KEEPING DAD SAFE: AN AUTOETHNOGRAPHY OF DOUBLE-DUTY CAREGIVING IN THE CONTEXT OF RISK AS AN ADVANCED PRACTICE NURSE IN GERIATRICS CARING FOR A HOSPITALIZED FRAIL OLDER ADULT PARENT

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CARING FOR A HOSPITALIZED FRAIL OLDER ADULT PARENT

submitted by Mary Kjorven in partial fulfillment of the requirements of

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Abstract

Particular challenges emerge when children who are health professionals become caregivers for their older adult parents who are hospitalized. This double-duty caregiving involves performing multiple roles and can create tensions for formal and informal caregivers that may impact the care of the older adult. In my case double-duty caregiving meant positioning as a daughter of an older adult family member and as a clinical nurse specialist in geriatrics within a change in risk culture toward patient-and-family centered care. Using autoethnography informed by poststructural perspectives, I conducted a discourse analysis and identified subject positions produced through and by these discourses. I applied analytic and evocative autoethnographic methods to my data that included medical records of my dad from two separate hospital admissions, journal notes, memory, and emails. Additionally, I conducted semi-structured interviews with my dad, three siblings, and the health service director at the hospital where my dad was hospitalized. My double-duty caregiving experience is reflected in my autoethnography that applied historical perspectives of risk and the influence of risk culture on in-the-moment caregiving. I identified safety as a predominant discourse that I, my participants, and the health care providers who cared for my dad took up and performed in my experience of double-duty caregiving for my dad. Within the safety discourse were sub-discourses of competency/incompetency, surveillance, trust/mistrust, fear, and control. Through this process of discourse analysis, biomedical discourses were unveiled as the most dominant discourses that produced the culture of risk within the context of double-duty caregiving for my frail older adult parent, and the tension between biomedical discourses and patient-and-family centered care is revealed. This study is unique in using autoethnography to look at double-duty caregiving for an older adult parent within the context and culture of risk. This research supports

other findings that enacting trust in relationships is complex when individuals not only position themselves in relation to multiple selves, but are positioned by others for a number of purposes. Future research into how best to shift the focus of risk imbued by biomedical discourses to a patient- and family-centred and team-based approach is essential.

Lay Summary

We have all been born into a world where some subject positions or roles are available to us and others are not. These subject positions are often taken for granted and in my case, included roles such as woman, daughter, nurse and expert. My research looked at my challenges in performing multiple roles simultaneously. These roles included double-duty caregiving as a nursing expert and a daughter of a frail older adult man within the context of risk culture in an acute hospital. I used autoethnography as a specific approach to tell my story, share my experience and invite you, the reader, to engage in my story. The goal of my research was to evoke a response in you. If I have succeeded I look forward to hearing from you. Please contact me @ Mary.Kjorven@interiorhealth.ca if you would like to share your thoughts on this research with me.

Preface

This dissertation is original, unpublished, independent work by the author, M. Kjorven. The research protocol for the study reported on in this dissertation was approved through a harmonized review between the Interior Health Research Ethics Board (Record 2017-18-013-H) and the UBC Behavioural Research Ethics Board (Certificate # H17-00995) on 5 July 2017.

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Dedication

I dedicate this work to my dad, Robert (Bob) James Magowan. When I tell people about my dad, I often include that he was an industrial arts teacher at the same school where I attended junior high. During the 1970s girls didn't take 'shop,' so he never taught me in school, he taught the boys. If you can remember back to your days in junior high you can appreciate that he had insider information about those boys and which ones (if any) he was comfortable for his daughter to hang out with, especially the daughter who was already giving him grey hairs as a risk-taker.

I believe my dad was connected to the culture of education and teaching much the same as I am connected to the culture of health care. He was a teacher. I am a nurse. Like him, I pursued graduate studies as a middle-aged adult. When I asked my dad how he felt about having a daughter who is a nurse and also involved in his care he answered, "Well, actually, I thought a number of times that is was kind of handy to have a daughter in the family who is part of the [healthcare professions]." Then he elaborated with, "I guess it is similar to what it was like for you to have a dad for a teacher."

Dad—it was a privilege to have you as a teacher and a privilege to care for you as a daughter and as a nurse.

Chapter One: Introduction

1.1 Background

1.1.1   Older adults and risk.

As in many developed countries around the world, Canada's population is aging (Novak, Campbell, & Northcott, 2014; Touhy, Jett, Boscart, & McLeary, 2012). In 2017, 16.9% of Canada's population (nearly one in six Canadians) was aged 65 and older. This percentage has steadily increased since the mid-1960s as a result of lower fertility levels and longer life expectancy (Statistics Canada, 2017a). The growth of this age group has accelerated since the beginning of the current decade, more precisely since 2011, when the largest birth cohort in Canada's recent history—the baby boomers—started to turn 65. In 2015, for the first time ever, the number of people aged 65 and older was greater than the number of children under the age of 15. Furthermore, according to the most recent population projections, by 2031 (12 years from now), the number of older adults will account for 23% of the population (Statistics Canada, 2017b). For the purposes of this study, I have defined "older adults" as a population 65 years of age and older, appreciating that this is not a homogeneous group. While I acknowledge that "older adults" is used as a classification to denote a social class this does not negate that it interacts with gender, ethnic realities and culture.

Older adults have been positioned as an 'at risk group.' Ageist Western society has constructed old age as undesirable, fraught with dangers and hazards, and signalling a period of decline, dependency, and loss (Rush, Murphy, & Kozak, 2012). For example, frailty, which is defined by deficit accumulation such as impaired grip strength and slow walking speed (Rockwood & Mitniski, 2011) is the extreme of physical decline and risk. Age is a major predictor of risk (Bestsennyy, Kibasi, & Richardson, 2013) for "as people age, they accumulate

deficits that are eventually manifested as frailty, disease, or disability" (Rockwood & Mitnitski, 2011, p. 17).

Hospitalization superimposes even greater risks on older adults. It is well acknowledged that older people are large consumers of acute hospital care (Canadian Institute for Health Information, 2014; National Institute on Aging & World Health Organization, 2011) and that hospitalization produces significant health risks for this vulnerable population (Baumbusch, Leblanc, Shaw, & Kjorven, 2015; Inouye et al., 2000; Parke & Hunter, 2014; Parke, Hunter, Bostrom, Chambers, & Manraj, 2012; Sager et al., 1996). These *hazards of hospitalization* (Creditor, 1993; Wilkerson, Iwata, Wilkerson, & Heflin, 2014) include delirium, falls, drug interactions, incontinence, constipation, malnutrition, general deconditioning leading to loss of function and independence, and death (Ahmed, Leurent, & Sampson, 2014; Inouye, 1999; Shearer & Guthrie, 2013; Vanderwee et al., 2011; Zisberg, Gary, Gur-Yaish, Admi, & Shadmi, 2011).

Acute care hospitals remain ill-prepared to address risks for this population (Cheek, 2004; Creditor, 1993; Parke & Hunter, 2014). Traditionally, the medical approach to risk within hospitals has focused on safety and survival (Gawande, 2014) and rescue (Sloan, 2009) within a culture that is risk-averse and defensive (Tadd et al., 2016). This culture is produced when "care is undervalued and [when] professional accountability and discretion is replaced by standardized checklists, pathways and audits" (Tadd et al., 2016, p. 33), in other words, when the priorities of the system and the organization, including the interests of staff and clinicians, take precedence over the interests of patients and families (Calnan et al., 2013).

These approaches to caring for and managing risk for older people in hospitals, particularly the frail elderly, are neither meeting the needs of this patient population nor are they

sustainable (Gawande, 2014; Morden, Jinks, & Nio, 2012; Powell, Wahidin, & Zinn, 2007; Rush, Kjorven, & Hole, 2014; Sloan, 2009). "Care of this population within this setting is consistently criticised for being inappropriate and inadequate" (Baumbusch, Leblanc, Shaw, & Kjorven, 2015, p. 150). Many older adults have multiple and chronic comorbidities, making it a challenge to provide appropriate care within hospitals that are designed to provide acute and episodic care. These challenges are complex; however, they are often framed in evaluative terms of 'lack', specifically lack of resources and support, such as lack of care providers/staff, lack of skilled geriatric specialists, and lack of collaboration/integration between various care providers and health sectors (Baumbusch et al., 2015; Prosad et al., 2014). Further contributing to the challenges is the failure of acute care staff to identify, include, and/or appreciate family members as care experts, and/or value them as a source of support to address this perceived 'lack' in acute care (Moyle, Bramble, Bauer, Smyth, & Beattie, 2016; Segaric & Hall, 2015). However, there are attempts underway to change this culture, and increasingly, patients and families are being positioned at the centre of health care.

1.1.2   Culture change: Patient- and family-centred care

In British Columbia, the Ministry of Health identified patient- and family-centred care as the foundational driver for planning and implementing all future strategic actions to address care for older adults (Ministry of Health, 2014a). In a keynote address to the British Columbia Council of Nursing Associations (BCCNA), Lynn Stevenson, Assistant Deputy Minister of Health, took this a step further, stating that health care needs to be patient/family *led* rather than *centred* (Stevenson, July 19, 2016), placing even greater emphasis on the need for patient and family participation. However, families' efforts to be involved in care and work collaboratively with acute care staff (including nurses) have not always been well received. Relationships

between family and staff have been "characterized by poor communication and lack of family involvement in decision-making" (Taverner, Baumbusch, & Taipale, 2016, p. 216).

There is substantial research related to the experiences of family members who provide care to older adult relatives and the tensions that arise between families and acute care staff when these relatives are admitted to acute care hospitals (Desbiens, Mueller-Rizsner, Virnig, & Lynn, 2001; Gallagher & Seedhouse, 2002; Li, Stewart, Imle, Archbold, & Felver, 2000; Lowson et al., 2012). In a British Columbia study, Baumbusch et al. (2015) identified the changing role of families of older people within acute care as uncharted territory, where "families were viewed as both a source of support and a contributor to challenging situations" (p. 153). In other studies, risk is implicit and alluded to within these relational tensions through language such as 'fear', 'crisis', 'standing guard' (Lindhardt, Bolmsjo, & Hallberg, 2006), and 'loss of control' (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001), where caregiving relatives expressed a heightened sense of responsibility for the care of older persons when they were admitted to hospital. Families often feel they need to keep a vigil at their older family member's bedside in order to mitigate a "culture of neglect" (Taverner et al., 2016, p. 218) and the potential accompanying risks of this neglect. Taverner and colleagues offer the theory of "normalization of neglect" (p. 215), that has become common practice within acute care specific to this vulnerable population. Normalizing neglect gives a reason why these neglectful practices were apparent and why they continued.

1.1.3 When health care professionals are the family

There is a small body of research that focuses on family members of patients admitted to acute care who are health professionals, such as nurses (Fry, Gallagher, Chenowith, & Stein-Parbury, 2014; Hanson, 2016; Kaiser & Kaiser, 2017; Olivet & Harris, 1991; Ward-Griffin,

2004). In these studies, families felt hospital nurses viewed them as a barrier, hindrance, or complication to providing care, while nurses expressed frustration with what they felt were unrealistic family expectations. As part of a risk-averse culture these "professional" family members may have heightened antenna to risk, such as a nurse caregiver who can only imagine negative outcomes: "I can't help but imagine the worst and think about the 'what ifs' and wonder how we will handle what might happen" (Olivet & Harris, 1991, p. 249).

Family members who are nurses with specialist roles, such as advanced practice nurses and/or clinical experts in geriatric care, may further escalate risk concerns. Due to their specialized knowledge, family members who are advanced practice nurses bring valuable expertise to conceptualize risk from both professional and personal standpoints as well as know-how in bringing available resources to address risk (Rush & Kjorven, 2015). Early evidence suggests that these multi-role caregivers assume multiple subject positions as they continually negotiate the boundaries between professional and personal caregiving roles and the feelings of isolation, tension, and "extreme physical and mental exhaustion" (Ward-Griffin, Brown, Vandervoort, & McNair, 2005, p. 379) that accompany this negotiation. As professionals in geriatric medicine and social work, Kaiser and Kaiser (2017) described how their experience of caring for their aged mother during one hospitalization quickly repositioned them from insiders to outsiders in a system where "the patient and family are not consistently listened to, or integrated, into the clinical team" (p. 46).

1.1.4 Now it's personal

This was my also my experience as a double-duty caregiver. Ward-Griffin, Brown, Vanervoort, and McNair (2005) described how female health professionals who assumed familial responsibilities of caring for older relatives continually negotiated "the boundaries

between professional and personal caring work" (p. 379), a process the researchers titled as "double-duty caregiving." In my case I was an advanced practice registered nurse who was a clinical nurse specialist (CNS) in geriatrics and at the same time a daughter/caregiver of a frail older adult parent admitted to an acute care hospital in 2013. During this experience, not only was I repositioned from an insider to an outsider, but I also came to understand the cultural experience of risk quite differently. For example, a large component of my CNS role focuses on reducing the risk of hospitalization on older adults. My practice is based on evidence that identifies potential hazards for this patient population including "insufficient knowledge of the special needs of older persons, risk of falls and delirium, frequent medication errors and insufficient coordination of care during transitions of care" (Kaiser & Kaiser, 2017, p. 47). It could be said that I am a nursing leader and hold a position of privilege, power, and influence within the organization where I work. However, when my frail older father was admitted to acute care within the same health authority where I work, I often felt excluded from his care and was scolded when I questioned nursing practice. I began to question why and how this was happening. I shared my story in conversations and email messages with friends, family, colleagues, researchers, gerontologists, hospital administrators, and practice consultants as well as in private journal entries. So began my autoethnography.

1.1.5 Autoethnography: Telling my story

While autoethnography has been described as writing lives and telling stories (Bochner & Ellis, 2016), it is much more than that. Autoethnography is an approach to research and writing that seeks to systematically analyze and write (graphy) about personal/self experience (auto) in order to understand cultural (ethno) experience (Adams, Holman Jones, & Ellis, 2015; Chang, 2008; Ellis, 2009). It allows for the reclamation of the voices of family members—voices that

have been rendered absent or misrepresented by dominant discourses. As I tell my story, I often hear the response, "It happened to me too." from nurses who were/are also caregivers for older adult parents. These nurses had similar experiences to mine and most often they felt powerless to change culture and practice. As an advanced practice nurse, I believe I have a unique opportunity to use my knowledge, experience, power, and position to create change. Using my story to make it personal evokes "the reader to care, to feel, to empathize and to do something, to act" (Ellis & Bochner, 2006, p. 433). In doing so, autoethnography has the potential to raise consciousness and shift representations of power within social and cultural borders. As an approach to research and writing, it creates opportunities to restore a sense of community and promote shared power, inclusion, and collaboration (Canales, 2010) for others. In this way, it utilizes power within relationships for transformation and coalition building rather than "animosity, division, and hierarchy" (Ellis & Bochner, 2006, p. 434).

Butler (2015; 2011; 2005) uses poststructural perspectives to offer an explanation of how individuals occupy and move between a variety of subject positions or identities within an interaction, depending on the power dynamics within the exchange. I will draw upon Butler's work, which posits a critical theory of social structure that elucidates subjectivity in terms of power struggles of compliance and resistance to discourses (Butler, 2015; Sundin-Huard, 2001) that then produce risk culture in particular ways. I will use autoethnography as an approach to research and writing that seeks to systematically analyze my personal experience in order to understand the cultural experience of attempting to mitigate issues of risk for my dad within an acute care setting, while also navigating my roles/positions of nursing expert; daughter; divorced, white, middle-aged woman; sibling; and leader.

To date, the emphasis of research in this area has represented family caregiver experiences. In contrast, recent research using critical or poststructural approaches demonstrates the discursive production of risk (Mitchell & Glendinning, 2007; Rush et al., 2014; Sandberg, Rosenberg, Sandman, & Borell, 2015). I have not located studies in this area that explicitly used autoethnography informed by poststructural perspectives nor have I located studies that explicitly investigated how discourses of risk operate within an acute care setting in relation to older adults and their family caregivers who are also nurses. Cheek (2000) describes a discourse as "a set of common assumptions which, although they may be so taken for granted as to be invisible, provide the basis for conscious knowledge" (p. 23). These common assumptions then direct and support actions and practice, *the way we do things around here*, or in other words, culture. In this way, individuals are not only bearers of culture but also active agents who produce, reproduce, reject, and/or transform cultural traits (Chang, 2008).

Poststructural perspectives focus on the relationship between power and knowledge where power relations are always implicated with knowledge, and therefore, no knowledge can be said to be *neutral* (Lupton, 2013). The focus is on the change and flux in social structures and meanings, including analysis of what is influencing and producing those changes. Such analysis is not simply descriptive; rather it is critical and reflexive, moving beyond the level of common-sense. It is this perspective that informs my research study. Autoethnography provides an opportunity to investigate experience as it is shaped by culture. Therefore, I will intentionally highlight the relationship of my experience to culture and cultural practices and I will draw on poststructural perspectives to illuminate how culture is produced by discourse.

