a lens of relational safety. Southern Illinois University.
- Wiig, S., Storm, M., Aase, K., Gjestsen, M. T., Solheim, M., Harthug, S., Robert, G., & Fulop, N. (2013). Investigating the use of patient involvement and patient experience in quality improvement in Norway: Rhetoric or reality? *BMC Health Services Research*, *13*(1), 206. https://doi.org/10.1186/1472-6963-13-206
- Wilkinson, B. G. Rev. (1879). Cleanliness is next to godliness. *The Wesleyan-Methodist Magazine*, 351–355.
- Williams, B. (1994). Patient satisfaction: A valid concept? *Social Science & Medicine (1982)*, *38*(4), 509–516. https://doi.org/10.1016/0277-9536(94)90247-x
- Williams, M. E. (2016). A series of catastrophes & miracles: A true story of love, science, and cancer.National Geographic Books.
- Williams, M., & Haverkamp, B. E. (2015). Eating disorder therapists' personal eating disorder history and professional ethics: An interpretive description. *Eating Disorders*, 23(5), 393–410. https://doi.org/10.1080/10640266.2015.1013393
- Willis, R. (2018). The use of composite narratives to present interview findings. *Qualitative Research*. https://doi.org/10.1177/1468794118787711

- Willison, D. J., Ondrusek, N., Dawson, A., Emerson, C., Ferris, L. E., & Saginur, R. (2014). What makes public health studies ethical? Dissolving the boundary between research and practice. *BMC Medical Ethics*, 15(1), 1–6. https://doi.org/10.1186/1472-6939-15-61
- Wilson, K. (2007). The Krever Commission 10 years later. *Canadian Medical Association Journal*, *177*(11), 1387–1389. https://doi.org/10.1503/cmaj.071333
- Wilson, R. M., Runciman, W. B., Gibberd, R. W., Harrison, B. T., Newby, L., & Hamilton, J. D. (1995).The Quality in Australian Health Care Study. *The Medical Journal of Australia*, *163*(9), 458–471.

Wilson, S. (2008). Research is ceremony: Indigenous research methods. Fernwood Publishing.

- Winkler, E. R. (1993). From Kantianism to contextualism: The rise and fall of the paradigm theory in bioethics. In E. R. Winkler & J. R. Coombs (Eds.), *Applied ethics: A reader*. Blackwell.
- Wolf, J. A. (2014). Patient experience or patient satisfaction? Such an important and timely topic...but easily misunderstood. The PFCC Community of Practice Blog: What Matters To You. http://mypfcc.demandco.webfactional.com/pfcc-blog/patient-experience-or-patient-satisfaction-2/
- Wolf, J. A. (2017). Patient experience: The new heart of healthcare leadership. *Frontiers of Health* Services Management, 33(3), 3–16. https://doi.org/10.1097/HAP.000000000000002
- Wolf, J. A. (2019). The state of patient experience 2019: A call to action for the future of human experience. The Beryl Institute.
- Wolf, J. A., Niederhauser, V., Marshburn, D., & Lavela, S. L. (2014). Defining patient experience. *Patient Experience Journal*, 1(1), 7–19.
- Wolf, S. M. (1994). Quality assessment of ethics in health care: The accountability revolution. *American Journal of Law and Medicine*, 20(1–2), 105–128.
- Wong, S., & Haggerty, J. (2013). Measuring patient experiences in primary health care: A review and classification of items and scales used in publicly-available questionnaires. Centre for Health Services and Policy Research, University of British Columbia.

WorkSafeBC. (2018a, July 9). Listen to your gut. https://worksafebclistentoyourgut.com

WorkSafeBC. (2018b, July 9). What I know now. http://worksafebcwhatiknownow.com

- World Health Organization (WHO). (n.d.-a). *What is quality of care and why is it important?* Retrieved January 5, 2020, from www.who.int/maternal\_child\_adolescent/topics/quality-of-care/definition/en/
- World Health Organization (WHO). (n.d.b). *Clean Care is Safer Care: Patients have a voice too!* www.who.int/gpsc/5may/5may2013 patient-participation/en/
- World Health Organization (WHO). (1986, November 21). *The Ottawa Charter for Health Promotion*. www.who.int/healthpromotion/conferences/previous/ottawa/en/
- World Health Organization (WHO). (2009a). *WHO guidelines on hand hygiene in health care: First global patient safety challenge clean care is safer care*. World Health Organization. www.ncbi.nlm.nih.gov/books/NBK144013/
- World Health Organization (WHO). (2009b). *More than words: Conceptual framework for the international classification for patient safety* (Technical Report Version 1.1 Final). World Health Organization. www.who.int/patientsafety/taxonomy/icps\_full\_report.pdf
- World Health Organization (WHO). (2009c). A guide to the implementation of the WHO multimodal hand hygiene improvement strategy. World Health Organization.

http://whqlibdoc.who.int/hq/2009/WHO\_IER\_PSP\_2009.02\_eng.pdf

 World Health Organization (WHO). (2009d). Guidance on engaging patients and patient organizations in hand hygiene initiatives. World Health Organization.
 www.who.int/gpsc/5may/5may2013 patient-participation/en

World Health Organization (WHO). (2010). *Improving value in health care: Measuring quality*.

www.who.int/maternal\_child\_adolescent/topics/quality-of-care/definition/en/

World Health Organization (WHO). (2012, April 17). *Empowering patients*. Patient Safety. www.euro.who.int/en/health-topics/Health-systems/patient-

safety/news/news/2012/5/empowering-patients

- World Health Organization (WHO). (2013a). Ethical issues in patient safety research: Interpreting existing guidance. World Health Organization. http://apps.who.int/iris/handle/10665/85371
- World Health Organization (WHO). (2013b). *Hand hygiene promotion in health care: Tips for patients*. World Health Organization. www.who.int/gpsc/5may/tips-for-patients.pdf?ua=1
- World Health Organization (WHO). (2016). Patient engagement: Technical series on safer primary care.World Health Organization.
- World Health Organization (WHO). (2017). *Patient safety: Making health care safer*. World Health Organization. https://apps.who.int/iris/bitstream/handle/10665/255507/%20WHO-HIS-SDS-2017.11-eng.pdf;jsessionid=CB4F9AA75DC5D3AC49DAC77CADD6D203?sequence=1
- World Health Organization (WHO). (2019). *Ethical considerations for health policy and systems research*. World Health Organization.

https://apps.who.int/iris/bitstream/handle/10665/330033/9789241516921-eng.pdf?ua=1

- World Health Organization (WHO). (2020a). Infection prevention and control during health care when novel coronavirus (nCoV) infection is suspected: Interim guidance. World Health Organization.
   www.who.int/publications-detail/infection-prevention-and-control-during-health-care-whennovel-coronavirus-(ncov)-infection-is-suspected-20200125
- World Health Organization (WHO). (2020b, March 11). WHO characterizes COVID-19 as a pandemic. https://youtu.be/sbT6AANFOm4
- World Medical Association. (1964). *Declaration of Helsinki: Recommendations guiding doctors in clinical research* (18th WMA General Assembly, Helsinki, Finland). www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/
- World Medical Association. (2013). *Declaration of Helsinki: Ethical principles for medical research involving human subjects* (64th WMA General Assembly, Fortaleza, Brazil).

www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-researchinvolving-human-subjects/

- Wyer, M., Jackson, D., Iedema, R., Hor, S.-Y., Gilbert, G. L., Jorm, C., Hooker, C., O'Sullivan, M. V. N.,
  & Carroll, K. (2015). Involving patients in understanding hospital infection control using visual methods. *Journal of Clinical Nursing*, 24(11–12), 1718–1729. https://doi.org/10.1111/jocn.12779
- Wynia, M. K. (2012). Making it easier to do the right thing: A modern communication QI agenda. Patient Education and Counseling, 88(3), 364–366. https://doi.org/10.1016/j.pec.2012.06.027

Yin, R. K. (2014). Case study research: Design and methods (5th ed.). Sage Publications.

- Young, J., Taylor, J., Paterson, B., Smith, I., & McComish, S. (2019). Trauma-informed practice: A paradigm shift in the education of mental health nurses. *Mental Health Practice*, 22(5), 14–19. https://doi.org/10.7748/mhp.2019.e1359
- Younging, G. (2018). *Elements of Indigenous style: A guide for writing by and about Indigenous Peoples*. Brush Education.
- Ziebland, S., Coulter, A., Calabrese, J. D., & Locock, L. (Eds.). (2013). Understanding and using health experiences: Improving patient care. Oxford University Press.