1.2   Study Aim and Objectives

The aim of this study is to evoke a response in readers by drawing on my own subjective experience of double-duty caregiving in the context of risk culture while caring for my hospitalized, frail older adult father. By welcoming readers into this experience and encouraging comparison and interrogation of their own perceptions with mine, all while revealing the challenges and opportunities we face in negotiating our worldviews with the understandings of others, we open opportunities to think and perform differently. The objectives for this study are as follows:

1. To illuminate how risk culture influences my engagement in the health care system, within the context of double-duty caregiving for my frail older adult parent.

2. To become vulnerable and acknowledge the inevitable privilege I experience as an *insider* and *expert* within this system and take responsibility for my subjective lens through reflexivity.

3. To explore how my multiple identities (nurse; daughter; expert; white, middle-aged, middle-class, divorced woman; etc.) are manifested within interactions with myself and others and how I take up discourses that produce cultural identities/subject positions.

4. To add to the body of knowledge about nurse family members/caregivers of older adults through writing/sharing my autoethnography.

1.3   Overview of the Chapters

This dissertation is written in six chapters. Chapter One provides the background to the study and the aims and objectives. Chapter Two presents a detailed review of the theories and existing literature related to risk and how they contribute to my knowledge of risk, including how

I take up and perform discourses of risk in caring for older adults. Understanding these prominent theories and discourses is an important grounding from which to build an understanding of how they produce (and reproduce) a culture of risk that then influences my experience of double-duty caregiving. Chapter Three outlines the theoretical perspectives that guide my methodology and methods of research: poststructural discourse analysis with a focus on risk. I describe how poststructural discourse analysis, guided by a Foucauldian/Butlerian lens, directed each step of this research process, from conceptualization to presentation to defence. Chapter Four describes the methodology and methods that flowed from this perspective. I explain how I came to use autoethnography as my methodology and outline my methods of writing, data gathering, analysis, and evaluation. Included in this chapter is a discussion of ethical and political concerns specific to autoethnographic research. Chapter Five presents my research findings. The findings are presented in two parts. Part one presents the findings from my research woven into my autoethnography. Using a process of "systematic sociological introspection" (Ellis & Bochner, 2016, p. 67), I actively recall thoughts and feelings from a social standpoint. In recalling these thoughts and feelings, I use data from my father's charts, interviews with research participants, emails, conversations from my doctoral committee, and memory. Part two presents the analysis of the findings specific to my guiding research questions including 1) how the culture of risk within my workplace contributed to my experience of double-duty caregiving; 2) identification of discourses that produced this culture, and how these discourses were at work to produce subject positions that were either available or unavailable to me; and 3) an analysis of what it means to perform multiple aspects of identities simultaneously and how taking up and performing multiple and mobile subjectivities was

manifested within interactions with others. Finally, Chapter Six provides recommendations and

implications from these findings and makes suggestions for further research.

Chapter Two: Review of the Literature

I begin this review by presenting the meaning of risk that informs this research, followed by a definition and description of the most salient theoretical perspectives of risk and empirical research that relates to risk, specifically within my context of caring for older adults. Next, I provide a review of the current knowledge, integrating discourses of risk, older adults who are admitted to acute care, and subject positions of family caregivers who are also nurses. I conclude this chapter with a summary of the literature review and identification/justification of how the proposed study will contribute to further understandings of risk within the context of nurses caring for older adult relatives within acute care.

2.1 Risk: What Are We Talking About?

An examination of the theoretical literature reveals that risk is a concept that is understood and applied in different ways across the disciplinary fields of knowledge, including logic and mathematics, engineering, economics, science, health, psychology, sociology, anthropology, geography, philosophy, law, and linguistics. Depending on one's disciplinary positioning, risk has different ontological and epistemological meanings and is researched and understood in different ways, using different tools, methods, and analytical frameworks (Lupton, 2013a).

I ascribe to risk as an evolving concept and recognize that any *definition* of risk has value while at the same time is limited and inadequate and produces knowledge about risk in particular ways. Originally, *risk* was considered a neutral term concerned with probabilities: losses and gains. A gamble or an endeavor that was associated with high risk meant simply that there was great potential for significant loss or great reward. Despite more recent support for the constructive nature of risk and its associated positive outcomes, such as quality of life, the term

risk remains largely reserved to indicate a negative or undesirable outcome. As such, it goes hand-in-hand with terms like *danger* or *hazard;* a hazard has been described as "a set of circumstances which may cause harmful consequences, while *risk* is the likelihood of its doing so" (Fox, 2002, p. 167). This meaning informs this study.

This hazard/risk differentiation also "introduces a moral dimension, such that the perpetrators of *risk* may be held to account in some way or another" (Fox, 2002, p. 167). In turn, this produces an exclusionary matrix by which subjects are constructed in particular ways (Butler, 1993) and individuals take up and perform these subjectivities through the authorization of risk discourses. In other words, certain discourses, such as 'expert,' are available to some (most often health care staff) but not all (patients and families). This leads to cultural practices that enable certain discourses and diminish, silence, or deny others (Holman Jones, Adams, & Ellis, 2013).

2.1.1   Theoretical perspectives of risk

In this section, I will provide a categorization of salient theoretical perspectives of risk applicable to my experience of caring for older adults, including my older adult father. The identified salient theoretical perspectives fall under three epistemological positions related to risk: *realism/positivism*, *strong social constructionism/relativism, and weak social constructionism/critical realism*.

2.1.2   Realist/positivist position

The realist epistemological position remains the most common approach to risk, developed and expressed principally using language such as *scientific/science*: for example *technico-scientific* and *cognitive science*. It is important to note the attachment of this language to these perspectives. The significance of language will be further discussed in Chapter Three.

Within these perspectives risk is identified as an objective hazard, threat, or loss that is understood as a real event or danger and can be measured independently of subjective social and cultural processes. The word *natural* is often attached to this position, indicating risk exists in the *natural world* as opposed to being produced *elsewhere* (Lupton, 2013a; Zinn, 2008). Although this measurement is assumed to be objective and real, there is an underlying assumption that peoples' perceptions of these risks may be distorted or biased through socio-cultural frameworks and interpretation (Lupton, 2013a).

Technico-scientific perspectives of risk are used in fields such as engineering, statistics, actuarialism, psychology, epidemiology, insurance, and economics that balance the notion of danger or hazard with calculations of probability and expected values (Aven, 2012; Aven & Kristensen, 2005; Lupton, 2013a). Risk is viewed as negative and defined objectively as "the product of the probability and consequences (magnitude and severity) of an adverse event (i.e., a hazard)" (Bradbury, 1989, p. 382) and is used to reflect loss or deficit. Zinn (2008) presents this technical-objective definition of risk as a simple equation: "risk = $\text{probability}_{event}$ x damage_{event}" (p. 5).

Various scientific instruments are used to measure, monitor, and calculate risks and then to construct predictive models of how risks may affect individuals or populations. The calculations produced are treated as "objective facts" [and] "absolute truths" (Bradbury, 1989, p. 382) and are assumed to be calculated separate from the individual. According to this model, risks pre-exist in nature and in principle and can be identified through scientific measurement and calculation; there is also an assumption that risks can be controlled using this knowledge (Lupton, 2013a). When limits in calculability occur, they are interpreted as a lack of knowledge that can be resolved by further research and more rigorous scientific analysis (Zinn, 2008).

2.1.3   Contributions to my knowledge of risk in caring for older adults

The techno-scientific perspective of risk continues to be the dominant discourse that produces my knowledge, understanding, and practice related to risk in older adults. One example from this perspective is evidence-informed knowledge on frailty, which is defined by deficit accumulation and reinforces discourses of *danger* and *hazard* that support risk as negative and something to be avoided. Statements from techno-scientific research, such as, "As people age, they accumulate deficits that are eventually manifested as frailty, disease, or disability" (Rockwood & Mitnitski, 2011, p. 17), reproduce the dominant discourse that age is a major predictor of risk (Bestsennyy, Kibasi, & Richardson, 2013). There is an assumption of moral responsibility (placed on individuals, families, and care providers) to reduce/avoid these risk factors by identifying and managing them.

This theoretical perspective is evident in societal valuing of risk avoidance at the expense of risk-taking, with the expectation that older adults identify and manage their personal risks. Risk-taking is generally regarded as negative and is often discouraged because of the potential for adverse outcomes for self and others (Rush et al., 2012, p. 2). As a clinical nurse specialist in geriatrics, one of my main roles is to mitigate the risk of hospitalization on older adults. Performing the subject position of expert, I often apply standardized testing to evaluate deficits and predict risk for the purpose of reducing it. This includes attention to the physical processes by which aging increases the risk of a whole range of diseases and how to slow and even reverse some of these processes which can lead to danger, harm, threat, or loss (Novak, Campbell, & Northcott, 2014). By recognizing and attending to these types of risks early on, I take up and perform the discourse of patient safety.

Patient safety is a key discourse that positions patients and their families as compliant within the system of health care that produces a sociocultural structure "that elucidates subjectivity in terms of compliance and resistance within a power struggle" (Sundin-Huard, 2001, p. 377). In other words, the normative power of safety controls what subject positions are available to persons.

It is clear that there is value in objective realist/positivist perspectives to risk in older adults. By neglecting these views, I limit my ability to offer older adults and their family's evidence-based information and choices for complex situations that occur in this population. However, it has been recognized that these perspectives are insufficient and inadequate because of their failure to acknowledge social, cultural, and political contexts in which risk is understood, lived, embodied, and negotiated in order to inform risk-related judgments and decisions (Adams, 2001; Rush et al., 2012). As a response to this limitation, sociocultural perspectives and positions emerged from cultural anthropology, philosophy, sociology, social history, cultural and media studies, gender studies, critical social psychology, cultural geography, and science and technology studies (Lupton, 2013a). One example is the strong constructionist/relativist position.

2.1.4 Strong social constructionist/relativist position

Exponents of the *strong* social constructionist/relativist epistemological position contend that "[n]othing is a risk in itself; there is no risk in reality. But on the other hand, anything *can* be a risk; it all depends on how one analyses the danger [and] considers the event" (Ewald, 1991, p. 199). Lupton (2013) explains that social constructionists argue that a risk is never fully real, natural, objective, or knowable outside of belief systems and moral positions: what we measure, identify, and manage as risks are always constituted from pre-existing knowledges and

discourses, and humans and their social worlds exist in a dialectical relationship where each creates and co-creates the other. Where positivist discourses support understandings that the material and social worlds exist as natural, objective, and pre-existing realities, constructionist discourses challenge that these realities are subjective, dependent on culture and shared definitions, and rely on the production and reproduction of meaning and knowledge through social interaction and socialization. Because of the continually constructed and reconstructed nature of reality, its meanings are precarious, vulnerable, and subject to change (Krimsky & Golding, 1992; Lupton, 2013a; Zinn, 2008). Poststructural theoretical perspectives complement strong/constructionist/relativist perspectives of risk and will be further discussed in Chapter Three under the theoretical perspective (poststructuralism) that guides this study.

2.1.5 Contributions to my knowledge of risk in caring for older adults

The quintessential strength that strong constructionist/relativist perspectives make to my understanding of risk is: "the view that people's actions are shaped by the meanings they attribute to events" (Houston, 2001, p. 222). Sociocultural theory is useful to add to my understanding of the social construction and reconstruction of risk and its inseparability from forces relating to experience, values, feelings, context, intuition, emotion, trust, power, knowledge, justice, and legitimacy that are used to inform decisions about risk and often used to *trump* positivist/objective information (Lupton, 1999; Lupton & Tulloch, 2002). Sociocultural theory sets norms and practices of risk where "the human actor is portrayed as anxious about and fearful of risk, eager to acquire knowledge so as to best avoid becoming the victim of risk" (Lupton & Tulloch, 2002, p. 114). This was my experience as a nurse specialist in geriatrics. My embeddedness in biomedical culture influenced how and what I saw as health risks of hospitalization to my dad.

Older people's needs "are located in the social and political environment of the time as well as any *objective* assessment of the individual's requirements" (Clarke & Members of the International Collaborative Research Network on Risk and Aging Populations, 2006, p. 170). Stories from geriatric clinical practice (Gawande, 2014; Sloan, 2009) and my own experience caring for older adults, including my frail older father, corroborate this theory. Older adults may not ascribe to the positivist view, not because they are ill-informed but because it does not meet their needs or add to quality of life within the sociocultural context in which they are situated.

Clarke and Members of the International Collaborative Research Network on Risk and Ageing Populations (2006) developed an emerging model of risk in older adults that incorporates sociocultural approaches to risk including values (for example, emanating from the individual's biography and society) and agency (which is culturally specific and dependent on capacity) of the individual and other stakeholders (including family members) to exercise their wishes. The model illustrates how risk mediates quality of life for older adults through a balance of risk-taking and risk avoidance. This view supports risk and risk-taking as a constructed and valued part of life for older adults. It emphasizes autonomy and the benefits of positive risk-taking for self-determination, thus increasing the value of older people's views of risk (Rush et al., 2012).

Another example of how strong constructionist approaches have contributed to my understanding of risk in older adults is related to the discourse of *successful aging* (SA) (Rowe & Kahn, 1998), specifically how SA is used to reposition risk as residing with the older adult. The origins of the successful aging discourse trace back to the 1980s, receiving support from the MacArthur Foundation Study, which led to the successful aging paradigm (Novak, Campbell, & Northcott, 2014; Rubinstein & Medeiros, 2015). This paradigm is used to encapsulate the notion of *aging well* and includes similar language such as *active aging*, *healthy aging*, *positive aging*,

productive aging, and *competent aging* (Foster & Walker, 2014). Tam (2014) discussed how SA is a value-laden concept that is culturally determined, and Gibbons (2016) illuminated how risks are produced in this way. To age successfully, one must maintain a low risk of disease and disease-related disability, high mental and physical function, and active engagement in life. According to Katz and Calasanti (2015), successful aging "has been churned into theoretical paradigms, health measurements, retirement lifestyles, policy agendas, and anti-aging ideals and disseminated through an industry of books, conferences, journals, funding, research programs, websites, and institutional identities" (p. 26-27). Performing the discourse of successful aging has reproduced it as a dominant discourse and one that produces risk and subjectivities in particular ways.

Gibbons (2016) uses the theory of *compulsory youthfulness* as a way to explore how ableism, ageism, and other systems of oppression "intersect to produce the social mandate that people must remain youthful and non-disabled throughout the life course, particularly in a cultural context that holds successful aging as the ideal" (p. 70). Butler (1993) refers to how thinking of an imperative (successful aging) in this way means that "a subject is addressed and produced as a norm, and that this norm – and the regulatory power of which it is a token – materializes bodies as an effect of that injunction" (p. 190). The successful aging discourse also represents a "power shift across political and economic domains *to the individual* as the locus of action, health, and efficacy in both public and private lives" (Rubinstein & Medeiros, 2015, p. 36). Responsibility is moved from the state to the individual to reduce risk and maintain a healthy lifestyle; one way that it is taken up and performed in health care is within patient- and family-centred care. I take up the discourse of patient- and family-centred care from both sides of the equation: as a clinical expert in geriatrics and as a caregiver for a frail older adult who is

not always aging 'successfully'. As a result, I often experience moral distress as I wrestle with discourses of responsibility within the context of risk culture.

Some approaches to risk are difficult to position; they interpret risks as real and socially constructed at the same time (Zinn, 2008). As well, boundaries between these perspectives and subperspectives of risk have become blurred and the need has been identified to harmonize important insights from a variety of epistemological positions (Houston, 2001). While realist/positivist and strong constructionist positions represent the extreme left/right perspectives on the binary of risk theory, the weak constructionist/critical realist epistemological position attempts to combine and integrate these perspectives. This position of integration has been reflected by some as the *weak* social constructionist perspective, described by others as *critical realism* and still others as *cultural relativism* (Lupton, 2013a).

2.1.6 Weak constructionist/critical realist position

The weak constructionist/critical realist epistemological position both acknowledges that phenomena exist that may harm people's health or well-being in some way (whether these are psychological, physical, emotional, or financial) and that these phenomena are singled out and labelled as *risks* (or not, as the case may be) via social and cultural processes and assumptions (Houston, 2001; Lupton, 2013a; Zinn, 2008). In other words, it asserts that the "real social and natural world exists apart from and thus independent of human perception and understanding" (Lupton, 2013a, p. 42) *and* that knowledge of reality is fallible, incomplete, and historically, culturally, and politically situated.

Critical realists argue that more and more phenomena are identified and named as *risks*, and that there is a danger of lapsing into relativism, where everything is identified as risky (Beck, 2007; Lupton, 2013a). For example, where cigarette smoking, alcohol consumption, isolation,

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Critical realists argue that more and more phenomena are identified and named as *risks*, and that there is a danger of lapsing into relativism, where everything is identified as risky (Beck, 2007; Lupton, 2013a). For example, where cigarette smoking, alcohol consumption, isolation,

and a sedentary lifestyle were once not considered *risks* to healthy aging, now they are labelled and treated as such. While these phenomena existed prior to being labelled as *risks* and had real effects on older adults' health statuses, "the ways in which they are viewed, managed, and regulated have changed since their identification as [*risks*]" (Lupton, 2013a, p. 42).