# Appendices

## Appendix A IHI QI Project Charter

IHI TOOL: Quality Improvement Project Charter

# **Template: QI Project Charter**

Team:

Project:

Sponsor:

**Project Start Date:** 

Last Revised:

#### What are we trying to accomplish?

**Problem** Describe in 2 to 3 sentences the existing condition you hope to improve (i.e., the gap in quality).

#### Project Description (defines what)

Document your current thinking about the activities of the project (e.g., design a new process, improve an existing product or service, etc.). Note the subsystem, pilot population, and/or demonstration unit where the work will take place. Consider including your long-term vision and short-term project goals.

#### Rationale (defines why)

Explain why the current process or system needs improvement. If possible, include baseline data and other benchmarks.

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#### **Expected Outcomes and Benefits**

How will this improvement benefit the team, the organization, customers, and/or the community? What is the business impact, such as reduced costs or other financial benefits?

Aim Statement

What outcome are you hoping to achieve? Specify how good, for whom, and by when (a specific date).

#### How will we know that a change is an improvement?

When defining your project-level measures, provide operational definitions, which specify unambiguously how to derive each measure, and be sure to define numerators and denominators in measures such as percent or rates.

**Outcome Measure(s)** List the measure(s) you ultimately want to affect as a result of this project.

Process Measure(s)

List the measure(s) that will tell you if the system is performing as planned to affect the outcome measure.

**Balancing Measure(s)** 

List the measures that will tell you whether you are introducing problems elsewhere in the system.

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#### What changes can we make that will result in improvement?

#### **Initial Activities**

Consider starting by exploring the process or system you are trying to improve with tools such as interviews, direct observation, cause and effect diagrams, driver diagrams, and process maps/flowcharts.

**Change Ideas** 

What ideas do you have for initial tests of change (Plan-Do-Study-Act cycles)?

Key Stakeholders

Whose input and support will this project require? How will you engage these key stakeholders?

#### Barriers

What barriers do you predict to your success? How will you overcome these barriers?

#### Boundaries

List any guidelines for the team, including project constraints, rules or procedures, technology considerations, what is out of scope, etc.

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#### Appendix B QI Interventions with Varying Levels of Patient/Family Involvement

The following scenarios illustrate varying levels of patient/family involvement in QI interventions in pursuit of the *Triple Aim* (improve patient experience of care, improve health of population, and lower health care costs) (Berwick et al., 2008). Each of the six scenarios describes a four-week pilot QI hand hygiene intervention in an acute care hospital aiming to decrease health care-associated infections, and assumes accompanying QI strategies for successful implementation such as appropriate education of the target groups.

**Scenario One:** A QI intervention to improve thoroughness of surgical hand preparation involves installing a motion sensor timer in the scrub room, and targets operating room staff. This QI intervention is 'behind the scenes' because the hygiene process itself takes place out of view of patients and families. Patients and families are not aware of the process, that the process is new, and that it is part of a QI intervention involving data collection about how long care providers scrub prior to surgery and post-surgical infection rates.

**Scenario Two:** A QI intervention to increase the rate of providers performing hand hygiene between patients on a hospital medical unit involves installing alcohol-based hand rub (ABHR) at the foot of each patient bed. The intervention targets care providers. However, unlike the previous scrub room example, the process may take place in view of patients (if they are awake and aware) and families (if they are present and aware). Patients and families do not have a role in the intervention and they may or may not be aware that the process is new and/or that it is part of a QI intervention involving data collection about provider hand hygiene compliance, quantity of ABHR used, and patient infection rates on the unit.

**Scenario Three:** A QI intervention to increase provider hand hygiene in a hospital emergency department involves: (1) putting posters on the walls that say "*Patients, it's ok to ask. 'Would you mind washing your hands again for me?*"; and (2) educating providers to respond positively when patients ask them to clean their hands. This intervention targets both patients/families and providers. Patients/families have a role in the intervention, and are given a new opportunity to be involved in the quality and safety of their own health care. Patients/families may or may not be

aware that this process is new, and/or that it is part of a QI intervention involving data collection about the number of times patients/families are observed asking providers to wash their hands, and a qualitative description of observed interactions.

**Scenario Four:** A QI intervention to increase provider hand hygiene on a hospital dialysis unit involves asking patients/families to complete a form at the end of each dialysis session reporting whether or not they observed their nurse clean his/her hands directly before connecting them to the dialysis machine. The intervention targets patients and families. Patients/families have a role in the intervention, and are given a new opportunity to be involved in the quality and safety of their health care. Patients/families may or may not be told that the process is part of a new QI intervention, and that data are being collected for four weeks about numbers of patient/family reports completed, nurse hand hygiene compliance, and patient infection rates on the unit.

**Scenario Five:** A QI intervention to increase patient hand hygiene on a hospital medical unit involves asking nurses to offer patients hand wipes before meals. The intervention targets nursing staff and patients. Patients have a role in the intervention, and are given a new opportunity to clean their hands before eating and be involved in the quality and safety of their health care. Patients/families may or may not be told that the process is part of a new QI intervention, and that data are being collected for four weeks about number of hand wipe canisters used, number of patients who accept hand wipes, and patient infection rates on the unit.

**Scenario Six:** A QI intervention to increase patient hand hygiene on a hospital surgical unit involves installing ABHR near the head of each patient bed so that patients can easily reach the hand rub before eating and after using the bedpan/commode. The intervention targets patients (if they are awake and aware) and families (if they are present and aware). Patients and families have a role in the intervention, and are given a new opportunity to be involved in the quality and safety of their health care. Patients/families may or may not be told that the process is part of a new QI intervention, and that data are being collected for four weeks about patient/family hand hygiene compliance, perceptions of hand hygiene mechanisms, quantity of ABHR used, and patient infection rates on the unit.

## Appendix C ARECCI Ethics Screening Tool

Alberta Innovates

## **ARECCI Ethics Screening Tool**

#### **Tool Background**

Policy or legislative requirements often stipulate that research projects involving people or their health information must be reviewed by a Research Ethics Board (REB). This raises a number of questions. For example, what should be done with projects that are not considered research but involve people or their health information? Should quality improvement (QI) or program evaluation projects also be assessed for their risk to people? What are the characteristics of research versus quality improvement/evaluation projects? How do you decide what to review? How should ethics oversight of these "non-research" projects be approached? Some of these questions remain the subject of lengthy debate.

A pRoject Ethics Community Consensus Initiative (ARECCI) (formerly The Alberta Research Ethics Community Consensus Initiative), an initiative of Alberta Innovates – Health Solutions (AIHS) (formerly the Alberta Heritage Foundation for Medical Research), developed this four-step, webbased ARECCI Ethics Screening Tool to provide practical "on the ground" decision-support assistance to project leaders and teams as they grapple with these very complex questions. Content experts have developed the tool, and its context validity continues to be enhanced through focused implementation with experts and their projects.



Step 1: PRELIMINARY SCREEN: Helps identify those projects which clearly require REB review.

**Step 2: PROJECT PRIMARY PURPOSE:** A primary purpose screen sorts research from other types of projects to determine the appropriate review pathway (i.e., REB review or organization/context based oversight).

**Step 3: RISK FILTERS:** Based on the result in Step 2 (i.e., determination of project primary purpose), one of two risk filters automatically become available: one for research and one for QI/evaluation. These risk filters help the user identify ethical risks from the perspective of participants in the project.

**Step 4: SCREENING RESULT:** A summary score produces the category of risk for project participants. The category of risk is highlighted together with the corresponding recommended review action for the project. Specific items and their values that contribute to the total score are also listed. This enables those responsible to plan appropriate risk-mitigating strategies before involving participants. Professional judgment is required in interpreting all screening results.

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## Appendix D Patient Voices Network: Invitation Email for Patient Partners

**Subject:** PVN Opportunity: Patient and Family Experience of Quality Improvement and Safety Initiatives Research Study at Study Hospital UBC

Hello Everyone,

The University of British Columbia – School of Population & Public Health is inviting two PVN Volunteers to join a research team in an advisory role on a study of patient and family experiences of health care quality improvement (QI) and safety initiatives at Study Hospital from an ethical lens.

#### Aim:

The purpose is to engage patients as participants on a research team studying how QI projects (specifically hand washing projects that involve patients and families) affect the care experience for patients and families in an acute care setting.

#### Level of engagement:

This opportunity is at the level of <u>collaborate</u> on the spectrum of engagement (www.iap2.org). The promise to you is that the health care partner will look to you for advice in developing solutions and include your recommendations into the decision as much as possible.