Critical realism contends that these phenomena that are labelled *risks* exist regardless of whether or not we act to intervene on them, as do other potentially harmful phenomena that we choose not to label *risks* (Lupton, 2013a). At the same time, "individuals can only ever achieve a partial understanding of the real world, and knowledges are always therefore subject to critique, revision, and change" (Lupton, 2013a, p. 42). It is clear that both ends of the spectrum of epistemological positions of risk are inadequate on their own. Therefore, especially with a complex and diverse population such as older adults, a position that integrates aspects from both the realist/positivist and the strong constructionist positions has value. This perspective is positioned as a *third way* between realist/positivist approaches and strong constructionist perspectives (Houston, 2001; Lupton, 2013a).   It is this position that informs this study.

2.1.7   Contributions to my knowledge of risk in caring for older adults

Houston (2001) uses the analogy of a beam of the torch that illuminates each of the objects on which it falls, but leaves the remaining foreground in shadow to illustrate the limitations of fixed perspectives: what he calls the *posts* and the *isms*. He argues that by combining and integrating these approaches, critical realism has the potential to shed a broader light on and transcend the fissure that exists between realist/positivist and strong constructionist positions. In particular, it illuminates the interplay of "various causal mechanisms and the social constructions of actors" who take up the discourses that produce risk in older adults.

This includes how I reconcile my responsibility to provide evidence-based and safe care for both my patients and my frail older adult father while advocating for their autonomy, which includes *risky* choices. This is especially difficult when my patients come from vulnerable populations like the frail elderly and patients with dementia (Adams, 2001; Hunt & Ells, 2011; Sandberg, Rosenburg, Sandman, & Borell, 2015). Supported by a plethora of evidence, patient safety is a key principle for both nurses and health care organizations and it is consistently used to direct policy (Canadian Patient Safety Institute, 2012; Institute of Medicine, 1999; Landrigan et al., 2010). Morden (2012) identified the urgent need to incorporate *lay* perspectives of self-management for chronic illness into dominant biomedical perspectives that are typically used to shape health policy. This includes family perspectives of risk and perspectives of risk to families.

Cooke (2009) stressed the need to integrate sociological theories of risk culture and risk society into technoscientific perspectives such as accident theory and high reliability theory that involved overreliance on empirical data and numerical indicators. As Finucane and Holup (2006) put it, "[T]he key to understanding risk will be found in understanding both analytic and affective processes and how they combine in judgment and decision making" (p. 145). This view was evident in a study by Rush et al. (2014) where older adults' constructions of risk as they transitioned from hospital to home were shaped and influenced by discourses of ableism. Older adults did not want to appear *othered*: different, disabled, dependent, incompetent, or unproductive. This value of normalcy influenced their decisions to a greater extent than objective biomedical knowledge. It was also evident in this study (Rush et al., 2014) that older adults and their partners found risk a challenging topic of discussion, which is similar to another study by Kilian, Salmoni, Ward-Griffin, and Kloseck (2008), where tensions and differing views

of risk were identified between older adults and their families. The next section of this chapter will focus on the current knowledge integrating discourses of risk, older adults who are admitted to acute care hospitals, and subject positions of family caregivers who are also nurses.

2.2   Risk: Older Adults, Acute Care and Subject Positions of Family Members/Nurses

Selecting literature for review that incorporates a focus on risk, hospitalized older adults, and family members who are nurses was not an easy task because these terms are not commonly combined within the literature. In fact, I did not identify a single study that integrated all of these terms. There is a substantial amount of writing about older adults living in community and residential care settings and relationships between the older adult, unpaid family member caregivers, and paid professional health care teams (Chapman, Keating, & Eales, 2003; Haesler, Bauer, & Nay, 2006; Nguyen, Pachana, Beattie, Fielding, & Ramis, 2015). Risk is often framed in terms of potential physical risks to the older adult and emotional risk (such as guilt and blame) to the family member (Bauer & Nay, 2003; Hertzberg & Ekman, 2000; Monin & Schulz, 2010). For example, in a study by Wolff, Spillman, Freedman, and Kasper, (2016), families helping older adults who were at high risk for poorly coordinated care experienced significant emotional difficulty and "role related effects" (p. 372).

There is a growing body of research that focuses on subject positions of double-duty caring. Much of this research focuses on health care providers who care for patients at work at the same time as caring for family members at home (Boumans & Dorant, 2013; Brindley, 2018; Ward-Griffin, Brown, Vandervoort & McNair, 2005). Brindley's study (2018) used a meta-ethnographic methodology to provide a synthesis of qualitative research by analysing the original words of the interviewees. Search terms: 1) work or profession or professional life; 2) caring or carer or caregiver or look after 3) personal or home or family; and 4) nurse or doctor or NHS or

national health service, led to the identification of the phrase 'double-duty caregiver'. Eight major themes were identified from the data: communication, identity, prescience, connection, expectation, advocacy, knowledge and powerlessness. While risk is not explicit in the findings, it is implicit in each of these themes including the key theme of identity as evidenced in these nurse's comments: "You never stop being the nurse [you] couldn't just be the daughter, you were still a nurse as well" (p. 20) and "I am finding it increasingly difficult to know who I am in relation to my mother" (p. 20).

Ward-Griffin and colleagues' feminist study (2005) examined the experiences of women in four different health professions (nursing, medicine, physiotherapy and social work) who provided care to elderly relatives. Similar to Brindley's (2018) study, although risk is not explicit in the study by Ward- Griffin and colleagues (2005), it is implied as female health professionals "continually negotiate the boundaries between their professional and personal caring work" (p. 379). This continual negotiation resulted in many of these women experiencing "a dramatic blurring or erosion of these boundaries, resulting in feelings of isolation, tension, and extreme physical and mental exhaustion" (p. 379). Other studies are specific to nursing and double-duty caregiving (Cicchelli & McLeod, 2012; Mills & Aubeeluck, 2006; St.-Amant, et al., 2014; Ward-Griffin, et al., 2015). Still other studies are specific to nursing and double-duty caregiving of older adult relatives (Ward-Griffin 2004; Ward-Griffin, St-Amant & Brown, 2011). Risk is identified in these studies as nurses experiencing risk to their own health, specifically risk of compassion fatigue.

Double-duty caregiving is prevalent and highly demanding. Ward-Griffin (2013) described how a survey she and her colleagues conducted in 2009 revealed that 40 percent of nurses across Canada were double-duty caregivers. In this article Ward-Griffin defines double-

duty caregiving as "non-stop caregiving – equivalent to working shift after shift without ever being replaced" (p. 15), putting "nurses who are unable to escape from these 24/7 responsibilities of caregiving, who take on the bulk of care...particularly at risk for mental exhaustion and/or physical illness such as hypertension" (p. 15). In another two-phase mixed methods study Ward-Griffin and colleagues (2015) identified further how nurses negotiated professional and familial care boundaries with a purpose to understand how health risks may vary between double-duty caregivers.

My experience of double-duty caregiving was quite different. I did not provide care to my dad at home, nor did I provide personal, round-the-clock caregiving. I did not experience compassion fatigue, mental exhaustion or other physical illnesses. My dad lived in a supportive care environment and was independent with his personal care. My experience of double-duty caregiving involved negotiating the roles of daughter and nurse when he was admitted to hospital. My experience was similar to other health professionals caring for aging parents who are hospitalized: given their expertise and knowledge, they are still unprepared for how difficult it is to coordinate the care of their older adult relative, including preventing adverse outcomes and protecting them from harm. Kaiser and Kaiser (2017) did not explicitly define themselves as double-duty caregivers when they talked about their subject positions changing from insider (as geriatric medicine and social work professionals) to outsider (as professionals caring for an aging parent) as they negotiated competing and intersecting roles. Their experience included negotiating these roles through a challenging hospitalization for their mother beginning with her admission to the emergency department and including her care in the intensive care unit.

It has been well established that older hospital inpatients are at particular risk of physical adverse events causing harm such as falls, dehydration/malnutrition, incontinence, medication

adverse events, delirium, and hospital acquired infections (Long, Brown, Ames, & Vincent, 2013). There is a growing body of research that incorporates risk to family caregivers (often framed as stress/exhaustion/fatigue) when caring for their family member who is admitted to acute care (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001). A small subset of this literature is specific to the caregiver as a nurse (Olivet & Harris, 1991; Ward-Griffin, 2004; Ward-Griffin, St-Amant, & Brown, 2011). In the study by Ward-Griffin et al. (2011), risk is evident in language such as "living on the edge" (p. 1), referring to practicing registered nurses who are doing double-duty as family caregivers.

In their work, Giles and Hall (2014) investigated the unique experiences of the nurse-family member when a loved one was admitted to hospital; however, this research was not specific to the older adult patient. They identified six characteristics of the nurse-family member experience: specialized knowledge, dual-role conflicts, competing expectations, building relationships, being *let in*, and healthcare setting (own vs other). Other key findings identified that due to their specialized knowledge, nurse-family member experiences as users of the health care system are very different than those of general public members; therefore, they want and need a different type of care than other health care consumers. Recommendations from this study recognized and acknowledged nurse-family members' specialized knowledge and the need for health care professionals to understand and utilize these unique resources to enhance the level of care provided for both the patient and the family.

To date, I have identified only one study, that of Taverner et al. (2016), that focused on nurses' experiences as family caregivers of hospitalized older adults. This grounded theory study identified "a culture of neglect that had normalized poor nursing care" (p. 215). Although this study was not specific to risk, I identified discourses of risk that were implicit within the

data, framed as *lack*, and then performed as discourses of control. Within this risk/lack discourse were six intersecting themes: *lack of care*, *lack of expert status/disruption of roles*, *lack of resources*, *lack of communication/collaboration*, *lack of nursing leadership*, and *lack of respect and dignity*. These themes are congruent with previously mentioned literature regarding family caregivers (including nurses) caring for older adults in other care settings.

2.2.1   Risk: Lack of care

Lack of care is one of the key discourses of risk that drive families to perform discourses of control. *Care* is framed as medical care and families express feeling worried, stressed, and fearful that their older adult relatives will not receive the care they require when they are admitted to an acute care hospital, placing them at great risk for functional decline. Hospitals are risky places. No one understands and feels this more acutely than nurses, who are bound by their professional standards to provide safe patient care (College of Registered Nurses of British Columbia, 2016). Due to their specialized knowledge, nurses who are family members are especially vulnerable to fear and anxiety that this care will not be provided and, in turn, are at risk for lack of care themselves.

In the study by Taverner et al. (2013), the registered nurse (RN) participants described how they believed "even basic care was not provided" (p. 35) to their older adult family member and the stress of knowing this is reflected in their responses: "Dad was grossed out coming home after three days and none of that personal care had been given" (p.35). Another participant described how the basic care was so lacking the family ended up providing care*:*

It was so bad to the point that my sister-in-law and I had to do all of Mom's care. My sister- in-law and I went three times a day to do her care; we gave her a bed bath every night, we did her dentures every morning. (p.35)

Another participant described how lack of care had caused her father to suffer a severe skin complaint*:*

He had a diaper rash; his skin was peeling off his thighs. We had been able to keep my Dad's skin intact for 3 years; I'm disappointed that the nurses could not achieve that outcome in hospital. (p. 35)

These types of experiences made families lose trust in professionals and become uncertain and worried. As Lindhardt et al. (2006) explained, "[families] engaged in activities aimed at securing the elderly person's safety, and also in substituting activities in the areas where they were not satisfied with the professional's performance" (p. 143). Security is another term that occurs within risk discourses related to older adults in acute care and is taken up as control. One example is within the context of wandering in hospitalized older adults with dementia (Rowe, 2008; Silverstein & Flaherty, 2008) and use of restraints. Securing patient safety is a key discourse for nurses in acute care and although attempts have been made to problematize this language, it remains entrenched in culture. For example, Gallinagh, Nevin, McAleese, and Campbell (2001) studied the perceptions of older people who had experienced physical restraints. Negative comments from patients were characterized in terms of institutional control, ritualized care, entrapment, and discomfort. However, nurses are working in an increasingly litigious society and continue to have difficulty managing an overprotective ethos of patient-centred care. Gallinagh et al. recommended individualized approaches to risk management and

inclusion of patients and families in the plan of care. This approach includes nurses

relinquishing control to patients and families and respecting/trusting their expertise.

2.2.2   Risk: Lack of expert status, disruption of roles

Risk is implicit as family caregivers and nurses caring for older adults in acute care

settings compete for control of care and negotiate the role of "expert" (Allen, 2000; Clissett,

Porock, Harwood, & Gladman, 2013). While these tensions have long been identified in

residential care, along with the need for patient/family and staff partnerships (Bauer, 2003), acute

care (with the exception of maternity/childcare areas) has lagged behind in including and

encouraging patients and families as partners in care (Lavoie-Tremblay et al., 2014). In a study

by Lowson et al. (2013), findings showed that family caregivers of older adults living in the

community were conceptualized as *conductors* by "maintaining the rhythm of good care

throughout the illness trajectory" (p. 1197). However, following their older adult relative's

admission to hospital, they experienced a disruption of their expert role status and were relegated

to the status of *second fiddle* where their ability to work with their relative and to make or

influence decisions was vastly reduced.

While patient- and family-centred care has been touted as *common sense*, it is not without

its challenges, including negotiating boundaries between professional and personal caring.

Ward-Griffin and colleagues (2005) found in their study that the continuous negotiation process

led to the female health professionals' "feelings of isolation, tension, and extreme physical and

mental exhaustion" (p. 379). Participants in Taverner et al.'s (2016) study also used negotiation

as a strategy to assert control and keep their family member safe as described by this RN/family

member:

This is what I said to the nurse, "So here is the deal, I am going to do everything for Mom

and get her settled. I am going to take her for a walk, I'm going to wash her up, I'm

gonna get her into bed. All I need from you [the nurse] is every 4 hours that you give

some Tylenol throughout the night so that she is comfortable and that she can move. (p.

221)

Clisett et al. (2013) outlined the challenges of sustaining personhood for patients with

dementia and satisfying the expectations of families in acute care hospitals that are not designed

to attend to the unique needs of older adults.

Lindhardt, Bolmsjo, and Hallberg (2006) described how relatives of older persons

admitted to hospital lacked confidence in nursing staff and provided this care themselves because

they were not confident that it would be provided by the nursing staff. Baumbush, Leblanc,

Shaw, and Kjorven (2015) identified how acute care nurses lack adequate knowledge and clinical

expertise to provide optimal care to older adults, in part because older adults and, by association,

those who care for older adults, are not valued. This leads into the next theme of lack of

resources.

2.2.3   Risk: Lack of resources

Family caregivers are worried about the quality of care for their hospitalized older

relatives in part because of what they see as a lack of resources, including lack of time. Not only

is there a lack of acute care staff with specialized skills to care for the older population, there is a

widespread belief that there are not enough nurses to provide even the basics of care. "Even

though there is no consensus around the effect of higher staffing levels, RNs have attributed

suboptimal care to their lack of time to provide adequate care due to a low staff: patient ratio"

(Baumbusch et al., 2015, p. 151).

Li (2003) identified that one way to address family worry was to include family caregivers in all aspects of their older adult relative's care, including early discharge planning. The problem is nurses remain unable to recognize, mobilize, and utilize families appropriately. Reasons for this difficulty may include lack of knowledge and skills, unclear roles, hidden expectations, negotiation failure, power struggles and lack of resources (Coyne, 2015). Giles and Williamson (2015) acknowledged the need to ensure nurse-family members' professional knowledge and skills are recognized and respected without being exploited. While some nurses appreciate the assistance family members provide, they also complain about interference (Auslander, 2011; Hemsley, Balandin, & Togher, 2008; Lindhardt, Nyberg, & Hallberg, 2008).

Ward-Griffin et al. (2011) uncovered in their findings the lack of personal and professional resources for nurses who were doing double-duty as nurse-family caregivers. Although risk was not the focus of the study, the risk of compassion fatigue in nurse-daughter caregivers emerged within the context of preforming double-duty roles. Nurse-daughter participants in this study felt that staff nurses caring for their relative expected a lot more from them than they would other family members who were not nurses. They also often believed they had no choice; they believed that potential harm might come to their family member if they did not provide care. "Due to their relative's lack of knowledge about the health care system, medical conditions, and/or treatment options, [the nurse-daughters] became their parents' advocate" (Ward-Griffin et al., 2011, p. 7), and risked developing compassion fatigue. The authors also addressed how the medicalization of compassion fatigue is problematic. First, while the identification and treatment of the medical symptoms (including physical and mental exhaustion) among double-duty caregivers is important, foregoing consideration of the social context in which they occur only addresses those who are already in crisis. Second, focusing on

the individual traits of nurses, such as a high degree of empathy or *at risk* individuals (those who have difficulty setting boundaries), tends to produce and reproduce the idea that the *problem* of compassion fatigue lies with the individual rather than the system. This contributes to *blaming the victim* and justifies the lack of external supports/resources. Third, the authors argued that this medical/behavioural approach to compassion fatigue suggests that it is the individual's responsibility to find the solution and implies that the solution is within the individual's control through use of language such as "finding an appropriate work-life balance." Lastly the authors identified how being socially positioned as women caregivers contributes to nurse-daughter's risk of compassion fatigue.