#### Criteria:

- Individuals who have personally, or as a family member, had a recent experience in an acute care unit at Study Hospital.
- Be comfortable participating in discussions with a diverse range of stakeholders including academics.
- Have the ability to clearly articulate opinions and concepts relating to quality improvement in patient care and what it is like to be a patient or family member in an acute care setting.
- Interest and/or experience with health research is considered an asset.

#### **Details:**

- Term of Commitment: 1 year
- Meeting frequency: Planning meetings will be held from July through October. From November 2015 – September 2016 patient partners will be invited to attend 1-2 meetings to discuss and provide feedback on preliminary study findings
- Meetings will be held during business hours at Study Hospital or at UBC (Point Grey Campus).
- The first meeting will be held in person. Further meetings may be attended in person or via teleconference.
- The health care partner will reimburse transit and parking (up to \$18/day) for in-person meetings. Mileage will not be reimbursed.

#### **Background:**

This research is being led by a graduate student as part of a doctoral thesis. The study plan has been accepted and ethics application has been submitted, however the plan will change in response to what is happening with the hand hygiene initiatives being studied. Please refer to the attached documents for additional information about the research study.

Appendix E Study Poster/Group Disclosure

# Research Study at Study Hospital: "The Patient/Family Experience of QI & Safety Study"

Many hospitals are trying to increase hand washing in order to reduce infections. Some hospitals are leading projects that involve patients and families, for example encouraging patients/families to use alcohol-based hand rubs and wipes, and encouraging patients to remind their health care providers to wash their hands.

## Why are we doing this study?

We think it is important to know not only how these kinds of hand washing projects help reduce infections, but also what patients and family members think about these projects and how the projects affect patients' care experience.

Part of this study involves a researcher observing everyday activities on hospital units, focusing on interactions between health care providers, patients and families related to hand washing. Please let us know if you are uncomfortable with or unwilling to be part of any direct observational activities. The researcher would also like to interview some patients and family members about how hand washing projects may be affecting their care experience. She will then talk to staff to understand their views. We hope this new information can improve patient care in the future.

# Who is doing this study?

This study is going on between August 2015 and March 2016 as part of a graduate student research project led by Brenda Sawatzky-Girling. [Researcher Bio]



# Would you like more information about this study?

If you have any questions or concerns about this study or would like to be involved, please contact:

Researcher: Brenda Sawatzky-Girling, BASc (Nutrition), MHA; PhD Candidate, UBC School of Population and Public Health, -----Study Hospital Contact: -----PhD Supervisor: Paddy Rodney, RN, MSN, PhD, UBC School of Nursing, -----

## Appendix F Researcher Observational Protocol

## "The Patient/Family Experience of QI & Safety Initiatives Study" Observational Protocol

#### Part A. Overall Study Focus

#### **Research question:**

How do patients and families describe their experience of being involved in a quality improvement initiative that asks them to take on specific responsibilities to improve the quality and safety of their own health care in an acute care hospital?

#### Argument on which thesis proposal is based:

Patient empowerment Power asymmetries Patient burden Patient capacity Competing interests Responsibilities of patients

#### Sampling frame:

Inpatients and their family/support network on target Study Hospital acute care units.

#### Part B. Data Collection Procedures

#### **Key organizational contacts:** Study Hospital contact information

#### Study Hospital contact miorin

#### **Events to be observed:**

- Everyday patient care on units where the hand hygiene case studies are implemented
- Quality improvement/safety meetings
- Organizational documents related to quality improvement/safety, patient-centred care (no patient charts will be reviewed)

#### C. Data Collection Questions: "Observing the Relational Interplay"

#### Researcher's mental line of inquiry/questions asked of the case studies during observation:

Step 1: Notice people and their behaviours:

- What do you see?
- Do you find yourself noticing some people over others?
- What curiosities arise as you watch the different people?
- Observe location sights, smells, sounds.

#### **Step 2:** Observe the situations in play:

- What are people doing?
- Who is talking to whom and how?
- How are the people, contexts, and situations shaping each other?
Step 3: Observe my response:

- Who is garnering my attention?
- How am I feeling?
- What am I thinking?
- What am I wondering?
- Of what am I particularly aware?

Step 4: Shortly after observation session, analyze:

A: Intrapersonally:

- How did I interpret the behaviour I observed?
- Did I experience some people's actions more favourably than others?
- Why might that be?
- What does that tell me about my own thinking?

#### **Overarching Intrapersonal Questions:**

- How are people making meaning of their situations? (interpretive analysis)
- How are different people interpreting situations differently? (interpretive analysis)
- How do relative positions of power shape understanding? (power analysis)

B: Interpersonally:

- What was going on among people? Patients, family, staff, others
- How were they influencing one another?
- Does anything surprise me?
- What questions come to my mind?

#### **Overarching Interpersonal Questions:**

- How are different interpretations shaping situations and interpersonal relations? *(interpretive analysis)*
- How are power dynamics shaping each interpersonal relationship? (power analysis)

#### C: Context:

Expand my thinking on how context was shaping the interplay:

- How does the physical setting (space, equipment, lighting) influence what happens?
- What does the setting look like? (clinical, home-like, sterile)?
- Can I infer any "rules" or policies at play?
- Were there signs conveying certain messages?
- How did I see the people, context and situations shaping each other?

#### **Overarching Contextual Questions:**

- How are people variously situated and constituted? (interpretive analysis)
- How are social structure and arrangements shaping people, situations, and interpersonal relationships? *(power analysis)*

**Step 5:** Observe my own thinking and response:

- What contextual features stood out for me and why?
- Putting it all together, can I see any habits or selective interests that shaped my observations?
- Did I feel uncomfortable about any of my observations or responses?

- Did I notice myself making any judgements that surprised me?
- Did I find myself averse to certain people?
- What might I want to explore further?

Adapted from G. H. Doane and C. Varcoe. (2015). *How to Nurse: relational inquiry with individuals and families in changing health and health care contexts*. Philadelphia: Wolters Kluwer. "Observing the Relational Interplay" Pages 33-4.

#### Part C. Data Collection Form

TT 1.
Unit:
Shadowing:
Pages of written notes:
Date:
Day of Week:
Start Time:
End Time:
Other:
Date Transcribed:

Descriptive Notes	Reflective Notes

#### **Reflection on shadowing experience:**

Shadower experience	
Any patient comments or opinions?	
Any awkward moments?	
What worked well?	
What worked less well?	
What would you improve?	

Adapted from Agency for Healthcare Research and Quality. (2005). A Toolkit for Redesign in Health Care. Rockville, Maryland: Agency for Healthcare Research and Quality (p. 39). Retrieved from (S. Berg, 2017; Grainger & Pointon, 2017; StuderGroup, n.d.); Creswell, J. W. (2013). Qualitative inquiry and research design: Choosing among five approaches. Los Angeles: SAGE Publications (p. 169).

#### Appendix G Information Sheet for Patients and Families

### INFORMATION SHEET ABOUT SHADOWING FOR PATIENTS AND FAMILIES Research Study: "The Patient/Family Experience of QI & Safety Initiatives Study"

#### Why are we doing this study?

Many hospitals are trying to increase hand washing in order to reduce infections. Some hospitals are leading projects that involve patients and families, for example encouraging patients/families to use alcohol-based hand rubs and wipes, and encouraging patients to remind their health care providers to wash their hands.

We think it is important to know not only how these kinds of hand washing projects help reduce infections, but also what patients and family members think about these projects and how the projects affect patients' care experience. This study involves a researcher observing everyday activities on hospital units, focusing on interactions between health care providers, patients and families related to hand washing, and interviewing some patients and family members about how these hand washing projects may be affecting their perceptions or care experience. She will also talk to staff to understand their views. We hope this new information can improve patient care in the future. This study is going on between August 2015 and March 2016 as part of a graduate student research project.

# Would you like to participate in this study by having the researcher shadow your care experience? It is completely voluntary.

You are being invited to take part in this research study because you are a patient or family member on one of the units where the hand washing projects of interest are being tested. *Agreeing to participate in this study would involve giving your permission for the researcher to "shadow" you for a few hours while you are on the unit.* In total your participation would take between about 2 and 4 hours. Information you share with the researcher when she is shadowing you will *not* be passed on to your health care providers. No one will be mad at you if you don't want to participate.

#### Would you like more information about the study?

If you have any questions or concerns about this study or would like more information about participating, please tell your nurse or contact Brenda Sawatzky-Girling:

Researcher: Brenda Sawatzky-Girling, BASc (Nutrition), MHA; PhD Candidate, UBC School of Population and Public Health, -----Study Hospital Contact: -----PhD Supervisor: Paddy Rodney, RN, MSN, PhD; UBC School of Nursing, -----

#### Appendix H Consent Form for Patient and Family Shadowing

#### **CONSENT FORM – PATIENT AND FAMILY SHADOWING**

#### Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

#### Who is conducting the study?

Principal Investigator: Patricia Rodney, RN, MSN, PhD Associate Professor, School of Nursing, University of British Columbia Tel: -----

#### Co-Investigator:

Brenda Sawatzky-Girling, BASc (Nutrition), MHA (referred to as "the researcher") PhD Candidate, School of Population and Public Health, University of British Columbia Tel: -----

I am a graduate student at the University of British Columbia, working with my faculty advisor, Patricia Rodney. This study is part of my doctoral research.

#### Why are we doing this study?

Many hospitals are trying to increase hand washing in order to reduce infections. Some hospitals are leading projects that involve patients and families, for example encouraging patients/families to use alcohol-based hand rubs and wipes, and encouraging patients to remind their health care providers to wash their hands. We think it is important to know not only how these kinds of hand washing projects help reduce infections, but also what patients and family members think about these projects.

Part of this study involves a researcher observing everyday activities on several Study Hospital units, focusing on interactions between health care providers, patients and families related to hand washing. We would like to "shadow" about 8 to 10 patients and family members – this means accompany patients through their care experience to help us understand this experience from the patient/family point of view. You are being invited to be in this study because you are a patient (or you are a family member of a patient) on a unit at Study Hospital where this study is taking place.

This study is intended to be descriptive, we are not evaluating how the unit staff and volunteers provide care or treat you. We hope this new information can improve quality improvement projects and patient care in the future.

#### What happens if you say "Yes, I want to be in the study"?

The study is under the direction of Dr. Paddy Rodney and involves being shadowed by the researcher Mrs. Brenda Sawatzky-Girling for a few hours while you a patient/family member on Unit \_\_\_\_\_. In total your participation would take up to 4 hours. If you say 'Yes', here is how we

will do the study:

- The researcher will ask you to read this consent form, answer any questions you have about the study, and if you agree to participate you will sign this form.
- We will then talk about the best time(s) and day(s) to shadow you. This includes when and where the shadowing will start and finish.
- During the shadowing, the researcher will follow along with your health care journey noting the details of the experience (such as where you go, what happens, your interactions with staff, family members and other patients, and any specific comments you might have). She will not interfere with or influence your regular care.
- The researcher will be wearing an ID badge and will introduce herself to other patients and staff, explain she is observing for a research study and not evaluating people, and obtain verbal permission from others to be observed for the purposes of this study.
- You may wish to have family members present, it is up to you.
- The researcher may chat with you and ask a few questions about what is happening, especially as it relates to hand washing. You do not have to answer any question if you do not want to.
- The researcher may record what she observes in a study binder. No confidential or identifying details about you, family members, other patients, or unit staff will be recorded.
- If at any time during the shadowing you want to have a break, stop, or find something distressing, please let the researcher or your nurse know.

# How will people find out about the study results?

Study results will be reported in a graduate thesis (available to the public), academic journal articles, presentations, and plain language summaries. You will not be identified in any of these reports. If you want to receive a report on the study results from the researcher, you can indicate this at the end of this form.

#### Is there any way being in this study could be bad for you?

We do not think there is anything in this study that could harm you or be bad for you. If the shadowing raises issues or feelings that you may need support to manage, please let the researcher or your nurse know and/or contact -----, Telephone: ----- or Email: -----.

You can pause the shadowing at any time, and you do not have to answer any questions that make you feel uncomfortable. You can also withdraw your participation in the study at any time.

# What are the benefits of participating?

We do not think taking part in this study will help you. This study is not designed to treat any illness or to improve your health. However, the shadowing will provide you with the opportunity to share your experience on how the hospital's hand washing projects may be affecting your care experience. In the future, others may benefit from what we learn in this study.

#### How will your confidentiality be protected?

Your confidentiality will be respected. Study Hospital staff and patients may be aware of your participation in the study; however your involvement will remain confidential by the researcher.

Information you share with the researcher during this study will *not* be passed on to your health care providers. You should give important information related to your medical care directly to your health care providers.

Information that discloses your identity (such as the consent form signed by you) will not be released without your consent unless required by law. Study documents will be identified only by code number. During the study, paper documents will be kept in the researcher's office in a locked filing cabinet to which only she has access. Electronic documents and audiorecordings will be password protected and kept on the researcher's computer and external hard drive to which only she has access.

Study documents will be shared with the researcher's supervisors (Dr. Patricia Rodney, Dr. Sam Sheps, Dr. Michael McDonald) and may be shared with the [UBC] Research Ethics Board for the purpose of monitoring the study. Study documents will be kept at UBC for at least 5 years after the graduate thesis is published.

Your identity will be kept confidential in the study results. Individual names and other personally identifiable information will be removed or changed if results of this study are published or presented.

#### Will you be paid for taking part in this research study?

We will not pay you for the time you take to be in this study.

#### Who can you contact if you have questions about the study?

If you have any questions or concerns about what we are asking of you, please contact Mrs. Brenda Sawatzky-Girling (the researcher) or Dr. Patricia Rodney (the study supervisor). The names and telephone numbers are listed at the top of the first page of this form.

#### Who can you contact if you have complaints or concerns about the study?

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604.822.8598 (toll free 1.877.822.8598) or e-mail RSIL@ors.ubc.ca, or Study Hospital at -----.

# PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate or pull out of the study at any time without giving a reason and without any negative impact on your regular medical care or loss of benefits to which you are otherwise entitled.

#### **Consent for Future Contact about Sharing Your Data (Optional)**

We may wish to contact you in the future to ask you questions about your data. Check one of the following to indicate your choice:

- □ Yes, I agree that you can contact me if you have follow-up questions about shadowing me or sharing my data with others. My phone/email is
- **D** No, I do not want you to contact me with questions about my data.
- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you voluntarily agree to participate in this study.

Participant Signature	Date
Printed Name of the Participant signing above	
Name of Person Obtaining Consent	Date

Date/Time of Shadowing

Beginning Location

# **OPTIONAL – PATIENT AND FAMILY – STUDY RESULTS**

# Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

Check one of the following to indicate your choice:

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or				
Mulan	ailaddraga	ia.		
My em	all address	18:		

■ No, I do not want to receive a report on the study results.

#### Appendix I Consent Form for Hospital Staff Shadowing

#### **CONSENT FORM – UNIT RESEARCH MENTOR**

#### Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

#### Who is conducting the study?

Principal Investigator: Patricia Rodney, RN, MSN, PhD Associate Professor, School of Nursing, University of British Columbia Tel: -----

#### *Co-Investigator:*

Brenda Sawatzky-Girling, BASc (Nutrition), MHA (referred to as "the researcher") PhD Candidate, School of Population and Public Health, University of British Columbia Tel: -----

I am a graduate student at the University of British Columbia, working with my faculty advisor, Patricia Rodney. This study is part of my doctoral research.

#### Why are we doing this study?

Many hospitals are trying to increase hand washing in order to reduce infections. Some hospitals are leading projects that involve patients and families, for example encouraging patients/families to use alcohol-based hand rubs and wipes, and encouraging patients to remind their health care providers to wash their hands. We think it is important to know not only how these kinds of hand washing projects help reduce infections, but also what patients and family members think about these projects and how the projects affect patients' care experience.

This study involves a researcher shadowing unit staff (such as nurses, patient care advisors or volunteers, referred to as "research mentors") and observing everyday activities on Study Hospital units. You are being invited to be a research mentor in this study because you work or volunteer on a Study Hospital unit where this study is taking place. During these observations, the researcher will focus on interactions between health care providers, patients and families related to hand washing. About 3 or 4 staff on your unit will be shadowed. The total time the researcher hopes to spend in Study Hospital is about 100 hours (25 x 4-hour shifts over several weeks).

After the observation phase, the researcher will interview about 25 patients/families (total across all units) about how the target hand hygiene initiatives may be affecting their perceptions or care experiences. Nearing the end of the study she will talk to staff (such as 6-8 frontline care providers or quality leaders) to interpret the significance of patient and family stories.

This study is intended to be qualitative and descriptive, not evaluative. We hope this new information can improve quality improvement projects and patient care in the future.