2.2.4 Risk: Lack of communication/collaboration

Clissett et al. (2013) recognized the core problem of disruption from normal routine and how families negotiated the process of gaining or giving a sense of control to cope with the disruption. Families tried to be proactive by attempting to make sense of the situation and gaining control for themselves and their older relative. They tried to "stay informed, communicate with staff about the patient and plan for the future" (p. 2707). However, while caregivers took a proactive approach to involve themselves in care by trying to work collaboratively with acute care staff, relationships between family and staff were often characterized by poor communication.

Lindhardt et al. (2005) identified how power issues influenced collaboration. For example, when collaboration happens in the elderly person's home it is on the caregivers' home ground so to speak; however, collaboration in the hospital may be considered to be on the home ground of the professional caregivers, thus, shifting power accordingly. This power shift relates to our social understandings and performance around 'expertise' and 'expert' and contributes to

anxiety and uncertainty in the caregiver often leaving them feeling powerless. Their findings also revealed how relatives took on different roles to ensure the safety and care of the elderly person. Family caregivers used metaphors to describe themselves such as a *watchdog* and *on standby*. One family member in this study put it this way: "I'm on 'stand-by' I also carry this mobile phone with me, you know, even though I usually never do that, and it's even turned on now, you know. When I'm at work too…" (p. 142). Giles and Hall (2014) recommended "acknowledging nurse-family members' specialized knowledge and dual role, keeping them fully informed, and allowing them to [contribute to the care of] the patient while in hospital can reduce their fear and anxiety" (p. 1451).

2.2.5   Risk: Lack of nursing leadership

Taverner et al. (2016) determined that a lack of nursing leadership contributed to a culture of *normalization of neglect* of older people in acute care. Much has been written about how nurses fail to support other nurses from the way nurses treat new graduates or "eating our young" (Johnson, 2015) to bullying and the risks that horizontal violence impose on the workplace (Longo, 2013). Longo and other nursing researchers and writers from the fields of staff development (Chipps & McRury, 2012), economics (al Palumbo, McIntosh, Rambur & Naud, 2009), leadership (Capitulo, 2009), and management (Friedrich, Prasun, Henderson & Taft, 2011) identify how this culture is normalized if management is unwilling to acknowledge and address it, despite the negative impact on patient care and safety. Johnson (2015) talks about using the Sensei role to address this issue. A Sensei is defined as "one who has gone before" (p. 49); a person "who has walked the path you are walking now" (p. 49). This approach creates the opportunity for a safe place to share stories, anxieties, and fears with a purpose to create change; however, it also requires a leader who is prepared to take risks and perhaps become vulnerable.

While management is taking note of the effect horizontal bullying has on nurses working side by side in the workplace and the research supports a need for change in practice, there remains a gap in the literature about how nurses treat other nurses who are performing dual or double-duty roles.

2.2.6   Risk: Lack of respect and dignity

Hillman et al. (2013) and Calnan et al. (2013) explored the key influences on the provision of dignified care for older people in hospitals and uncovered a lack of consistency in providing dignified care that was caused by the "dominance of priorities of the system and organization tied together with the interests of ward staff and clinicians" (Calnan, et al., 2013, p. 465). In addition, the lack of attention to elder-friendly hospital environments results in acute care wards that are poorly designed, confusing, inaccessible, "and 'not fit for purpose' to treat their main users, those over 65 years, with dignity" (p. 465) and are therefore unable to meet their needs.

In a 2016 study by Taverner et al., all of the participants talked about lack of dignity for their elders with issues around mixed gender bed areas and lack of provision of privacy*:*

> At ---------- you know there they have male/female beds, rooms. Well I think that's actually common everywhere, but it's particularly common at--------. Anyways, and in her confusion she got up out of bed one night to go to the bathroom and she went back to bed and she got in bed with a man. In the context of my parents, there could be nothing worse. (p. 220)

Another participant gave a particularly disturbing account that demonstrated the complete lack of respect and preservation of dignity for an older lady and while the mixed gender bay was an issue, the apparent neglect of the patient's privacy was more so*:* "The lack of privacy, she was

in a room with two other men. A male nurse came in and didn't even pull the curtains and was

doing something with her catheter (urinary catheter)" (p. 220).

Similarly, in their pilot study, Gallagher and Seedhouse (2002) identified staff as the

dominant theme and greatest contributor to promoting or diminishing dignity. Dignity was

closely linked with respect and while risk was not explicit, it was linked to older adults'

responses about the need to be treated equitably and without age discrimination. Older adults

spoke about feeling embarrassed, degraded, and depressed in situations where they were treated

without dignity.

2.3   Summary of State of Knowledge

This chapter began with a focused definition and detailed review of the existing

theoretical and empirical knowledge related to risks specific to older adults and how this

informed my own knowledge and practice. Using this as a foundation, I then layered a review of

the current knowledge integrating discourses of risk, older adults who are admitted to acute care,

and subject positions of family caregivers who are also nurses. While risk is implicit within this

growing body of literature, it is often only referred to in other terms such as hazard, fear,

uncertainty, living-on-the edge, and worry. Discourses of risk are embedded in language of

control as nurses seek to control the conditions of their work, whereas older patients and their

families, including nurse-family members, seek to control the conditions of their hospital

experience (Allen, 2000). Negotiation of control takes place in situations of power and

knowledge.

All of the studies recognized the need for future research to develop understandings of

the unique experiences, challenges, and needs of nurse-family members to develop sound

recommendations that will further contribute to the development of an enhanced level of care for

older adults and their families. Ward-Griffin et al. (2013) identified the need for policy changes that clearly support nurse-daughters and other double-duty caregivers. "Given the structural basis of continuing gender inequities on society today, and the magnitude of the change required, the need to advocate for policy changes that clearly support nurse-daughters and other double-duty caregivers is great" (p. 13). Ogle and Glass (2006) recognized that "most scholarly work is usually written from the perspective of the author being a unitary subject occupying a sole, rational, and unified position" (p. 170). They also acknowledged that the "notion of the unified rational author appears to be expected for credible scholarly work, and dominates other conceptions of subjectivity and identity even in articles arguing for different conceptions of subjectivity" (p. 170).

For my study, I incorporated the principle of the researcher/myself occupying multiple subject positions to build on the work of Ward-Griffin et al. (2011) and Taverner et al. (2016). In this way, my research will support the urgent need for healthcare providers, managers, educators and policy makers to consider the unique social position of double-duty caregivers within the context of caring for older adults and to address the socio-political factors that predispose this unique group to risk.

Chapter Three: Theoretical Perspective

In this chapter, I describe the theoretical perspectives that guide my methodology and methods of research: poststructural discourse analysis with a focus on risk. First, I provide an explanation of poststructuralism drawing on Foucauldian/Butlerian ideas. Second, I describe how discourse analysis fits within this perspective. Third, I illustrate how subjectivity/subject positions and specifically mobile subjectivities are informed by this perspective. Fourth, I incorporate how poststructural perspectives inform approaches to risk, which leads to my study purpose and research questions. Lastly, I provide a summary of this chapter.

3.1   Poststructuralism

Poststructuralism is not one monolithic approach or perspective and does "not [have] one fixed meaning but [is] generally applied to a range of different theoretical positions" (Weedon, 1987, p. 19). What is generally agreed upon is that poststructural perspectives interrogate language, meaning, subjectivity, social organization, and power (Cheek, 2000; Denzin & Lincoln, 2000; Weedon, 1987). In doing so, these perspectives focus less on overly rigid definitions of structures identified in structuralism and more on the change and flux in social structures and meanings, including what is influencing and producing those changes. Power relations are also viewed differently than from a structuralist perspective; poststructural perspectives focus on the relationship between power and knowledge where power relations are always implicated with knowledge and therefore no knowledge can be said to be *neutral*. Where critical structuralists tend to view power as coercive or oppressive, poststructural perspectives view power as productive and inevitably present in any social relation. It is important to note that from a poststructural perspective the words *productive/produce* do not always connote

something positive; they also signify limitations. As well, individual identities[1] are not assumed

to be fixed in poststructural perspectives, rather they are viewed as constantly shifting and

repositioning, the products of various combinations of power-knowledge formations (Lupton,

2013a). This close relationship between power and knowledge is present in modern forms of

governance or *governmentality* in what Foucault (1982) called "structuring the field of action of

others" (p. 221), where authorities, or those with expert knowledge and power, shape beliefs and

the conduct of the population (Cheek, 2000) to be rendered productive.

Poststructural perspectives challenge unwritten rules and assumptions. In the health care

arena, the challenge is on "correct" or "accepted ways of acting and thinking" (Cheek, 2000, p,

41). Questions outlined by Cheek that might be asked from a poststructuralist research approach

include the way that health care is represented and "why this representation is the one accepted

as 'normal' or 'given'; what are the alternate ways of representing the same reality; and why

these ways are absent and/or marginalized and suppressed" (p. 41). In other words,

poststructural perspectives challenge how things come to be the way they are and at what costs.

Representation of *truth* as singular, objective, and positive is problematic in poststructural

research because it can cause a fear of inconsistency and *not getting it wrong*, leading to a

stiffening of ethnographic writing and impeding the richness of data (Ogle & Glass, 2006).

Poststructural perspectives also challenge the notion that language is a neutral, objective,

value-free conveyer of aspects of reality, and expose it as being "constituted by and constitutive

of, the social reality that it seeks to represent" (Cheek, 2000, p. 40). In other words, "language

does not 'reflect' social reality but rather produces meaning and creates social reality" (Denzin &

Lincoln, 2005, p. 961). An example of how language is not neutral is the attachment of value-

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[1] I acknowledge that the ideas of agency, identities, and self are where many writers deemed poststructural diverge.
For example, Foucault changes his view of the self across his writing.

laden nomenclature such as *scientific* to risk perspectives; the techno-*scientific* perspective of risk is produced as legitimate, because *scientific* is accepted as legitimate.

Language is how social organization and power are defined and contested, in other words, control the language = control the power (Reid, personal communication, December 2016). Understanding language and text as competing discourses (competing ways of giving meaning and of organizing the world) makes language a site of exploration and struggle (Cheek, 2004; Denzin & Lincoln, 2005; White, 2004).

3.1.1 Discourse

Poststructuralism emphasizes the importance of identifying discourses that participate in the production of ideas or realities, meanings, and understandings. There are numerous definitions of discourse in the literature, and just as often it is either undefined or poorly defined (Cheek, 2004; Parker, 1992; Wodak & Meyer, 2006; Wood & Kroger, 2000). The understanding of discourse for this study is informed by Foucauldian/Butlerian ideas.

3.1.2 Foucauldian/Butlerian discourse analysis

Numerous studies in nursing research draw on Foucault and discourse analysis (Crowe, 1998; Crowe, 2005; Kjorven, Rush & Hole, 2011). Cheek (2004) explains that "[f]or Foucault, discourse refers to ways of thinking and speaking about aspects of reality" (p. 1142) and that discourses consist of common assumptions that are "so taken for granted as to be invisible or assumed" (p. 1142). As well, they "both enable and constrain the production of knowledge, in that they allow for certain ways of thinking about reality while excluding others" (p. 1142). Foucault (1972, 1980) described discourse as the assumptions, the ideas, the talk, the text, and the images that produce understanding and meaning. These discourses are at work in multiple layers as a matrix that allows for shifting, movement and repositioning in terms of how particular

discourses work in different contexts. Foucault (1972) identifies the work of discourses as regimes of truth, which are the dominate ways of knowing—those hegemonic discourses that prevail over other discourses. The assumption is that by troubling and exposing this hegemonic thought it is possible to raise consciousness toward social justice. In doing so, it is also assumed that social justice is not an end product but a process of change. In addition, a Foucauldian/Butlerian analytic lens examines the relationship between language practices and power and how power is productive (Foucault, 1980).

Poststructural approaches also acknowledge that while a researcher may not be able to represent either nurses' individual or collective truths, the researcher can represent multiple voices (Ogle & Glass, 2006). The use of multiple perspectives helps to elucidate alternate interpretations that might otherwise escape consideration. Cheek (1995) noted that "nursing is enriched if it is informed by multiple viewing positions and even, at times, contradictory notions of reality" (p. 239). This is where an acknowledgment that subjectivity is both multiple and mobile is helpful.

3.2   Subjectivity/Subject Positions

Davies and Harre (1990) asserted the notion of *position* as "an appropriate expression with which to talk about the discursive production of a diversity of selves" (p. 47). Positioning is the vantage point a person sees the world from "in terms of the particular images, metaphors, story lines, and concepts which are made relevant within the particular discursive practice in which they are positioned" (p. 46).

3.2.1 Roles, subject positions and identity

Rather than collapse the three terms: role, subject position and identity, I offer an explanation of how and why I have come to include each and all of these terms within my

writing. Sundin-Huard (2001) provides an explanation of the difference, beginning with a description of how role theory was used in the mid-twentieth century to explain individual's status and function within society:

> Role theory consisted of two different approaches: a social anthropological approach which focused on the clusters of normative rights and obligations of the roles (for example the sick role), or alternatively a social psychological approach focused on the active processes in taking, making and playing at roles. Role theorists suggest that the most helpful way to view the connection between a person and their role is one in which the individual is seen as interacting with and being formed by the role 'role taking' and in turn, shapes and influences the role 'role making'. The individual's success in society is determined to a large extent by their ability to conform to or fit society's expectations of the role. Criticized as deterministic and simplistic this theory is said to lend itself to the production of marginalized stereotypes while ignoring the influence of power on a person's position in society. (p. 377)

I include the language of 'role' within my writing because it fits with poststructural perspectives of taking up and performing discourses. It is also commonly used by nurses in clinical practice and research who talk about the changing roles of patients and families (Dahlke & Baumbush, 2015; Purveen, Cooke, Gill & Baumbusch, 2019) and specifically researchers and writers on double-duty caregiving/caregiver *roles* (Brindley, 2018; Ward-Griffin, 2013; Ward-Griffin, St-Amant & Brown, 2011; Ward-Griffin, et al. 2015).

Criticized as "deterministic and simplistic especially by feminist scholars" (Sundin-Huard 2001, p. 377), role theory is said to lend itself to the production of marginalized stereotypes while ignoring the influence of power on the individual's position in society (Sundin-

Huard, 2001; Street, 1992). Subject position theory then, has become more useful in providing both consideration of the power dynamics inherent in any interaction and an explanation of the fluidity of agency and identity characteristic of the human condition.

Post-structural writers (Butler, 1993; Cheek, 2000) tend to use the language of subjectivities, subject positions and identities. Butler (1993) drew on the work of Foucault to offer an explanation of the individual's ability or inability to occupy and move between a variety of identities or subject positions, depending on the power dynamics and context of the exchange. Sundin-Huard (2001) described how Butler elucidates subjectivity in terms of compliance and resistance within shifting power processes and argues that normative power processes control which identities particular individuals can assume and which identities are unavailable. Society offers these identity possibilities/impossibilities in binaries where the one is privileged and the other is marginalized from acceptable subjectivity, for example, hard-working/lazy; good woman/witch. Identity is assumed in response to the threat of punishment and the threat of punishment arises out of knowing the rules of society, which constitute *the law* (Butler, 1993). Consisting of a series of demands, taboos, sanctions, injunctions, prohibitions, impossible idealizations, and threats, *the law* defines appropriate and mutually exclusive forms of identification. Recognition of these *laws* results in the individual's *choice* of identity in response to the potential retribution associated with the assumption of identities not sanctioned by the abject:

> Once an identity has been assumed by [the] individual, there is a particular discourse
> available to that identity or subject position. For example, the discourse available to the
> subject *good woman* is completely different to the discourse that accompanies the subject
> positions *witch* or *whore*. Similarly, the discourse choices available to the subject

positions 'good nurse' and 'uppity nurse' are different. (Sundin-Huard, 2001, pp. 377-

378)

Using this method of inquiry uncovers ways in which discourse, power, and knowledge come

together in spaces such as hospitals to mould subjectivities and also reveals how marginalized

groups are historically constructed through authoritative discourses and scientific practices

(Crowley, 2009).

3.2.2   Mobile subjectivities

While the process of identification exists as a result of enabling one identity and

foreclosing an alternative (Butler, 1993), poststructural accounts refute the notion of a unitary

rational subject and view the subject as constituted by multiple subjectivities or subject positions.

The notion of subjectivity being nonunitary has been described as contradictory, partial, flexible,

fragmentary, and strategic (Butler 1993; Hollway, 1989; Ogle & Glass, 2006) and constituted by

an ensemble of subject positions, participation in a multiplicity of social relationships, and the

plurality of collective identifications. 'I' then is not a unified subject or a fixed identity; 'I' is

itself, in infinite layers. There is no one *true* representation of self and identity. At any given

moment there will be varying possibilities for self-construction. Every person comprises a

multiple selfhood that is discursively constituted and it is "that aspect of self that is involved in

the continuity of a multiplicity of selves" (Davies & Harre, 1990, p. 47). Positioning occurs

interactively and reflectively as a function of narratives employed in speaking and from a

subjective history brought to each encounter. Identities are actively negotiated and transformed

in discourse, and language is the site where strategic construction and reconstruction of self

occurs (Ogle & Glass, 2006).