#### What happens if you say "Yes, I want to be in the study"?

The study is under the direction of Dr. Paddy Rodney and involves being shadowed by the researcher (Mrs. Brenda Sawatzky-Girling) during one or more of your shifts on Unit \_\_\_\_\_. If you say 'Yes', here is how we will do the study:

- The researcher will ask you to read this consent form, answer any questions you have about being a research mentor in the study, and if you agree to participate you will sign this form.
- Make arrangements to schedule the researcher to shadow you during several shifts.

#### During job shadowing:

- Orient the researcher to the unit.
- Introduce the researcher to patients and staff, explain her role, and obtain verbal permission from others to be observed for the purposes of this study (for example, "Brenda is a UBC graduate student studying what patients and family members think about hand washing projects on the unit and how these projects affect patients' care experience").
- Commentary on what is happening on the unit during the observation shift, especially as it relates to hand hygiene.
- The researcher may make some notes to record her observations of everyday activities, focusing on interactions between health care providers, patients, and families related to hand washing. No confidential details regarding patient illness/identity or staff practice/identity will be recorded. Note-taking will be done discreetly (e.g., at the nursing station, not at the bedside). The researcher will not review patient charts.
- You can ask the researcher to withdraw at any time if you think her presence is inappropriate.

#### Facilitate access and recruitment of patients/family members for interviews:

- Help identify which patients and/or family members may be suitable for interviews (respectful of their comfort, health status, and ethical rights) and discuss with researcher.
- Distribute "INFORMATION SHEET FOR PATIENTS AND FAMILIES" to potential patient/ family participants. Patients/families can indicate their interest in participating by (1) telling a staff member (who will relay this information to the researcher), or (2) contacting the researcher directly. The researcher will then approach patients/families who have expressed interest while they are on the unit, or by telephone if they have been discharged to explain the study.

#### How will people find out about the study results?

Study results will be reported in a graduate thesis (available to the public), academic journal articles, presentations, and plain language summaries. You will not be identified in any of these reports. If you want to receive a report on the study results from the researcher, you can indicate this at the end of this form.

#### Is there any way being in this study could be bad for you?

We do not think there is anything in this study that could harm you or be bad for you. The only foreseeable discomfort associated with the study is the invasion of your privacy.

#### What are the benefits of participating?

There are no direct benefits from participation in the study. However, in the future, others may benefit from what we learn about patient/family experiences in this study.

#### How will your confidentiality be protected?

Your confidentiality will be respected. Study Hospital staff and patients may be aware of your participation in the study; however your involvement will remain confidential by the researcher. Information you share with the researcher during this study will *not* be passed on to Study Hospital authorities in a way that identifies you.

Information that discloses your identity (such as the consent form signed by you) will not be released without your consent unless required by law. Study documents will be identified only by code number. During the study, paper documents will be kept in the researcher's office in a locked filing cabinet to which only she has access. Electronic documents will be password protected and kept on the researcher's computer and external hard drive to which only she has access.

Study documents will be shared with the researcher's supervisors (Dr. Patricia Rodney, Dr. Sam Sheps, Dr. Michael McDonald) and may be shared with the UBC Research Ethics Board for the purpose of monitoring the study. Study documents will be kept at UBC for at least 5 years after the graduate thesis is published.

Your identity will be kept confidential in the study results. Names and other personally identifiable information will be removed or changed if results of this study are published or presented.

#### Will you be paid for taking part in this research study?

We will not pay you for the time you take to be in this study.

#### Who can you contact if you have questions about the study?

If you have any questions or concerns about what we are asking of you, please contact Mrs. Brenda Sawatzky-Girling (the researcher) or Dr. Patricia Rodney (the study supervisor). The names and telephone numbers are listed at the top of the first page of this form.

#### Who can you contact if you have complaints or concerns about the study?

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604.822.8598 (toll free 1.877.822.8598) or e-mail RSIL@ors.ubc.ca, or Study Hospital at -----.

#### PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. Your participation in this research is in no way a part of your Study Hospital duties, and your refusal to participate will not in any way affect your employment with Study Hospital, or the benefits, privileges, or opportunities associated with your employment at Study Hospital. You have the right to refuse to participate or pull out of the study at any time without giving a reason and without any negative impact or loss of benefits to which you are otherwise entitled.

#### **Consent for Future Contact about Sharing Your Data (Optional)**

We may wish to contact you in the future to ask you questions about your data. Check one of the following to indicate your choice:

Yes, I agree that you can contact me if you have any questions about my role as a
research mentor or sharing my data with others. My phone/email is

**D** No, I do not want you to contact me with questions about my data.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you voluntarily agree to participate in this study.

Participant Signature

Date

Printed Name of the Participant signing above

Name of Person Obtaining Consent

Date

# **OPTIONAL – UNIT RESEARCH MENTOR – STUDY RESULTS**

### Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

Check one of the following to indicate your choice:

1019 1110	ining addres	5 15.		
or				
My em	ail address	is:		

■ No, I do not want to receive a report on the study results.

#### Appendix J Consent Form for Patient and Family Interview

#### **CONSENT FORM – PATIENT AND FAMILY INTERVIEW – OUTPATIENT**

#### Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

#### Who is conducting the study?

Principal Investigator: Patricia Rodney, RN, MSN, PhD Associate Professor, School of Nursing, University of British Columbia Tel: -----

#### Co-Investigator:

Brenda Sawatzky-Girling, BASc (Nutrition), MHA (referred to as "the researcher") PhD Candidate, School of Population and Public Health, University of British Columbia Tel: -----

I am a graduate student at the University of British Columbia, working with my faculty advisor, Patricia Rodney. This study is part of my doctoral research.

#### Why are we doing this study?

Many hospitals are trying to increase hand washing in order to reduce infections. Some hospitals are leading projects that involve patients and families, for example encouraging patients/families to use alcohol-based hand rubs and wipes, and encouraging patients to remind their health care providers to wash their hands. We think it is important to know not only how these kinds of hand washing projects help reduce infections, but also what patients and family members think about these projects.

Part of this study involves a researcher observing everyday activities on Study Hospital units, focusing on interactions between health providers, patients and families related to hand washing. Now we would like to interview some patients and family members to learn more about how hand washing projects may be affecting your care experience. We hope this new information can improve quality improvement projects and patient care in the future.

You are being asked to be in this study because you are a patient (or you are a family member of a patient) in Study Hospital, where this study is taking place.

#### What happens if you say "Yes, I want to be in the study"?

The study is under the direction of Dr. Patricia Rodney and involves being interviewed by the researcher Brenda Sawatzky-Girling. In total, we will interview about 25 patients and family members. The total time required for this study is expected to be about 2 hours. If you say 'Yes', here is how we will do the study:

- The researcher will ask you to read this consent form, answer any questions you have about

the study, and if you agree to participate you will sign this form. We will then make arrangements to interview you.

#### Main Interview

- The main interview may take place while you are in hospital, or after you go home at a location convenient for you, it is up to you. The interview will be held in a private space where you won't be overheard.
- The interview will take about 60 minutes.
- The interview may involve just you, or you may wish to have family members present. Each family member will need to sign his/her own consent form.
- We would like to ask you some questions about how one or two hand washing projects at Study Hospital relate to your current hospital experience. We will also ask you some basic questions such as your age, how long you have been in the hospital, family support, and the general nature of your medical problems. You do not have to answer any question if you do not want to. If at any time you want to stop, have a break, or find answering distressing, please let the researcher know.
- We would like to audio record the interview to accurately record your views and opinions. If you would prefer the interview not to be recorded, written notes alone will be taken.

#### Follow-up Interview

After the main interview, the researcher will ask you if you want to participate in one shorter follow-up interview (about 20 to 30 minutes) about two weeks after the main interview to check if you have anything else you'd like to share about how the hand washing projects may have affected your care experience. The follow-up interview can either be in person or on the telephone, preferably after you have been discharged from the hospital.

#### How will people find out about the study results?

Study results will be reported in a graduate thesis (available to the public), academic journal articles, presentations, and plain language summaries. You will not be identified in any of these reports. If you want to receive a report on the study results from the researcher, you can indicate this at the end of this form.

#### Is there any way being in this study could be bad for you?

We do not think there is anything in this study that could harm you or be bad for you. As the interview will deal with the topic of your experiences as a patient or family member, it is possible that it may raise issues or feelings that you may need support to manage. If this happens, please let the researcher know and/or contact -----, Telephone: ----- or Email: -----.

You can stop the interview at any time, and you do not have to answer any questions that make you feel uncomfortable. You can also withdraw your participation in the study at any time.

#### What are the benefits of participating?

We do not think taking part in this study will help you. This study is not designed to treat any illness or to improve your health. However, the interview will provide you with the opportunity to voice your opinion on how the hospital's hand washing projects may be affecting your care

experience. In the future, others may benefit from what we learn in this study.

#### How will your confidentiality be protected?

Your confidentiality will be respected. Study Hospital staff and patients may be aware of your participation in the interview; however your involvement will remain confidential by the researcher. Information you share with the researcher during interviews in this study will *not* be passed on to your health care providers. You should give important information related to your medical care directly to your health care providers.

Information that discloses your identity (such as the consent form signed by you) will not be released without your consent unless required by law. Study documents will be identified only by code number. During the study, paper documents will be kept in the researcher's office in a locked filing cabinet to which only she has access. Electronic documents and audiorecordings will be password protected and kept on the researcher's computer and external hard drive to which only she has access. Audiorecordings may include information that would identify you, and will be shared with a transcriptionist who has signed a confidentially agreement. The audiotapes will be transcribed removing any names you may have mentioned.

Study documents and audiorecordings will be shared with the researcher's supervisors and may be shared with the UBC Research Ethics Board for the purpose of monitoring the study. Study documents and audiorecordings will be kept at UBC for at least 5 years after the graduate thesis is published.

Your identity will be kept confidential in the study results. Individual names and other personally identifiable information will be removed or changed if results of this study are published or presented.

In situations where several family members choose to be interviewed at the same time, we encourage participants not to discuss the content of the interview to people outside the group; however, we can't control what participants do with the information discussed.

#### Will you be paid for taking part in this research study?

In order to acknowledge the time you have taken to be involved in this project and defray the costs of transportation (if applicable), each participant will receive a \$10 coffee shop gift card on the day of the last interview. Please discuss this with the researcher.

#### Who can you contact if you have questions about the study?

If you have any questions or concerns about what we are asking of you, please contact Brenda Sawatzky-Girling (the researcher) or Dr. Patricia Rodney (the study supervisor). The names and telephone numbers are listed at the top of the first page of this form.

#### Who can you contact if you have complaints or concerns about the study?

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, you may contact the Research Subject Information Line in the UBC

Office of Research Services at 604.822.8598 (toll free 1.877.822.8598) or e-mail RSIL@ors.ubc.ca, or Study Hospital at -----.

# PARTICIPANT CONSENT AND SIGNATURE PAGE

Taking part in this study is entirely up to you. You have the right to refuse to participate or pull out of the study at any time without giving a reason and without any negative impact on your regular medical care or loss of benefits to which you are otherwise entitled.

# **Consent to Audio record Interview (Optional)**

Check one of the following to indicate your choice:

- **D** Yes, I agree that my interview can be audio recorded.
- No, I do not want my interview to be audio recorded.

We will confirm your permission to audio record just before starting the interview.

# **Consent for Future Contact about Sharing Your Data (Optional)**

We may wish to contact you in the future to ask you questions about your data. Check one of the following to indicate your choice:

□ Yes, I agree that you can contact me if you have any questions about my interview or sharing my data with others. My phone/email is

**D** No, I do not want you to contact me with questions about my data.

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you voluntarily agree to participate in this study.

Participant Signature

Date

Printed Name of the Participant signing above

Name of Person Obtaining Consent

Date/Time of Main Interview

Location

Date

# **OPTIONAL – PATIENT AND FAMILY FOLLOW-UP INTERVIEW**

#### Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

After main interview is completed:

# 1) Follow-up Interview (Optional)

Please indicate if you agree to participate in one shorter follow-up interview in person or on the telephone about two weeks after the main interview (or after you have been discharged):

**D** Yes, I agree to participate in one shorter follow-up interview.

Date/Time of Follow-up Interview

Follow-up Interview Location (or Telephone Number)

■ No, I do not want to participate in any more interviews.

#### 2) Consent to Audio record Follow-up Interview (Optional)

Check one of the following to indicate your choice:

- Yes, I agree that my follow-up interview can be audio recorded.
- No, I do not want my follow-up interview to be audio recorded.
- I am not participating in a follow-up interview.

We will confirm your permission to audio record just before starting the follow-up interview.

Participant Signature

Date

Printed Name of the Participant signing above

Name of Person Obtaining Consent

Date

# **OPTIONAL – PATIENT AND FAMILY – STUDY RESULTS**

# Title of Study: A qualitative study of patient/family experience of health care quality improvement and safety initiatives from an ethical lens

Check one of the following to indicate your choice:

My mailing	address is:		
or			
-			
My email ac	ldress is:		

■ No, I do not want to receive a report on the study results.

Appendix K Researcher Trigger Questions for Patient and Family Interviews

The Patient/Family Experience of Quality Improvement & Safety Study Trigger Questions for In-depth Interviews with Patients and Families

### Part A. Trigger Questions

#### At Beginning of Interview

\*In this study I'm interested to know about the backgrounds and experiences of the people I'm interviewing. I know that things such as how you understand your medical situation, where you've come from, and what's important in your family might have an influence on how you feel while receiving health care [in this hospital, on this unit]. Tell me a bit about yourself ...

# General Hand Hygiene

\*I'm wondering what patients notice about what Study Hospital is doing to promote cleanliness at the hospital?

• What is missing?

# Patient Hand Washing

- What supplies are available at the hospital for patients to clean their hands? How is this working for you? How do you think this works for other patients?
- How do the staff (or volunteers/family/others) facilitate hand washing while you are here?

# \*What have your experiences been of the offering of hand wipes to patients?

- Who offers? How often? How would you describe how this works to someone who did not know about it?
- I notice volunteers coming through the unit with a coffee cart. How would you describe what the volunteers do, to someone who did not know about it?
- I wonder if you can tell me about what your understanding of the purpose of the hand wipes initiative is?
- How did you feel the first time someone offered you a hand wipe? (vs subsequent)
- Does the idea of using a hand wipe before eating, or being offered a hand wipe before eating, change the way you feel about coming to the hospital [e.g., specifically study units]?
- Does the frequency of being offered a hand wipe tell you anything about the importance the hospital places on [e.g. hand washing, infection control]?
- You've seen lots happening here and I'm wondering, what do patients do when they'd like a hand wipe, they aren't offered one? How might that make you feel?

- What would happen if somebody did ask for a hand wipe? (Volunteer? Nurse? Doctor?)
- How important is it to you to clean your hands before eating while in the hospital? What is more important to you than cleaning your hands before eating?

# Staff Hand Washing

# \*You've seen lots happening here and I'm wondering if you notice your health care providers washing their hands before caring for you?

- While you've been in Study Hospital, has it been suggested to you that you should ask the nurses and doctors if they've cleaned their hands?
- How would you describe the message in this poster [show generic "it's ok to ask" poster] to someone who did not know about it?
- I'm wondering how patients feel about asking health care providers to wash their hands? What is your view?

# In What Ways Do Patients Think About Safety

# \*When it comes to cleanliness, what comes to mind when you think about being "safe" [or insert word previously used by patient] when you come to the hospital?

- What are your impressions about what the hospital is doing to keep you [safe, or insert word used by patient] while you're here?
- What are your thoughts about what's going well to help keep you [safe, or insert word used by patient] while you're in the hospital [e.g., for dialysis treatments]?
- Are there things that you do [are expected to do/want to do/wish you could do/don't want to do] while you're in the hospital [e.g., for dialysis treatments] to ensure you receive [highly quality or safe care, or insert word used by patient]?
- How would you describe anything you've experienced that hasn't gone so well while you're in the hospital [e.g., for dialysis treatments]? Do you have concerns about coming to the hospital?
- What's one thing that makes a difference to your experience as a patient on [study unit]?
- What's one thing you wish you'd known about coming here as a patient on [study unit]?
- How would you say your care experience here on [study unit] is the same or different than other hospital experiences you've had?

#### Summary & Closure

#### \*What do you think your role is in all of this?

# \*Is there any more you'd like to share about your experience [related to the quality and safety] of care on [study unit]?

#### Part B. Neutral Prompts

- How did you feel about that?
- What does this mean to you?
- What else could it mean, for example to other people?
- What was that like for you?
- What was going on for you at that moment?
- What was happening at the time?
- What did it mean for you to do that?
- Could you explain to me what you mean by this?
- What happened next?
- Can you describe how it affects you?
- What is your view?
- What more could you tell me about that?
- What else comes to your mind when you think about that?
- What other kinds of things come to your mind?
- Have you heard about other people who ...?
- What do you notice that other patients (do, say)?
- Paraphrase to clarify respondent's meaning: Is seems like what you're saying is ...
- *Interpreting:* Is it fair to say that you feel ...