Similarly, Hollway (1997), integrating Foucauldian thought, utilized notions of consciousness raising, multiple subjectivities, and discourse analysis to explain how people make a reasoned decision on which discourses or positions they take up. However, this is not always conscious and people may be positioned in various discourses that are contradictory to each other at the same time. For example, some of the multiple subject positions of proposed participants and respondents in my study included nurse, manager, director, health service administrator, and my own multiple subject positions including researcher, expert, nurse, daughter, student, resistor, contrarian, and acquiescer.

3.2.3 Poststructural perspectives of risk

A perspective informed by poststructural ideas of governmentality uncovers how risk and responsibility shift from government to the individual. Revised relations of expertise and power reposition risk within the community: risks are posed by government to the individual (and/or family) themselves if they (or their family) cannot adequately manage their life within the community and risks are posed by government to the community if the individual (and or family) fails to govern the individual. *Experts*, including social workers, psychiatrists, nurses, doctors, and others "have been allocated responsibility and accountability not so much for cure or reform for clients, patients, and other problematic individuals, but for their administration according to a logic of risk minimization" (Miller & Rose, p. 107). What is most important here is the shift from governments governing the masses to the individual self-governing.

Therefore, governing does not only include the population or the social *body* requiring intervention, management, and protection so as to maximize wealth, welfare, and productivity for the population, it also focuses on the *individual* body. This focus on the body includes uncovering how power is distributed through manipulation of the body and how the body is

normalized and controlled (Brown, 2015; Foucault, 1965; 1972; Rose, 2007). Foucault explored how the body is disciplined into certain forms of control in three particular ways: 1) surveillance and observation; 2) normalization of behaviour; and 3) process of examination and evaluation (Foucault, 1972). Anything that resists these forms of control can be produced as risk.

A subset of this perspective may be the *edgework* (Brown, 2005; Lyng, 2005) perspective of risk where "the emotional excitement of risk-taking contrasts with the instrumental rationality and the idea that unnecessary risk must be avoided" (Zinn, 2008, p. 191). Zinn (2008) links this type of risk-taking to:

> changing societal conditions of living [that draws] on a *subjective rationale* which is ultimately rooted in the nature of the human being: the desire for self-creation as a "free being," to "discover the creative possibilities of an acting self," to "explore the possibilities of the body," or to develop a "self-determined, soulful human being." (p. 191)

In this way, edgework resists the traditional ways that the body is governed, disciplined, and controlled. Edgework may not (yet) be considered one of the most salient theoretical perspectives related to risk in older adults; it is not explicitly linked to older adults in the literature. However, my purpose for including it here draws on poststructural thought, which is concerned not only with what is visible but also with what is absent.

The poststructural epistemological position to risk has proven useful to address the limits of technical and psychological analysis in explaining the dynamics of risk discourse and responses to risk. Most importantly, they have exposed the issue of power/knowledge between expert and lay-people's perspectives on risk where the superiority of objective, science-based knowledge is valued as *real* and *natural* and lay-people's (including families') "understanding of

technologies and risks [is] seen as inferior and biased as a result of a lack of objective information and a contamination with irrational beliefs and emotions" (Zinn, 2008, p. 12). In doing so, these approaches have provided opportunities to reflect upon the social forces of aging within the conditions of risk constraints that have previously been taken-for-granted in this population, contributing to our understandings of risk in older adults (Powell, Wahidin, & Zinn, 2007).

3.3 Purpose

In this study, I place myself in a position of vulnerability by asking and answering questions about my experience of caring for my older adult parent, so that I, as a researcher/daughter/nurse/expert, as well as my participants (family, father, key informant), and readers, might understand these experiences and the emotions they generate with a purpose towards uncovering possibilities for transformation. By reflecting on the nuances of this experience, I will write to illustrate how the aspects of my experience illuminate more general cultural phenomena specific to risk (Holman Jones et al., 2013).

3.4 Research Questions

It is important to note that autoethnographers do not always explicitly identify or include research questions, often because research questions are still developing at the beginning of a project and/or because questions would disrupt the flow of the story. They also might be left for readers to determine (Adams et al., 2015). Having said that, I believe there is value in these guiding research questions:

- How has the culture of risk contributed to my experience of double-duty caregiving?

- What are the discourses that produce this culture and how are these discourses at work to produce subject positions (for example: insider/outsider, expert) that are either available or unavailable to me?

- What does it mean to perform multiple aspects of identities simultaneously and how taking up and performing multiple and mobile subjectivities were manifested within interactions with others?

- How can I invite readers and audiences to use my story and experiences for their own sense-making?

3.5   Chapter Summary

In this chapter, I provided an explanation of the theoretical perspective that will guide my methodology and methods of research. I described how poststructural discourse analysis, guided by a Foucauldian/Butlerian lens, directed my purpose and research questions, which will use my story to inform and create opportunities for change. Chapter four will describe the methodology that flows from this perspective.

Chapter Four: Methodology

In this chapter, I will present my methodology and methods of study. To begin, I will provide a description of autoethnography and an explanation of how it fits with my theoretical perspective. Next, I will describe my methods, including data-gathering methods, data analysis and interpretation, and data evaluation. Included in this section will be ethical and political concerns. Lastly, I will provide a summary of this chapter.

4.1 Autoethnography: Methodology and Method

Autoethnography evolved from ethnography, which was developed as a methodology in anthropology and sociology (Hammersly & Atkinson, 2007).

> In contrast to the term's *auto* (which refers to the author's presentation of critical reflections and interpretations of personal experience), *ethnography* is commonly used to refer to a key qualitative approach studying the rules, norms, and acts of resistance associated with cultural groups. Consequently, the hybrid term *autoethnography* has come to be the favored name for a form of critical reflexive narrative inquiry, critical reflexive self-study, or critical reflexive action research in which the researcher takes an active, scientific, and systematic view of personal experience in relation to cultural groups identified by the researcher as similar to the self or as others who differ from the self. (Hughes and Pennington, 2017, p. 11)

Debate continues whether autoethnography can be defined as a method or a methodology. Hughes and Pennington (2017) define *methodology* as "the established and evolving approach and foundation of a research study" (p. 11) and *methods* as "the actual techniques, tools, or means used for data collection and analysis" (p. 11). They defend autoethnography as a methodology this way:

It is precisely the hybridity of the genre that allows it to be applied as a stand-alone **methodology** as well as a complementary **method** for assembling data from the five traditional empirical approaches to **qualitative research:** phenomenology, ethnography, narrative inquiry, case study, and grounded theory.

It is also the hybridity of the genre that fits nicely with poststructural theoretical perspectives. Poststructural thinking supports "many ways of knowing and inquiring [as] legitimate and that no one way should be privileged" (Wall, 2006, para. 4). Hendricks (2019) explained how autoethnography as a methodology allows for a focus of multiplicity of truth and subjectivity. This differs significantly from the positivist/realist perspective, where "there is only one way to 'do science' and any intellectual inquiry must conform to established research methods" (Wall, 2006, para. 5). So strong is the positivist tradition that even peer-reviewed writers using well-established qualitative research methods are continually asked to defend their research as valid science (Denzin & Lincoln, 2000; Wall, 2006). Ellis' response (Ellis & Bochner, 2006) speaks to my own experience:

> Norms of realist writing demand that you engage in a language game that encourages point-to-point rebuttal, critique of the other's position, and showing how your own position is superior and smarter. I don't find this style at all attractive. It breeds animosity, division and hierarchy. Point-to-point refutation has never changed my mind; it certainly has never changed what I feel in my heart. (p. 434)

This fresh approach to research as well as the opportunity to include, rather than limit the self within research, was what drew me to autoethnography as both a method and a methodology. For me, stories are what engage and draw in readers, including nurses. I wanted a research methodology that would be accessible to nurses, rather than only satisfy the requirements of

academia. At the same time, I wanted to challenge the status quo of the academy, not to engage in a point-to-point rebuttal, but to open a window for reflection on the usefulness of traditional research methods. I saw autoethnography as a way to bridge the knowledge-to-practice gap; where I could write not only for *both* the academy and nurses in clinical practice, but *also* the end-users: patients and families.

According to Holman Jones et al. (2013), four interrelated (and relatively recent) historical trends contributed to the formation of autoethnography: 1) a recognition of the limits of traditional knowledge and a growing appreciation for qualitative research; 2) a heightened concern about the ethics and politics of research; 3) a greater recognition of the appreciation for narrative, the literary and aesthetic, emotions and the body; and 4) the increased importance of social identities and identity politics.

Over the last 20 years an impressive growth of research has been "variously referred to as auto-anthropology, auto-biographical ethnography or sociology, personal or self-narrative research and writing, and [now] more commonly autoethnography" (Anderson, 2006, p. 373). Even the term *autoethnography* has multiple meanings (Reed-Danahay, 1997). Traditionally, it meant "the cultural study of one's own people" (Van Maanen, 2011, p. 106), and it referred to both a method and a product of researching and writing about personal, lived experiences and their relationship to culture (Ellis, 2004; Ellis, Adams, & Bochner, 2011). It involves the "turning of the ethnographic gaze inward on the self (auto), while maintaining the outward gaze of ethnography, [and] looking at the larger context wherein self experiences occur" (Denzin, 1997, p. 227). Ellis, Adams & Bochner (2011) defined autoethnography as "an approach to research and writing that seeks to describe and systematically analyze (graphy), personal experience (auto), in order to understand cultural experience (ethno)" (para. 1).

Ellis and Bochner (2000) also use this triadic model (*auto/ethno/graphy*) to explain the complexity and variety of autoethnographic approaches. They observe that autoethnographers vary in their emphasis on the research process related to each of the components of the triad, and different examples of autoethnography fall at different places along the continuum of each of these three axes. In other words, the three components are not equally weighted within researchers' and writers' autoethnographies.

In addition, similar to theoretical perspectives of risk, autoethnography has not avoided the tug of war between the two positions of objectivity and subjectivity in social science (Reed-Danahay, 1997). The objectivity position promotes the "scientific", systematic approach to data collection, analysis, and interpretation that can be validated by more than researchers themselves; on the other hand, the subjectivity position allows researchers to insert their personal and subjective interpretation into the research process. The two "camps" in autoethnography tend to be those that ascribe to the "analytic" method (Anderson, 2006; Atkinson, 2006; Atkinson, Coffey, & Delamont, 2003), which leans toward the objective, realist, theoretical side and the "evocative" method (Denzin 2005; Ellis & Bochner, 2006), which is positioned as the opposing end arguing for more subjective and emotionally-engaging autoethnography. The analytic side is expected to satisfy the following conditions where the autoethnographer: 1) is a full member in the social world under study; 2) engages in reflexivity to analyze data on self; 3) is visibly and actively present in the researcher's published text; 4) includes other dialogue with other informants beyond the self in data collection; and 5) is committed to theoretical analysis and understandings of broader social phenomena (Anderson, 2006; Chang, 2008). As stated by Ellis and Bochner (2006), the key goal of the evocative side is just that: to create evocation through narrative writing:

We, [the evocative side] think of [autoethnography] as a journey; they [the analytic side] think of it as a destination. They want to master, explain, grasp. Caring and empathizing is for us what abstracting and controlling is for them. We want to dwell in the flux of lived experience; they want to appropriate lived experience for the purpose of abstracting something they call knowledge and theory. (p. 431)

The evocative genre pays particular attention to historical representation of *the other*, is critical about generalizing theoretical discourse, and contests "issues of authority, representation, voice and method" (Ellis, 2015, p. 3). The personal story is what is evocative, it is what engages the reader into the world of lived experience where "you know, feel it, taste it, sense it, live in it" (Ellis & Bochner, 2011, p. 431). Not unlike theorists and writers of risk (Best, 2006), some scholars straddle both positions and autoethnographers expand, collapse, categorize, and modify positions, perspectives, and approaches of/to autoethnography differently for a variety of purposes and to various degrees along the continuum of objective/subjective. Although perspectives and approaches differ, generally, "as a method, autoethnography combines characteristics of autobiography and ethnography" (Ellis, Adams & Bochner, 2011, para. 5). Reed-Danahay (1997) explained autoethnography as an intersection of three writing genres:

1) "native anthropology" in which people who were formerly the subjects of ethnography become the authors of studies of their own group; 2) "ethnic autobiography," personal narratives written by members of ethnic minority groups; and 3) "autobiographical ethnography," in which anthropologists interject personal experience into ethnographic writing. (p.2)

This is what sets autoethnography apart from other ethnographic approaches: autoethnographers use their personal experiences as primary data. The richness of autobiographical narratives and

insights are valued and intentionally integrated in the research process (Chang, 2008; Ellis,

Adams & Bochner, 2011). As Muncey (2005) states, "Autoethnography celebrates rather than

demonizes the individual story" (p.2).

4.1.1   Insider/outsider: Exploring 'self'

When researchers *do* ethnography, they study a culture's relational practices, common

values and beliefs, and shared experiences for the purpose of helping *insiders* (cultural members)

and *outsiders* (cultural strangers) better understand the culture (Ellis, Adams & Bochner, 2011;

Maso, 2001). "When researchers *do* autoethnography, they retrospectively and selectively write

about epiphanies that stem from, or are made possible by, being part of a culture and/or by

possessing a particular identity" (Ellis, Adams & Bochner, 2011, para.7). From a Foucauldian

perspective, the concept of the self as a singular and coherent entity is a fictional construct;

rather, the individual is composed of conflicting tensions, contradictory positions, and competing

knowledge (Berg, 1993). Chang (2008) explained how *self* is depicted from multiple

perspectives in terms of social roles the individual plays, people groups the individual belongs to,

diversity criteria by which the individual judges self, and primary cultural identities that the

individual gives their self.

This is where poststructural thought provides usefulness and supports an

autoethnographic approach with a value on "plurality, fragmentation, and multivocality" (Cheek,

2000, p. 40). The self, or "Ethnographic I" as Ellis (2004) illustrated, is multi-vocal in its

meaning and has capacity to hold/move between multiple positions, including positions of

insider/outsider. Poststructural thinking offers a supporting framework to extend and

complement autoethnographic research approaches where "the task of autoethnography is not to

discredit the antagonist (if there is one)" (Giorgio, 2013, p. 415), either in the research

perspective or the process. Rather, autoethnography seeks to "understand and elucidate the perspectives and feelings of 'the other", and in doing so, deepens the value of the story for the writer and reader, especially if and when the reader is someone in the story" (p. 415). In other words, the goal of poststructural research approaches is not to eliminate conflicting perspectives, including the traditional scientific research method, the goal is to question its dominance and demonstrate that it is possible to share knowledge in many ways (Wall, 2006).

Berg (1993) offered a position of "betweenness" (p. 491) to illustrate how competing positions (subjective/objective), rather than being conceived as confined by epistemological barriers, can be seen as "dynamic and fluid extending along the lines of tension, continuity, and discontinuity" (p. 491). Rush et al. (2014) identified this position as "liminality" (pp. 494 & 499) or "in-between" (pp. 494 & 499) as older adults negotiated between subject positions of abled/disabled as they contemplated risk. Bochner and Ellis (2016) also talk about "autoethnography's liminality – it's between-ness" (p. 67), in that it sits in the middle of things, between art and science, between rationality and emotionality, moving between epistemology and ontology.

> Twenty years ago, autoethnography had no status or ranking whatsoever. It existed in the liminality that anthropologist Victor Turner (1967, p. 97) calls 'a realm of pure possibility'. Actually, that can be a good place to occupy, because that's where novel and creative ideas arise. Ultimately, liminality ends in recognition. (p. 67)

For me, dwelling in this liminality meant attempting to reconcile the boundaries between the subject positions of nurse expert and daughter. In doing so, I explored how these and other subject positions were either available or unavailable to me. Uncovering and valuing multiplicities and multiple subject positions within autoethnography creates opportunities to

disrupt those binary positions. This is where poststructuralist perspectives are useful as they negotiate the tension between philosophical ontological contradictions such as objective/subjective, and are able to hold multiple theoretical approaches. Poststructural perspectives do not choose. They do not produce binaries (black/white; right/wrong). In this way, poststructuralism can be closely linked to pragmatism (R. Hole, personal communication, December 9, 2015) in that poststructural perspectives look at the practical application/usefulness of discourses/perspectives/positions. Therefore, I intend to draw on both evocative and analytical positions of autoethnography to inform my methods.

4.1.2 Methods

4.1.2.1 Sampling

I used purposeful sampling to select a group of participants who have specialized knowledge about me and my experience of caring for my older adult father while he was admitted to acute care: "When developing a purposive sample, researchers use their special knowledge or expertise about some group to select subjects who represent this population" (Berg, 2004, p. 32). Glesne (1999) concurs that qualitative researchers tend to select their participants in a purposive manner to ensure that the information generated is rich in depth. Selecting participants that meet specific criteria listed above will also ensure quality assurance (Patton, 1990; Silverman, 2002).

When we do autoethnography we study and write culture from the perspective of the self. "We look *inward* - into our identities, thoughts, feelings, and experiences – and *outward* – into our relationships, communities and cultures" (Adams et al., 2015, p. 46). Therefore, I am the main participant in this study. The other participants are my father, my siblings (one sister and two brothers), and one other key informant: the health service administrator of the hospital where my father was admitted, who has since retired but has expressed interest in participating in this

study. I chose these individuals as participants because they were actively involved in my experience of caring for my father as a nurse/daughter during his admissions to hospital and because their perspectives are useful for a number of reasons: 1) to stimulate my memory; 2) to fill in gaps in information; 3) to gather new information about me; 3) to validate my personal data; and 4) to gain their perspectives on me (Chang, 2008).

I acknowledge that my participant sample did not include the nurses or other health care providers who cared for my dad during his hospital stay. While this decision may be critiqued as a limitation, I turn to Bochner and Ellis (2016) for my defence, who talk about compassionate interviewing and intimate interviewing as methods for autoethnographic research. In these approaches they recommend interviewing participants who know the researcher best. They add that "while the goals include understanding, knowledge, and social justice, we emphasize compassion for, and protecting the well-being of our participants" (p. 183). My family and the Health Service Administrator who was a friend and colleague, knew me best. The health care providers have come to know me better through this experience; however, at the time they did not know me. When I interviewed the Health Service Administrator she had retired, therefore there was reduced risk to her in participating in my study. As well, there was a significant period of time (two years) between when these events occurred and when I recounted them in this dissertation. Within that time staff change and there are logistical issues to finding the staff that cared for my dad during this time.

4.1.2.2 Participant recruitment

Once ethics approval was obtained, I sent an Information and Consent Form attached in an email to my three siblings (Appendix C) and the one key informant (Appendix D) inviting them to participate in my study. Because my father does not consistently use email, I delivered this form (Appendix B) to him in person. This form introduced and explained the purpose and

methods of the study. I appreciate that this process is not consistent with third party recruitment and could be considered coercive. Therefore, a statement was included on the consent forms that our relationship would not be altered if participants choose not to participate. All of these individuals were involved in ongoing discussions with me over the last five years about my proposed research and each of them independently expressed interest in participating prior to me deciding what form this research would take. Therefore, I believe as long as I remained transparent about the process there would have been no ethical advantage to having a third party recruit these participants. This is consistent with other researchers and writers who have engaged in autoethnographical interviewing (Chang, 2008; Poole, 2008). The potential participants had two weeks to decide if they would like to participate.

4.1.2.3 Data-gathering collection

I wrote my autoethnography using texts, including my father's medical charts (from two separate hospital admissions), notes (my journals), memory, emails, and information from interviews. Incorporating texts such as nursing notes and email correspondence is useful to address criticisms that autoethnography focuses excessively on self in isolation from others, and relies exclusively on personal memory and recollection as a data source. This method also works to add to the "thick description" (Denzin & Lincoln, 2005; Goodall, 2001) of a culture, where the purpose of this description is to help facilitate understanding of a culture for insiders and outsiders and self and other. From a Foucauldian poststructural perspective, it also showcases how power produces knowledge in particular kinds of ways.

I have access to information from my father's two admissions to an acute care hospital (July 12, 2013 and June 14, 2016), including my story (autoethnography) and his medical charts. With his written permission and following the appropriate IH policy—Access to Personal Health

Records through Freedom of Information and Protection of Privacy (Appendix E and F), and legal processes (Appendix G), I have the data from his medical charts.

4.1.2.3.1 Interviews

Once ethics approval and consent was obtained, I conducted individual interviews with the participants. Interviews are not commonly associated with autoethnography because this research methodology focuses primarily on one's own life. However, they are still useful, as explained by Adams et al. (2015):

> Interviews are a way to connect our personal experiences, epiphanies, and intuitions to those of others. Sometimes these connections confirm our experiences; other times, interview conversations contradict or conflict with our experiences. In both instances, the insights we acquire from talking with and listening to others can deepen and complicate our own stories. (p. 55)

The interviews were digitally recorded and used semi-structured questions:

1. What did you see as risks to you/our dad/my dad when you/he was in the hospital? (How did they perceive risk in this situation—the same/different than me—and if different, how was it different?)

2. What are your thoughts about risk within the context of me caring for you/our dad/my dad as a double-duty caregiver? How do you perceive risk in this situation (Is it the same? How is it different as/than me?)? Did you see any risks to me?

3. What are your thoughts about the roles I performed/continue to perform caring for you/our dad/my dad and did you see any risk in my performing these roles? For example, did you see me as an insider, outsider or both?

Subquestions:

    a) Do you think I exploited/am exploiting my relationship with you/our dad/my dad? I want to ask this question directly because it is a question I wrestle with, and one that Ellis (1996) talked about as a loving daughter trying to take care of her mother and how they were both vulnerable: her mother was vulnerable in Ellis' descriptions and revelations about her and her illness, and Ellis was vulnerable as well in that she risked harming her relationship with her mother and how others (readers) would view her.

    b) What do you think about the decisions/choices I made about your/our father's/my father's care?

    c) Did/Do you feel/believe you could/can challenge me about the decisions I made?

While each technique has advantages and disadvantages, I used a semi-structured interview approach rather than open-ended questions. Because autoethnography focuses primarily on one's own life, and interviews are usually used to draw out life experiences from other people, I chose semi-structured interviews to keep the discussions on track. Also, the risk literature has documented difficulties in the lay public understanding the concept of risk (Rush, Kjorven & Hole, 2014). For this reason I anticipated my family would not be familiar with the term in the same way that health care providers are.

Rather than recruit a third party to administer the interviews I chose to conduct them myself. My reason for this was because I believed my family would be more open with me about my behavior than with someone they didn't know. On the other hand, Chang (2008) explains that:

Familiarity with interviewees can be both blessing and bliss. Established rapport and the

interviewees' knowledge of you help you get to the core of business quickly and more

deeply. At the same time, when the topic is about you, your presence may inhibit honest

exchanges during interview sessions. (p. 106)

Choice of data collection including interview formats and question types, and

presentation and analysis of this type of data should always reflect the goals of the research.

Like Cheek (2000), from a poststructural perspective I challenge that there is a "'right' way to

produce particular genres of work" (p. 41). "The methods of representation…are themselves

embedded inside a standpoint of power and authority" (De Montigny, 1995, p. 213). I believe

my choice to use semi-structured interviews that I conducted myself reveals more about myself,

reflecting where I stood, or where I positioned myself: as 'the' expert on risk for older adults

who are hospitalized. My participation in research projects that studied risks of hospitalization

on older adults and publication of articles that disseminated this knowledge (Baumbush, Leblanc,

Shaw & Kjorven, 2015) conferred expert status and further separated my perspectives of risk

from my siblings and my dad's perspectives. Not only was my perspective more academic than

theirs, risk was on my radar differently because of my clinical professional role. This also

reflects the glaring gap between research, practice, academia and laypeople.

4.1.3 Ethics and political considerations

Application for ethics approval was submitted to the University of British Columbia

Behavioural Ethics Board and involved the Interior Health Research Ethics Board through a

harmonized review process. I worked under the supervision of Kathy Rush, University of British

Columbia Okanagan. I adhered to the Canadian Nurses Association Code of Ethics and the

College of Registered Nurses of British Columbia Standards of Practice.

Prior to asking participants to sign the consent form, I asked if they had read the *Information and Consent Form* and if they had any questions. Consenting participants were provided with a copy of this form. This form outlines the background, purpose, procedure, benefits, and risks of the study. As well, it confirms voluntary participation. It is important to note that because of the nature of this study, it was not possible to maintain confidentiality of the participants; this was noted on the consent form. I will not reveal their identities; however, people who know us will be able to identify them. The consent form also explained possible future uses of data and dissemination of results.

Written material from the study (including the participant interviews) were kept in a locked filing cabinet in my home office. I attached a number to each of the participants and I did not use their name on any of the data. Only my supervisor, my doctoral committee, and I have access to the data. My study falls under minimal risk to study participants. Minimal risk is defined as "those risks that would be encountered in normal, everyday life" (Interior Health Research Ethics Office, 2008).

4.1.4 Data analysis and interpretation

In an autoethnographic study, moving to data analysis and interpretation does not mean abandoning data collection because data collection is likely to continue along this step to fill gaps and enrich certain components of data (Chang, 2008). Autoethnographic data analysis and interpretation involved shifting my attention back and forth between self and others, the personal and the social/cultural context. The terms are often used together; however, Chang (2008) separates them, where "data analysis urges you to stay close to the data and 'work on' them, [while] data interpretation focuses on finding cultural meanings beyond the data" (p. 127). Data analysis and interpretation cannot be separated from the writing and "are quintessential to

autoethnography because this process transforms bits of autobiographical data into a culturally meaningful and sensible text" (Chang, 2008, p. 126). Instead of merely describing what happened, I explained how the data (memories, texts) were strung together to explain my cultural tenets and relationship with others in my story.

I began by writing my story from my notes, my memory, and emails/written correspondence from that time/experience. Once I had completed this first draft of my autoethnography, I conducted interviews with the other participants. I personally transcribed the interviews verbatim to become further immersed in the data. I formatted the transcripts of the interviews onto landscape format 11 X 17-inch paper, numbered each line, and set a three-inch margin on the left side and a six-inch margin on the right side. I then divided the six-inch margin into three columns to represent analytic readings on this data based on the data analysis and interpretative process described by Hole (2007) and Chang (2008) and adapted for this study. A visual of this is included as Appendix H. The first reading read for content and served as a checking process to ensure that the transcription best reflected the participant interview. The second reading analyzed the subject positions that I take up and perform; this analysis was recorded in column one. The third reading analyzed relationships between self and others (for example how others position me); this analysis was recorded in column two. The fourth reading searched for recurring and dominant discourses of risk within the data, including the cultural contexts in which those discourses are situated, how the discourses are at work in multiple layers, and how they both enable and constrain the production of knowledge in that they allow for certain ways of thinking about reality while excluding others; this analysis was recorded in column three. I assigned different coloured pens to each reading.

As I read through the transcribed interviews I wrote notes to myself in the margins on the left-hand side of the formatted sheets. I completed multiple readings on each participant. The initial readings were relatively basic and stayed close to the language used by participants. When each reading of each participant was complete I transferred recurring themes from the data onto larger flip-chart paper. I compiled the analysis of the reading for each participant onto two pieces of flip-chart paper; one reflected how I am positioned, the other reflected the risk discourses identified in the participants' narratives.

I used a similar process to analyze my father's medical charts. The difference is that rather than using columns, I began recording the analysis from the medical records on flip-charts. The first reading read for content and served as a checking process for my memory of the experience. The second reading analyzed the subject positions that I take up and perform; this analysis was recorded on the first flip-chart. The third reading analyzed relationships between self and others (for example how others position me); this analysis was recorded on the second flip-chart. The fourth reading searched for recurring and dominant discourses of risk within the data, including the cultural contexts in which those discourses are situated, how the discourses are at work in multiple layers, how they both enable and constrain the production of knowledge in that they allow for certain ways of thinking about reality while excluding others; this analysis was recorded on the third flip chart. Again, I assigned different coloured pens to each reading. I then incorporated this analysis into my first draft autoethnography and conducted a fifth reading of the result.

4.1.5 Presentation of findings

I believe it is important to note that I was not entirely sure in the beginning how I would present my findings, other than I planned to create/write an autoethnography. I considered a

multi-vocal text with the findings from the discourse analysis interspersed within the text of the autoethnography, similar to Moneypenny (2013) who produced a poststructural autoethnography for her Master's thesis. Moneypenny troubled the binaries of discourses using letters, personal photographs, poetry, stories and an interview with herself to facilitate critical reflexivity and movement towards subjectivation" (p. 48).

4.1.6 Legitimation of findings

Topics of legitimacy and validity become problematic from a poststructural lens because of the connection the topics have to the positivist paradigm (Hole, 2004). I propose a concept of *Reflexive Validity*. Cheek (2004) explains:

> Postmodern thought is enabling in that it encourages us to think about reality in a
> reflexive way. Such reflexivity unmasks "complex political/ideological agendas hidden
> in our writing [and practice]. Truth claims are less easily validated now; desires to speak
> 'for' others are suspect" (Richardson, 1994, p. 523). Thus, as much as postmodern
> thought is "undetermined" it is also "undetermining" in that it serves to "weaken…the
> constraining impact of the past and effectively prevent…colonization of the future"
> (Bauman, 1992, p. 190). (p. 20)

This issue of legitimacy in poststructural research has been identified by many (Cheek, 2004; Cheek & Porter, 1997; Denzin & Lincoln, 2005; Hole, 2006; Lather, 1993); however, "a postmodern, poststructural consciousness does not release social scientists [including nurses] from confronting validity" (Hole, 2006, p. 55). Cheek's recent work (Cheek 2011; Morse & Cheek 2014; Morse & Cheek 2015) uncovers the continuing navigation of qualitative researchers to position themselves, their research, their careers and qualitative inquiry within the politics of what counts for evidence. "As Denzin (2009, p.142) drawing on Morse (2006), points out, it "is

not about evidence or no evidence". Instead, it is about what counts as evidence and who can say that it counts" (p. 697). Bochner (2001) suggests that autoethnography has been questioned because it challenges the privileged position of orthodox, analytical social science. It has been criticised for being unscientific, biased, not generalizable and lacking in methods to ensure rigour (Peterson, 2014). Autoethnographers have responded that "rigour can be improved by appending transcripts, leaving an audit trail and providing adequate descriptions of the original context to facilitate judgements regarding transferability" (Peterson, 2014, p. 230).

Cheek (2011) calls for qualitative researchers to stop reacting to the politics of evidence and use their "time and energy to try to make a difference to the lives of the participants in [their] research, or the participants in the health care systems where [they] research" (p. 698). She calls on qualitative researchers to open up and move into different spaces from which to conduct, think and write about research while remaining relevant to the world of health care practice. By relevant she means:

> doing research that makes a difference to that world and those who live and work in it…[in the] hope that undertaking this exploration may help us to work, research, practice, co-exist and thrive in a practice-based and evidence-based world of health care and health care delivery. (p. 700).

 It was a desire to be relevant that drew me to autoethnography. While other research methods require researchers to "hide behind a veil of objectivity" (Peterson, 2014, p. 231) autoethnography offers the opportunity to study aspects of human behavior that others may not have the opportunity to observe, whether that be due to stigma, fear, guilt, limited self-awareness, position or power differentials. "By making the private public, there is an

opportunity to enhance the lives of others as well as the self (Foster et al. 2006), expand

consciousness (Grant, 2010) and create therapeutic value (Ellis, 1999)" (Peterson, 2014, p. 231).

I used criteria for evaluating both an analytical and evocative autoethnography; I believe

this fits within a poststructural perspective that informs my autoethnography. From this

analytical perspective I followed the following goals for evaluating autoethnographies (as

outlined by Adams et al., 2015):

1. Making contributions to knowledge; have pragmatic value

2. Valuing the personal and experiential

3. Demonstrating the power, craft, and responsibilities of stories and storytelling

4. Taking a relationally responsible approach to research and representation

5. Creating evocation through narrative writing

6. Demonstrating verisimilitude

Postmodern/poststructural thought emphasizes that reality is plural and there are multiple

positions from which it is possible to view any aspect of reality (Cheek, 2003). In addition,

theorists drawing on postmodern/poststructural ideas argue that "every knowledge is

contextualized by its historical and cultural nature" (Agger, 1991, p. 117). Therefore, the

researcher is situated in the act and process of research attempting to "produce a likeness or

similitude to the truth, as close as possible" (Hole, 2006, p. 55). Once data was analyzed and

preliminary findings documented, I scheduled a one-hour follow up interview to engage in

member-checking with my participants, after which I revised my autoethnography as needed.

"Pragmatic value refers to the usefulness of the findings" (Hole, 2006, p. 56). As a

clinical nurse specialist who is performing the double-duty, nurse/daughter caregiver role, there

is value in adding to the body of nursing knowledge around this topic and in revealing the

discourses that guide our practice. I believe I am in a position of privilege within the

organization where I work. When I share my story of my experience, I often hear other nurses'

similar experiences. Yet, most often these nurses were unable to address the issues and influence

change in practice because of perceived lack of power and control and fear of repercussions to

their older adult relative or to themselves. In other words, although not explicitly stated in their

conversations to me, they were influenced by discourses of risk. By sharing my story and

unveiling the potential power of patients and families within a context of relational practice, I

believe I am able to create possibilities for change. I plan to disseminate this knowledge in

seminars and workshops that focus not only on the risk, but also the historical and contextual

practice of nursing. I also plan to publish my findings. This where the evaluation of evocation

will continue. As I disseminate my findings and analysis in presentations, I will distribute an

evaluation tool that questions whether the research evoked a response in participants. I will also

include my contact information on publications, with an invitation to readers to contact me if the

article evoked a response in them.

4.2   Chapter Summary

In this chapter, I presented my methodology and methods of research. I provided a

description and justification of the proposed data collection methods, data analysis and

interpretation process, justification of findings, and ethical considerations. I also outlined how I

intend to disseminate the findings from this research, beginning by sharing these findings as an

autoethnography.