Pseudonym	Role
Aaron	Researcher's Family Member
Amir	Research Sponsor
Ben	Patient
Carol	Patient Partner
Charlotte	Patient
Chloe	Patient
Ella	Nurse
Emily	Patient
Emma	Patient
Ethan	Volunteer
Evelyn	Patient
Hannah	Family Member (Noah's Spouse)
Harry	Patient
Henry	Family Member
Isabella	Patient
Jenny	Nurse
Jin	Patient
John	Patient
Liam	Patient
Lisa	Volunteer
Logan	Patient
Lorenzo	Patient
Lucas	Family Member (Olivia's Spouse)
Mandy	Nurse
Marie-Thérèse	Patient Partner
Mark	Composite Volunteer
Mei	Researcher's Family Member
Mia	Patient
Nancy	Volunteer
Noah	Patient
Oliver	Nurse
Olivia	Patient
Pardeep	Volunteer
Rupi	Clinical Unit Leader
Scarlett	Family Member (Patient's Daughter)
Sophia	Patient
Susanne	Composite Patient/Family
William	Patient

# Appendix L List of Pseudonyms

#### Appendix M Transcriptionist Confidentiality Agreement

#### **CONFIDENTIALITY AGREEMENT – TRANSCRIPTIONIST**

I, \_\_\_\_\_\_ transcriptionist, agree to maintain full confidentiality in regards to any and all audiotapes and documentations received from Brenda Sawatzky-Girling (the researcher) related to her doctoral research study titled "A qualitative study of patient/ family experience of health care quality improvement and safety initiatives from an ethical lens." Furthermore, I agree:

- 1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the transcription of audiotaped interviews, or in any associated documents.
- 2. To not make copies of any audiotapes or computerized titles of the transcribed interviews texts, unless specifically requested to do so by the researcher, Brenda Sawatzky-Girling.
- 3. To store all study-related audiotapes and materials in a safe, secure location as long as they are in my possession.
- 4. To return all audiotapes and study-related materials to Brenda Sawatzky-Girling in a complete and timely manner.
- 5. To delete all electronic files containing study-related documents from my computer hard drive and any back-up devices.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Transcriber's Signature

Date

Printed Name of Transcriber

**Contact Information:** 

*Researcher:* Brenda Sawatzky-Girling, BASc (Nutrition), MHA; PhD Candidate, UBC School of Population and Public Health, -----*Study Hospital Contact:* -----

PhD Supervisor: Paddy Rodney, RN, MSN, PhD, UBC School of Nursing, -----

#### Appendix N Post-Study Reflections of the ARECCI Ethics Screening Tool

Flowing from my central recommendation that health care leaders ought to more fully appreciate the ethical implications of QI implementation, in this appendix I provide a detailed account of my post-study reflections of the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2010). These recommendations target two main audiences: (1) individuals and groups applying ethical frameworks to their QI activities (or related learning activities such as research); and (2) the ARECCI team (A pRoject Ethics Community Consensus Initiative) to consider as they further develop their program.<sup>208</sup> As I described in Chapter 5, at the outset of my data collection I applied the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2010) to the patient hand wipes before meals QI projects that comprised my primary case study. At the end of my analyses, I re-applied an updated version of the tool (Alberta Innovates, 2017b).

In what follows, I offer reflections on particular areas of the *ARECCI Ethics Screening Tool* (Alberta Innovates, 2017b) in the context of my study findings and related literature. My awareness highlights the gap between what Guillemin and Gillam (2004) term "procedural ethics" (how I estimated ethical implications before my study of the QI projects) and "practice ethics" (how I came to recognize and address the day-to-day ethical implications and issues that arose while doing my research). Using relational ethics framing assumes that all understanding, relationships, and the context of social structures have elements of power (Doane & Varcoe,

<sup>&</sup>lt;sup>208</sup> After my dissertation is published, I plan to follow up with ARECCI to discuss my recommendations for consideration as they further develop their programs.

2013). Thus, to better identify and manage ethical strengths and tensions in QI implementation, my reflections on reinterpretations of the *ARECCI Ethics Screening Tool* have particular relevance to aspects of self, agency and power in three categories: (1) risks and burdens; distress, discomfort or anxiety; (2) sensitive issues; and (3) being informed and expressing consent.

# (1) How do patients and families experience 'ethical impact'<sup>209</sup> when QI is implemented at the point of care?

My analyses that patients and families can be highly perceptive to any change that could disrupt a new or existing patient–provider relationship helped me think about benefit, risk and QI (and, in QI) in new ways. For example, ARECCI Question 16 asks about *power relationships*: "Does your project involve a power relationship between the investigator and participants (e.g., manager/employee, therapist/client, service provider/recipient, teacher/student)?" (Alberta Innovates, 2017b).

Extending from my background in research ethics, my interpretation is that Question 16 targets situations of undue influence or coercion in the context of participation in, and data collection within, the confines of a time-limited QI project. People (e.g., the project leader, QI team members) who design a QI intervention, collect data, and evaluate the intervention may not be the same people (e.g., care providers, other staff, volunteers) who interact with patients/families about the new care process at the point of care. Yet, as was evident from the perspective of many

<sup>&</sup>lt;sup>209</sup> As described in Chapter 2, in my study, the term *ethical impact* refers to the totality of the effect of an episode of care (or more specific aspects of that care, such as a QI intervention) that may positively (benefit) or negatively (risk of harms and burdens, or risk of being denied benefits) affect the rights, interests and experiences of patients and families (Adapted from Faden et al., 2013; Jardine, 2008; M. McDonald et al., 2014).

patients/families in my study, an important dimension of risk includes relational risk. One example that arose in my study is the potential for enhanced relational safety and/or relational danger for patients/families when interactions with frontline care providers change as a result of a QI intervention.

Because many areas of health care require patients and families to have ongoing relationships with care providers and health care settings (including many patients/families with chronic conditions in my study sample), on the basis of my findings and analyses I suggest that a state of relational safety in short-term *and* long-term relationships is important for many patients/families. My study echoes that of other researchers (for example, see (Dixon, 2017; Goderis et al., 2009) in that we need to pay closer attention to the potential impacts that QI interventions have on patient/family-provider relationships in the context of real-world implementation. In a closely related area, Cascio and Racine (2018) focus on participantresearcher relationships in the research context. On the basis of these findings, I further suggest that any aspect of a QI intervention that may cause a patient or a family member to feel more (or less) relationally safe with care providers or the health care setting is an ethical impact that a QI screening tool ought to flag when considering risk (ARECCI Question 28: "Does your project involve risks or burdens for participants which are beyond what would be experienced in routine care or beyond what a reasonable person might expect in day-to-day interactions?" (Alberta Innovates, 2017b)). In this sense, I found that risk goes beyond *psychological distress*, discomfort or anxiety (ARECCI Question 29: "Does your project involve questions or procedures that might cause participants psychological distress, discomfort or anxiety beyond what a reasonable person might expect in day to day interactions?" (Alberta Innovates, 2017b)).

Building on Slovic's (1999) claim about the power of controlling the definition of risk (p. 699), I argue that broader social constructions of benefit, risk, harm and burden in QI, including those of a trauma-informed perspective (Boilevin et al., 2019; e.g., Geller & Porges, 2014; Parnas & Isobel, 2019; Porges, 2009; Young et al., 2019), have the potential to narrow power asymmetries, to enhance benefits (including relational connection and relational safety) and to mitigate potential harms and burdens in QI implementation. In so doing, relevant ethical concepts such as welfare, equity, trust, solidarity, and autonomy may be strengthened.

Furthermore, explicit attention to ethics in QI implementation has the potential to not only identify and mitigate risks, but also to increase benefits from a QI intervention. For example, a patient's (or family member's) increased sense of relational safety with care providers or a health care setting ought to be positioned as a possible benefit to the patient/family and to both the organization and the community. As I have shown, applying a relational lens to the ARECCI framework – a "project ethics" framework – helps us understand that the potential ethical impact of QI interventions on patients/families and on patient/family–provider relationships does not stop at the boundaries of the intervention or project.