Chapter Five: Findings

This chapter presents a discussion of the findings of my study related to the research questions which were as follows:

- How has the culture of risk contributed to my experience of double-duty caregiving?

- What are the discourses that produced this culture and how are these discourses at work to produce subject positions (for example: insider/outsider, expert) that are either available or unavailable to me?

- What does it mean to perform multiple aspects of identities simultaneously and how taking up and performing multiple and mobile subjectivitieswas manifested within interactions with others?

- How can I invite readers and audiences to use my story and experiences for their own sense-making?

I have divided this chapter into two parts. Part one presents findings from my research woven into my autoethnography. The findings are not presented in traditional research processes and I lean on leading writers, teachers, and scholars of autoethnographical research (Bochner & Ellis, 2016; Denzin, 1997; Ellis, 1995; Ellis, Adams, & Bochner, 2011) for my defence. Bochner and Ellis (2016), originators of the method, described how autoethnographers tend to "resist the temptation to surrender to orthodox conventions of social science writing…and extend the borders of legitimate scholarship to matters of practical, moral, aesthetic and emotional importance to human well-being" (p. 80) in order to evoke feeling and induce readers to personally connect with the story we are telling. Following their direction, my writing is not an activity that stands apart from the rest of the research process.

The process I used is what Bochner and Ellis (2016) describe as "systematic sociological introspection" (p. 67), which means actively recalling thoughts and feelings from a social standpoint. In recalling these thoughts and feelings, I used various artifacts: data from my father's charts, conversations from interviews with research participants, emails, and memory. Ellis (2009) illustrates how autoethnography requires willingness on the author's part to become vulnerable and give up a certain amount of personal safety "in order to achieve a new understanding of reality, self and truth" (Peterson, 2015, p. 228).

As a reader, you will not find the 'truth' within this writing: my autoethnography. Rather than a binary of truth/untruth, poststructural approaches unveil multiple and partial truths. My purpose for using these approaches is to produce verisimilitude as I invite you, the reader, to use my story and experiences for your own sense-making, keeping in mind that "autoethnography is not about focusing on self alone, but about searching for understanding of others (culture/society) through self" (Chang, 2008, p. 48-49).

Part two of this chapter presents a discussion of discourses at work within the data (autoethnography and artifacts) and an analysis of how these discourses were at play, both informing and being informed by the culture of risk. This analysis includes 1) how the culture of risk within my workplace contributed to my experience of double-duty caregiving; 2) identification of discourses that produced this culture and how these discourses were at work to produce subject positions that were either available or unavailable to me; and 3) a discussion of what it means to perform multiple aspects of identities simultaneously and how taking up and performing multiple and mobile subjectivities was manifested within interactions with others. This analysis draws on poststructural thought to trouble and expose taken-for-granted discourses that "both enable and constrain the production of knowledge, in that they allow for certain ways

of thinking about reality while excluding others" (Cheek, 2004, p. 1142). Applying a poststructural Foucauldian/Butlerian critical discourse analytic lens, I focus my discussion on the prominent discourses of risk at work in the autoethnography. Other discourses, which move within and between these dominant discourses, are offered as they relate to the research questions.

5.1   Part One: I Have a Story to Tell You

A thought to enter in:

Where to start is the problem, because nothing begins when it begins and nothing's over when it's over, and everything needs a preface: a preface, a postscript, a chart of simultaneous events. History is a construct…any point of entry is possible and all choices are arbitrary. Still, there are definitive moments, moments we use as references, because they break our sense of continuity, they change the direction of time. We can look at these events and we can say that after them things were never the same again. They provide beginnings for us, and endings too. Births and deaths, for instance, and marriages. And wars.

Margaret Atwood, *The Robber Bride*

An arbitrary choice then: my definitive moment. After attempting unsuccessfully to manage what I perceived as lack of appropriate care for my dad who was admitted to an acute care hospital, I was left feeling frustrated and angry. I understood the power I had to exercise control within the health system. I used that power to send this message from my work email to the health services administrator of the hospital where my dad was receiving postoperative care:

Hi Noreen[2],

I have a story to tell you about my dad's care on XX at XXX. Yesterday afternoon my brother arrived from Vancouver to XXX and found my father completely delirious. He phoned me and put my father on the phone. The phone went to voice message and my father left his "message". He was slurring his words, he thought he was talking to my aunt, he thought my brother (his son) was my cousin (who is in Sweden); he told me he had just escaped a fire in Slave Lake. My brother called my sister and my father told her he had been held up in the parking lot at knife-point.

This is not the way we left my father on Sunday. As you may know, I was reluctant to leave my father and I had concerns about his care in acute care. These concerns included a physiotherapist telling my father in my presence (in the context of "teaching" my father to communicate with staff about his pain), "It's OK to complain Bob. Just don't complain too much, otherwise you will be blacklisted" followed by a chuckle. This was after I noticed my father holding his breath as he tried to mobilize for the first time postoperatively. When I asked the nurse what he had been given for pain that day, she answered, "He hasn't had anything. He isn't in any pain. He said he only has pain when he moves." When I told her he was moving now (as if it was not obvious) and asked her to bring something for him, she stated, "Well I didn't know he was getting up – the physiotherapist didn't tell me. I will get him something but I need to finish what I am doing." Later, when I tried to explain to this nurse (and the RN in charge) about "My dad" and what I know about his experience with pain, I was silenced (with a stop hand signal) and given teaching that "some people do not feel pain the way others do." I

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[2] All identifiers of persons not already published in media have been replaced with pseudonyms with the exception of my own and Belinda Parke, whose name was used with her permission.

felt scolded; I also received a clear message that the staff were not interested in learning from me about who my dad is as a person.

Perhaps you can imagine my anger and frustration as I listened to my father and my brother's bewilderment as to what was happening yesterday afternoon. I asked to speak to my father's nurse. When she came to the phone, she began to explain to me that this was "her first day with my father and she didn't know him very well." This was close to 1700. She did not know what the CAM [Confusion Assessment Method] was or how to complete it.

You may be aware of another incident in Fraser Health a number of years ago. This incident spurred many of the changes to care of older adults in Fraser, Providence, Vancouver Coastal, and Vancouver Island Health Authorities. If you are not familiar with this story, here is the website: http://esthersvoice.com/

The outcome for Esther and her family was not a good one. I am committed to making certain this outcome is not the same for my father. Last week I spoke to Belinda Parke (leading researcher on Elder Friendly environments and care of older adults in acute care, also a CNS like me) about my experience and how I was trying my best not to become a "raging lunatic" trying to advocate for my father. She told me that she believes there is a time to become a Raging Lunatic. My family has tried to be patient, and I believe they have trusted me to manage these ongoing issues, based on my expertise and my relationships with leaders in the organization. They are not so patient anymore, and I am truly disappointed to say I do not trust the system and I feel vulnerable advocating for my father.

Noreen I respect you and I trust you – which is why I am coming to you first.

I will be leaving within the next hour to drive to XXX.

Mary

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It is NEVER "just your age"!

Figure 1. Email Letter

And then everything changed. I can't say that I was a skilled strategist and outlined a

plan of action to execute. Rather, acting from a position of frustration and emotion, I gathered

my arsenal of weapons: knowledge, evidence, and relationships and deployed them all at once. I

used my social standpoint and all of the power attached to it to address what I perceived as poor

care for my dad at the point of care in the hospital. I copied the email to the patient care

coordinator and the manager of the care unit where my dad was staying in the hospital, both who

reported to Noreen. Was that fair? Probably not. At the time, I was willing to do whatever it

took to keep my dad safe, regardless of what was/is considered fair or appropriate.

5.1.1 My social standpoint

I am proud to be a registered nurse. I am privileged to be included in the group of

individuals who have the right to call themselves nurses. In declaring my pride I acknowledge

that nursing is replete with discourses of class. To begin with, in Canada, 'nurse' is a protected

title supported by provincial legislation (British Columbia Ministry of Health, 2019). Licensed

practical nurses, nurse practitioners, registered nurses and registered psychiatric nurses who are

registered with their provincial regulatory body are permitted to use the title. Other members of

what I will call 'the nursing family': care aides, home support workers, and personal care assistants are not. These titles reflect binaries and categories of power; they are not neutral.

The titles within nursing language: "advanced/specialist" versus "practical", "registered" versus "licensed" further support this hierarchical structure. Advanced practice nurses (APNs) like me are positioned as experts in clinical practice and leaders in nursing; they require postgraduate preparation and advanced knowledge and skills in their area of practice. For example, as a CNS in gerontology, I require (at least) a masters' degree as well as certification(s) in gerontology, to represent my expertise. Nurses with doctoral degrees are rare within hospital settings, so classed as a doctoral candidate I receive greater status.

Another one of my recent roles has been a member of the board of directors for the College of Registered Nurses of British Columbia (CRNBC). I held the role of board chair for this college for four of the six years I served on that board.[3] The legal obligations of a nursing regulatory college are to protect the public through the regulation of nurses, set standards of practice, assess nursing education programs in B.C. and, address complaints about nursing registrants. Every individual using the title "Registered Nurse", "Registered Psychiatric Nurse" and/or "Licensed Practical Nurse" within British Columbia must be registered with the regulatory college.

The reason I am mentioning these specific roles is because they are positions of power, and therefore, set me apart from nurses working on the front lines. For example, when one nurse heard I was the board chair for CRNBC, she stated, "Oh, you're the nursing police."

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[3] Until recently, CRNBC was the regulatory body for Registered Nurses and responsible for regulation and governance of all Registered Nurses within British Columbia (B.C.). In September 2018, the three nursing colleges (College of Registered Nurses, College of Registered Psychiatric Nurses, and College of Licensed Practical Nurses) amalgamated to form the British Columbia College of Nursing Professionals (BCCNP), which serves the same function as CRNBC did in the past. I have been appointed to the governance committee for the new board.

At one point Noreen asked me to reflect on why I was doing my PhD. I responded with the usual explanation: that I believe this work will cast a light on system deficits that impact patient- and family-centred care and double-duty caregiving and will ultimately help to improve care of older adults. She wasn't satisfied. "Yes, I understand that," she responded. "But I would like you to think deeper about why you are pursuing your PhD to do that." It took me a while to unpack it and where I ended up was that I had chosen to complete my PhD because it provided me an opportunity to use power differently. In a system where older adults and, by association, those who care for them, remain unvalued, I knew that a doctorate would provide me another way to use power to impact this system.

Depending how this power is used, it can create adversarial relationships perhaps even wars. I acknowledge that the metaphor of war comes from a position of white privilege. I also acknowledge that it is contradictory to poststructural thinking. War means that likely one party will win and the other will lose. Winning was all I wanted at the time.

5.1.2   How the war started

Another busy day of work. Busy. Such a meaningless word now. Overused and irrelevant, the word annoys me even though I still think it, say it and use it. After dinner with a friend, I arrived home and eventually notice the red flashing light on my answering machine.

The message is from the manager of the supportive housing facility where my dad lived. "Hi Mary, it's Denise. Your dad had a fall this morning. He was reluctant, but we convinced him to go to the hospital." In my head I can hear him: "No, no, I am fine. It's not serious. No, I don't think you need to call Mary. She's so busy." Denise continues: "They discharged him back this evening. They said it is a soft tissue injury. We have set up a wheelchair and urinal at his bedside." I look at the glass of wine in my hand. One glass with dinner and now another. I

can't drive; I am impaired. <u>Or am I?</u> I call my dad; I am a good daughter. <u>Or am I?</u> What I am

at the moment is tired, frustrated, worried, and feeling guilty. I am an Advanced Practice Nurse:

a Clinical Nurse Specialist in Gerontology. I know the risks and I know my dad.

I wake early the next morning and drive the 80 kilometres from my town to where my dad

lives. I take the elevator up to his floor, open the door to his apartment (he never locks it), and

call out: "Good morning, Dad." No answer. The wheelchair, his cane, and his walker are in

his bedroom; he is not. Not good. I go downstairs to the front desk where Denise intercepts me.

"Mary I am so sorry. We tried to reach you this morning, but you must have already left. The

care aide who went in to help your dad get up this morning felt he was doing poorly and thought

he should go back to the hospital. We just received a call that the radiologist looked at the x-ray

and confirmed his hip is broken."

They made a mistake. Mistakes happen and will continue to happen, despite all of our

quality improvement measures. I've made some myself and some of those have affected my

patients. Questions swirl around in my head: biomedical/scientific questions, political questions,

emotional questions. Answers are there too. I produce them, reproduce them, and insert them

for my own sense-making and for my own use as I drive to the hospital. I let myself into the

Emergency Department (ED). Other family members would need to gain permission from the

admission clerk; I have my security pass. I am an Insider. <u>Or am I?</u>

I find my dad easily enough. I know how the ED is organized. No one questions me; no

one greets me or introduces themself to me. Dad and I chat for a few minutes. He answers my

questions. He knows his hip is broken and tells me that the doctor (I am assuming the ED

doctor) told him he needs to have surgery. He knows he is not to eat or drink. I wait. I feel

invisible. Finally, I walk to the nursing station and extend my hand to the person sitting at the

desk. "Hello, my name is Mary. I am Bill Moser's daughter. I have some questions about why

and how my dad was discharged yesterday with a broken hip." I am a nurse. These should be

'my people'/'my tribe'[4]. But they are not. Now we are adversaries.

5.1.3   Subject positions: Aggressor vs pacifist

Looking back on this conversation I acknowledge that these are highly inflammatory

questions, and it is not surprising that they evoked a defensive response—I was demanding that

the staff in the ED explain themselves. As in most cases, the most visible staff in the ED were

the nurses. By taking up the position of aggressor, I created the adversarial relationship:

positioning the nurses as my adversaries without even having met them. I was determined not to

be a passive family member. Instead, I took up the position of aggressor and I continued to hold

nurses responsible for the mistakes in my dad's care.

5.1.4   Peace offering

Later that day as I wait for my dad to be called for surgery, a woman approaches me in the

hallway. She speaks softly as if she does not want to be overheard. "Mary, [she knows my

name!] I was with your dad for part of my shift yesterday. We weren't comfortable sending him

home. We knew he would be a 'Bounce Back'." Then she is called away; she is busy. I noticed

on her name tag that her name is 'Brenda' and she is a registered nurse. I feel better and more

troubled at the same time. I feel better because I finally feel connected to someone in this place,

and that person has given me some meaningful information. However, I am left troubled with

more questions. Why? If the nurses knew he would be readmitted, why were they not able to

intervene? How did my dad become a 'Bounce Back'? I feel she has given me clandestine

---

[4] 'Tribe' in this sense refers to Logan, King, and Fischer-Wright's (2008) definition of tribe in their book Tribal Leadership, where tribe is defined as: 1) any group of people between 20 and 150 who know each other enough that, if they saw each other walking down the street, would stop and say hello; 2) people who are likely to be listed as contacts in your cell phone and in your e-mail address book. A small company is a tribe and a large company is a tribe of tribes.

information, and she did not feel entirely safe doing so.

5.1.5   Subject position: Informant

By taking up the subject position of aggressor I also forced the nurses into subject positions. The only subjectivity that was available to this nurse was that of informant. The 'we' that she is referring to is the other nurses, her colleagues who were working side-by-side with her, in 'the trenches' as nurses often refer to their work on the front lines. It could be interpreted that by providing this information to me she was crossing enemy lines and that becoming a collaborator was not a safe choice for her.

5.1.6   Subject positions: Allies

Finally, my dad is called for surgery. I accompany him and I am greeted by the anesthesiologist who is joined by the surgeon. We introduce ourselves. They speak directly to my dad and they include me in the conversation. I tell them about his history of postoperative delirium and they listen. They agree with my recommendation not to insert an indwelling urinary catheter based on best evidence. I feel respected and valued—this is patient- and family-centred care! They are competent and compassionate and I believe they are on my side. As they wheel my dad away on the operating room stretcher, I am relieved. He is in good hands. I trust them. They've got this.

The feelings I experienced that day are validated and reinforced when I read the anesthetist's documentation in my dad's chart (Figure 2). The anesthesia report is succinct, objective, thorough, and accurate, including the reference to "all questions were answered."

This pleasant 83-year-old gentleman was seen in the Preoperative Hold Area at the request of Dr. ███████

He is booked for a right hip fracture and percutaneous pinning.

Mr. ███████ is an ASA Class 4 patient, 4E.

PROBLEM LIST
1. Right fractured hip requiring percutaneous pinning for stabilization and pain control.
2. COPD.
3. Coronary artery disease. History of an MI 13 years ago.
4. Hypertension.
5. Prostate CA with metastatic lung disease as well.

LABORATORY INVESTIGATIONS
Hemoglobin is 138, platelets 229, sodium 140, chloride 100, potassium 4, bicarbonate 25, creatinine 66, glucometer 9.4. INR 1, PTT 30. O-positive blood typing. He has a sinus rhythm with a first-degree block and a ventricular conduction delay and some PVCs. Denies reflux regularly, is NPO appropriately, does not smoke, never has but he does have longstanding COPD and childhood pneumonias.

MEDICATIONS
Amlodipine, domperidone, ASA, bisoprolol, valsartan.

ALLERGIES
He has no allergies to medications.