# (2) How do patients and families experience 'sensitive issues' when QI is implemented at the point of care?

ARECCI Question 17 asks, "Does your project involve questions that collect information about sensitive issues, illegal behaviour, stigmatizing conditions or behaviours, or religious or cultural beliefs or practices?" (Alberta Innovates, 2017b). Since QI is generally assumed to be a benign and beneficial extension of routine medical care, health care leaders and care providers might

need to readjust and anticipate how questions, a new/changed care process and its associated interactions *could* raise sensitive issues for patients and families in larger contexts, and what the implications of raising these issues could be. For example, while implementing a process such as offering a patient a hand wipe may seem beneficial (or at the least benign), my findings showed that this process raised sensitive issues for some participants even without asking questions, collecting data, or requiring a specific patient action. In particular, the extent to which patient and family study participants conveyed that personal hygiene was an important aspect of their personal and family identity surprised me. Before analyzing my data, I had not considered hand hygiene to fit into this "sensitive issues" category. Thus, as I have argued in my data analyses, new care processes themselves – and the way the processes get implemented in clinical contexts – can have intended as well as unintended impacts on patients, families and staff.

In my findings, I endeavored to show how the situatedness of each patient or family member shaped what appeared (to me) to be sensitive to that person. While some patients felt valued from the new hand wipe process, patients who described social exclusion generally, and in their prior health care interactions specifically, appeared to be more sensitive to the messages tied to 'being clean', 'being dirty', and 'being valued' (see also Boilevin et al., 2019). Furthermore, my study showed that, as with other learning activities such as clinical trials, sensitive issues are difficult for researchers and REBs to envision ex ante (Cox et al., 2019; M. McDonald et al., 2014; Townsend et al., 2014). Moreover, in my study most patients appeared motivated to have staff to perceive them as 'good patients'; therefore, patients and families may conceal their offence or discomfort during health care interactions. For these reasons, at all stages of a QI activity, QI leaders/teams need to think about how they are going to determine what sensitive

issues are from the perspective of patient, family, and staff participants, how they will learn what the impacts of these sensitive issues are on patient/family/staff experience and the QI implementation, and how they will respond to this learning.

# (3) How do patients and families experience being 'informed' when QI is implemented at the point of care?

My study reinforced the importance of *informing* people about learning activities that might<sup>210</sup> alter aspects of their usual care processes and/or health care interactions. As I have noted earlier, QI is not generally thought of as requiring patient/family expressed consent to proceed (as opposed to research). ARECCI Question 14 emphasizes that informed consent ought to be sought from all participants if the QI project involves a "likelihood that a breach of confidentiality could place participants at risk of legal liability, denial of insurance or other damage to financial standing, employability, or reputation" (Alberta Innovates, 2017b). Indeed, in many cases, for patients there is no 'opt out' option available other than declining treatment (Baily et al., 2006, p. S10). On the basis of my findings and analyses, I suggest that in QI at the point of care, being informed – helping patients and families understand why, how and for whom a new or changed care process is being implemented – contributes to patients' and families' sense of relational safety and reduces relational uncertainty or danger. In so doing, relational safety is potentially linked to patients' and families' "inherent moral worth" (Faden et al., 2013, p. S20), which is one goal of respect and dignity. Patients and families can be informed in

<sup>&</sup>lt;sup>210</sup> Note: "might alter" instead of "will alter" is intentional to reflect anticipated gaps between WAI, WAD and WAE. As described in Chapter 6 (Section 6.3) and Chapter 8, particularly towards the end of my data collection, many patient/family participants told me that they were offered hand wipes infrequently or not at all.

various ways, such as verbally (e.g., by care providers/staff) and with written materials (e.g., brochures, posters, hospital forms) (for example, see World Health Organization (WHO), 2013a). Furthermore, during the process of informing patients/families, providers/staff might engage in a conversation with patients/families about how they feel about the initiative and how it might impact them (for example, see the *Rewriting the QI Script at the Point of Care* example in Section 9.3.2.1). As I acknowledge throughout my recommendations in this dissertation, in busy clinical environments such as the acute care units on which I conducted my study, conceptualizing the need to inform patients and families about QI requires organizational support in terms of time, planning, reinforcement, and monitoring.

#### Appendix O Summary of Recommendations

My central recommendation from this study is that health care leaders ought to more fully appreciate the ethical implications of OI implementation, such that

more fully appreciate the ethical implications of QI implementation, such that

ethical attention to QI, including relational safety, become integral aspects of health care improvement. Based on my interpretations of the ethical strengths and tensions in my findings and in relevant literature, I summarize a series of actionable strategies simultaneously across micro, meso, and macro levels to enhance QI (see Table O.1). I encourage academic and practice communities to trial and evaluate these strategies with existing and new processes to support a relational ethical approach to QI.

Но •	ealth Care System Level Stakeholder Group	Strategies	Potential Advances in QI
<i>Micro level:</i> <i>The point of care where care</i> <i>providers and patients make</i> <i>connection</i>		Rewriting the QI script at the point of care	Facilitate shared meaning about QI interventions (purpose and people's potential roles)
•	Patients and Families		<ul> <li>Patients/families learn and are empowered.</li> <li>Patients/families understand goal of QI interventions and what it means to them in the context of their values, preferences, and circumstances.</li> <li>Patients/families engage in QI processes without risking relational safety with care providers and staff.</li> </ul>
•	Care Providers and Staff who implement the QI Program/Unit Leaders in which QI projects are implemented		<ul> <li>Providers understand what QI intervention means to each patient; anticipate diversity between individuals.</li> <li>Providers find it easier to incorporate new processes into their routine, thus QI more likely to happen in busy health care settings.</li> </ul>

Table O.1	Summary	of recommendations	to strengthen	ethics in Q	)I implem	entation.



<ul><li>Health Care System Level</li><li>Stakeholder Group</li></ul>	Strategies	Potential Advances in QI
		<ul> <li>Providers strengthen their communication and relational connections with patients/families.</li> <li>Providers convey awareness of strengths and problems in QI interventions that would otherwise be unidentified.</li> </ul>
<ul> <li>Meso level: Processes to incorporate a relational approach into QI activities at an organizational level</li> <li>Health Care Leaders</li> <li>Quality Leaders</li> <li>Program/Unit Leaders in which QI projects are implemented</li> </ul>	<ul> <li>Project Team engages all stakeholders</li> <li>Project Charter integrates relational approaches to:</li> <li>1. Patient/family– provider relationships</li> <li>2. Relational processes</li> <li>3. Relational measures</li> <li>4. Relational and parallel mechanisms</li> <li>5. Work-as- Experienced (WAE) essential evaluation data</li> <li>6. Ethical screening</li> </ul>	<ul> <li>QI leaders improve QI processes.</li> <li>QI project teams better anticipate range of possible patient/family experiences, values of significance, what is realistic, outcomes of QI care processes and related interactions, patient/family provider relationships during and beyond the bounds of QI interventions.</li> <li>QI project teams better understand QI intervention through considering and studying functional, transactional and relational aspects of QI processes (work done to/for/about), including ways that QI may be neutral, bolster or erode patient/family sense of relational safety.</li> <li>QI project teams identify ways to enable patients/families and providers to modify attitudes, acquire knowledge and skills, and change desired behaviours in the long term.</li> <li>QI project teams better understand gaps between WAI, WAD, and WAE from process and ethical perspectives.</li> </ul>
<ul> <li>Macro level: Societal ideologies and values shape power and voice</li> <li>Policy-Makers</li> <li>Health Care Leaders, including Ethicists</li> </ul>	<ul> <li>Strengthen relational capacity throughout health care systems (leadership; providers, staff, volunteers; patients, families, public):</li> <li>Relationship-centred care philosophy</li> <li>Quadruple Aim philosophy</li> </ul>	<ul> <li>Leaders acknowledge importance of relationships between health care staff and patients/families in QI, and differing meaning the staff, patients, families have about QI as they experience it.</li> <li>All stakeholders benefit from their strengthened relationship and communication skills (e.g., collaboration, shared decision making, cultural sensitivity, health literacy,</li> </ul>

He •	<i>ealth Care System Level</i> Stakeholder Group	Strategies	Potential Advances in QI
•	Governments, Organizations (e.g., Health Authorities, Professional and Patient/Family Groups)	<ul> <li>Relational and communication skill building</li> <li>Incorporate relational aspects into QI frameworks (e.g., ARECCI, SQUIRE):</li> <li>Provide feedback to researchers and decision-makers about the utility of QI ethical frameworks</li> </ul>	<ul> <li>effective listening, respect in personal interactions, compassion and empathy).</li> <li>Leaders assess success of QI activities inclusive of patient/family experiential data and how activities respond to patients' and families' need for connection and safety.</li> <li>Researchers and administrators evolve and improve QI ethical frameworks and publication guidelines to build on strengths and best practices of QI, and to enhance a learning health care system.</li> </ul>