He has had multiple anesthetics in the past including spinals and general anesthetics. We discussed spinal anaesthesia for this procedure as well as a general.

He prefers spinal anaesthetic. His daughter was present who has concerns about postoperative delirium. This discussion has taken place, she understands and accepts that we will try minimal

medications other than sedation comfort and spinal anaesthesia primarily as the main anesthetic for his procedure for his fractured hip repair and all questions were answered. They do accept a blood transfusion should one be required in an emergency setting.

███████ MD, FRCPC

Figure 2. Anesthesia Report

The physicians and I took up subject positions of allies. References to me in this report further solidify this alliance: "His daughter was present who has concerns about postoperative delirium. This discussion has taken place. She understands and accepts that we will try minimal medications…" Another sentence references 'they' meaning Dad *and* me: "They do accept a blood transfusion should one be required in an emergency setting." I felt included.

Postoperatively, I did not have the same positive experience with the nurses as I had preoperatively with the physicians. The anesthetist's documentation in his report sharply

contrasts with the nurses' documentation in the nurses' notes after I questioned their postoperative care of my dad (Figure 3). When I spoke about this difference to a nursing colleague, she rolled her eyes and said, "Of course the physicians treated you differently. *They didn't feel threatened!*"

Figure 3. Nurses' Documentation A

The story told in the nursing notes in Figure 3 is not the way I remember it. I remember walking into my dad's hospital room and seeing him attempting to mobilize from sitting on the side of his bed to standing. There was a man with him who I later learned was the physiotherapist assigned to his patient care ward. Seeing my dad wince as he stood up, I immediately asked, "Has he had anything for pain?" The woman who was in the room, who I later learned was his nurse (LPN) replied, "No. He said he wasn't in any pain." This alarmed me. To clarify, I did not ask if he had received any <u>extra</u> pain medication, as is indicated in the nursing notes. Rather, I was inquiring if he had received any pain medication at all.

I was later told by the charge nurse that he had received extra-strength Tylenol, although I was still not clear if this was regularly scheduled. As I attempted to clarify, I felt I was being dismissed and treated like a troublemaker. Based on my clinical expertise, what I know about my dad, and best evidence for pain management for postoperative orthopedic surgery, I would have recommended and been satisfied for him to receive regularly scheduled (every four hours) extra-strength Tylenol. I did not want or request Tylenol #3 because of the side effects of this medication, particularly for older persons. These side effects include constipation and delirium, both of which he had experienced before.

As I was trying to communicate this to the LPN, I noticed another woman enter my dad's room and begin what appeared to be an investigation of the sharps disposal container on the wall. I thought her actions were a bit odd as she lingered there for quite some time. The nursing notes reflect that she was not at all interested in the sharps container. Rather, she had apparently inserted herself into the situation to protect her colleague from me. I remember feeling frustrated as I tried to give and receive accurate information to/from them.

Unlike the conversation with the physicians, my conversation with the nurses did not

leave me feeling listened to, valued, or respected. Reading the nursing documentation and the medication record from that day verified these feelings. Communication was not clear. All my questions are still not answered. For example, the data from my dad's medication record on that day indicates that one dose of extra-strength Tylenol was given, although it is not clear what time (see Appendix I) as the time is illegible. His regularly scheduled medications on that day do not include "Tylenol extra-strength QID (every four hours)" as the LPN told me Dad was on. Rather than regularly scheduled, his Tylenol orders are listed under prn (as needed) medications. The medication record for the next day includes a notation that the last dose (LD) was given at 21:30. Therefore, if the only dose listed on the previous day medication record was given at 21:30, then he did not receive a dose earlier in the day as the charge nurse told me he had. Based on the medication records he received no pain medication on that day (one day post-operative for a fractured hip repair) until the LPN gave him Tylenol #3 at 14:45 after my questions.

Unlike when I left my dad with the physicians the day before, as I left him in the care of the nurses on this day I did not feel that I was leaving him in good hands.

I don't trust them. There. I've said it, even though by saying it I feel guilty, like I am betraying my profession. I was a surgical nurse like them. I know what they know and what they don't know, and they don't know older adults. I know that because I didn't know. And they don't know my dad. They don't know that he will never complain. They don't know how proud and private he is and that he will always answer "No." when he is asked if he is in pain. They don't know that they need to look further, that they need to notice that he is holding his breath and wincing as he stands and appreciate what that means. They don't know that he has a history of delirium. They don't know delirium. They don't know that delirium is one of my specific areas of expertise. They don't know how he presents when he is entering a delirium or how to

look for the cause. I trust knowledge: specialised knowledge in gerontology and person-centred care, and I know they don't have it.

I call my brother and we set up a schedule for one of us to be with him at the hospital every day for the next week. Together we will watch over him and keep him safe. My brother will drive down tomorrow. I am fortunate. I have siblings who I trust and who trust me.

I drive back home and go back to work as a CNS. My job takes me to Vancouver for the week. As I drive there I picture my brother on this same road leaving from Vancouver and heading this way. It's like a relay: pass the baton; pass the responsibility. I think again how we move through the stages of our lives and the odd familiarities. I have passed the stage where phone calls in the middle of the night evoked fear of teenagers in distress. The calls have begun again, only now they are about my dad. I don't see this responsibility as a burden. Rather, the burden is navigating my relationship with my dad's care providers.

I finish my clinic in downtown Vancouver. I fish my phone out from my briefcase and notice the missed call from my brother. Immediately I call him back. "Hi Mary," he answers. "Hey, Dad is cuckoo. He keeps calling me Edgar and he thinks there is a dog under his bed. I left you a message." I can feel the anger rising up in me. My dad is delirious. I have spent my nursing career teaching health care providers that delirium is a medical emergency that can often be prevented and I couldn't prevent it from happening to my own dad in my own health authority. "Brent, can you find his nurse so that I can speak with her please?" My voice is calm. Dangerously calm. It masks that I am about to lose my mind.

His nurse comes to the phone and stumbles a bit in the beginning of our conversation. I ask her for her name; she tells me and adds that she is a new graduate nurse. She doesn't know what the Confusion Assessment Method (CAM) is or that it is the tool we use to prevent, assess,

and intervene for delirium. I repeat to her what I have already told at least three of his other

nurses: that he presents with delirium from urinary retention, which then often leads to a urinary

tract infection. An indwelling urinary catheter is not the solution; he needs regular toileting and

post void residuals. If he is retaining more than 300 mls he needs in-and-out catheterizations for

a few days to retrain his bladder.

She listens. She is the first nurse who I feel has listened to me. When I am finished she

assures me she will monitor him closely. "Mary I am sorry. This is my first day with him. Yes, I

will find someone to help me do the CAM and I will monitor him closely. I will be here when you

come tomorrow." She is unlike the nurses I describe in my email to Noreen who I believed made

excuses and tried to silence me:

> "Well I didn't know he was getting up—the physiotherapist didn't tell me. I will get him
>
> something, but I need to finish what I am doing." Later, when I tried to explain to this
>
> nurse (and the RN in charge) about "my dad" and what I know about his experience with
>
> pain, I was silenced (with a stop hand signal) and given teaching that "some people do
>
> not feel pain the way others do." I felt scolded; I also received a clear message that the
>
> staff were not interested in learning from me about who my dad is as a person. (Figure 1).

In contrast the new graduate new isn't defensive. She doesn't try to "teach" me or "set me

straight." She doesn't push me away. She draws me in. She calls me by my name. She doesn't

have all the knowledge but she has something else: compassion. I trust her. She is caring for us

both.

Yet, it is not enough. Although I trust her, I don't trust the system that cares for him, and I

am not going to take that risk. I will take other risks though: I declare war. I send the email

and things change.

You have to run risks. There are no certainties in war. There is a precipice on either side of you -

a precipice of caution and a precipice of over-daring.

Winston Churchill (1952). "War Speeches: From September 11, 1943 to August 16, 1945"

5.1.7   How others remember me: Responses from my participants

This section presents the responses from my research participants: Noreen, who at the

time was the health service administrator of the hospital where my dad received care; my

brothers Brent and Jason; my sister Megan; and my dad. Their names have been changed in an

effort to address confidentiality. The responses are presented in five vignettes, representing the

conversations from the interviews. All of my participants are white and all have post-secondary

education. Other than my dad, who is widowed, all of my other participants are married. With

the exception of Jason, who has experience as a volunteer firefighter, none of my other family

members have a background in health care. My interviews with my dad and my siblings were

short (15 and 16 minutes for my brothers, 20 minutes for my dad, and 25 minutes for my sister)

compared to my interview with the Health Service Administrator, Noreen, which lasted over one

hour.

5.1.7.1 Five vignettes

The interviews with participants are presented as conversations with me as they respond

to the research questions. Presenting data in this way is congruent with how many

autoethnographers write in conversational styles (Bochner & Ellis, 2016; Ellis, 1995; 2016;

Laurendeau, 2011).

5.1.7.2 Health Service Administrator: Noreen

Noreen is a colleague. We are master's prepared nurses and we are recognized throughout the organization as nursing leaders. Noreen was the health service administrator of the hospital where I worked as a staff nurse and nursing educator before I moved into my regional CNS role. As a nurse moving through the trajectory of novice to expert I made mistakes. She, my manager, and other expert nurses supported me through those mistakes. At the time of my dad's hospitalization she had moved to become the health services administrator of another hospital in my region where he lives and receives care. Noreen retired shortly after my dad was discharged postoperatively from this hospital, although she continues to mentor and support me through my career. As a result, we have a close professional relationship. I consider her one of the members of my tribe.

Noreen: I guess one of my questions going into this process is: Do you believe, in your research and in your experience, that all nurses are thinking about risk at the same level that 'we'— you and I and our cohort— would be thinking about risk?

Me: No.

Noreen: Yes. I agree. The way I see it there was a lot of risk for your dad in his initial visit to the emergency room around missing the original injury or break. From a cultural perspective it's the risk around the older adult and what else is going on in the emergency department at the time. It's a risk around skill level, so when I received your initial note there were all these things that went through my head. And I was sad and distressed that this was happening to you with your father, as I would be with any person with their parent. I kept asking, "Did we miss something?" Because initially we did in the end. And I wonder what else we missed. And that was a judgement from my end, but I'm thinking: were the nurses not

paying attention, or what was it, what was the culture like, what was the environment like on that particular day? Were they just not interested? What was it?

I think to a certain extent that there are inherent risks for any person using our health care system. And I hate to say it but one of the risks is being an elderly person.

You might have to sift through this because I am relying a lot on my memory.

Me: That's okay. Memory is a legitimate component of autoethnographical data.

Noreen: That's interesting because memory is how we shape our perception, and how we live in the world is shaped by our perception…versus the pure data or the quantitative side of things.

Me: What are your thoughts about risk within the context of me caring for Dad as a double-duty caregiver? The way I have defined 'double-duty caregiver' is in the broad sense: providing care for family members while also providing care within my personal nursing role.

Noreen: Double-duty caregiving is very difficult. And I think as nurses, it is even harder, speaking from my experience with my father. Your family will look to you for answers and as an expert. Certainly my experience with my dad was not yours, but they will be asking questions like: "So, you're the nurse. What do you think?" I don't think it increases the risk for your dad because your dad had a very strong advocate. However your exceptional advocacy for your father may have presented some risks in terms of…I hate to use this label, but we have talked about it…the Crazy Daughter.

It may set up the person who is unwell to be…targeted? That's not the right word…

Me: Would [the right word] be stigmatized?

Noreen: Yes! It might create a situation where your dad…I'm not condoning anyone's behaviour but in the current environment it's just that sometimes things are too hard, and there isn't enough time…and now I've got a crazy daughter looking over my shoulder…

Me: …making me nervous. Like, "I'll never be able to please her."

Noreen: Right. And I think that does set up some risk for your dad because then it's like, what's the easy route out? I just won't go see him enough times a day. And when I was thinking more about this, it's like, how sad is that? That we've set that culture up. I don't want to say that we have set it up that that's okay, but as a human nature kind of thing…

Me: It's fear too.

Noreen: Oh, it's absolutely fear. So, I think that for you, it put you at risk as well because you are the expert in this field. Like, we had no other expert in the health authority that comes with the same level of expertise as you. And now you're a caregiver and adversarial relationship or not, that is very scary. That's possibly perceived as threatening, whether you intend that or not. And I know you didn't.

It's like, "Oh my goodness, now I have to look at absolutely everything I'm doing because now I've got someone looking over my shoulder." So, before you even meet the team it will change their response to you.

Even the part about how you were able to access the emergency department. You were able to get into the "inner sanctum" because you had access. It's like, I've got my [security] card that will give me access. I don't have to wait for somebody to press me in. I've done the same thing. When my mother-in-law had a cardiac event in [name of town] and was transported to [name of another town where Noreen worked as a hospital administrator] while I was working there. I went directly into the emergency department to find her. And boy did that ever make

everybody nervous. Really, really nervous. I think the person who initially talked with me knew who I was, and it didn't matter, but I was able to walk right to the bedside and not ask permission. It was quite interesting. So, you do play an insider and an outsider role.

The other thing that sets us up and you up a little bit is that you have a personal relationship with me. So, you can send a note to [the manager and the patient care coordinator of the unit where my dad was cared for] and they see that I am copied on it. And they see that you are speaking quite personally to me. Which is quite appropriate…but it adds another level of: "Oh my God! Not only do I have an expert whose father is unwell on my floor, she knows our boss really well!" So, I can only imagine what is playing out in their minds. Because for them, your behaviour is going around…

Me: And is that appropriate? Because I struggle with that. I struggle with how to introduce myself. Do I give them my card? What I really want is to be a member of the team and for them to be comfortable asking me for help like any other member. I don't know whether to let them know 'who I am' but I don't want to send the message, "Do you know who I am?" It's so tough.

You have been very gracious stating that what I did was appropriate but, you know, sometimes I don't always take the high road. Sometimes I will use the opportunity to create evidence. Here's an example: When my dad was in the hospital and I asked the LPN some questions about my dad's care he answered, "Well, we will know more after the team meeting this afternoon." To which I questioned, knowing full well what the answer would be, "Are families ever invited to those rounds? Because I will make myself available for that." And his answer was predictable: "Oh no, we don't have time for that! Because, you know we've got so

many patients." So, when I hear something like that in practice when we are trying to change the culture of practice toward patient- and family-centred care, it puts me on the offensive.

Noreen: Yes. I get it. But let's back up a bit. So, is it appropriate for you to sit in on those conversations? In your case, you have specialized clinical expertise. However the average daughter may not. So, that is one of the reasons that from my perspective it is really difficult to bring family members into that level of daily conversation in a huddle, because in my mind those huddles need to be a place where everybody can say what they need to say without any fear of recrimination. So, it absolutely needs to be open and honest. So, absolutely the family needs to be part of the team, but how do we do that in the most effective way? I also don't want to add on any more meetings. Perhaps it is a daily connection in a different way. I think we need to pay attention to who the patient and the family are. Like, she's one of us. So, when we call you we can say, we've discussed several options, these are some of our ideas, what do you think? I'm just thinking about me and my siblings and questions about whether to continue antibiotics for our parent. If you asked my brother, he'd have no clue. He doesn't have the background, the context, the understanding to make an informed decision.

Me: Same with my family.

Noreen: Mary, what you bring to the table is exceptional and I believe unusual. So, it is trying to unpack the difference between being the clinical expert and the daughter.

Me: And what the family has to offer. I mean, you might have a family member who is a geriatrician, so how do you bring that person in and use that knowledge and bring them onside, rather than someone who may not have the same degree of clinical knowledge?

Noreen: Yes! Totally! And how do we develop that skill base to a really high conceptual level, shift the culture and create a shift in health care. I remember being on one of

the units in [name of hospital] and somebody had their personal Blackberry on the drug cart. I almost threw it out. I was so mad about distractions and all we know about giving medications when you are distracted.

Me: Yes. And I hear a lot about time and how "we don't have time for that."

Noreen: The perception of time fascinates me. I probably don't believe this any longer, but there was a point in time when I believed that if our teams were as organized as they used to be, we would actually have enough resources. A friend of mine who I worked with in the hospital had surgery and she mentioned a nurse who cared for her who was very organized. So much so that this nurse knew what was going on with everybody on that ward. We talked about how our perception of risk may be different than other nurses and it made me think about how we were trained and how we practiced and how we paid attention to the patient every time we were in the room. We weren't just giving them water or performing a task. There was so much value in that and I don't know that that happens as much anymore.

Me: I don't know either. I haven't been working on the front lines for a long time.

Noreen: Me neither. I'm sure it will to a certain extent be very person-specific.

Me: Yes. There is attitude. There is knowledge and skills and then there's attitude. Do you remember when I did the teaching at your hospital about delirium after this happened with my dad, and you and your staff came?

Noreen: Yes.

Me: I used this experience with my dad as an example and shared how the nurse who made the connection with me did it through compassion. It wasn't her knowledge and skill that reached me. It was her compassion and openness. To me, that is what made the difference.

Noreen: Yes. Absolutely.

Me: She was able to bring me in and connect with me and then I trusted her. I don't know how we can teach compassion or if you can teach that.

Noreen: Yes. It hasn't been my experience. I am absolutely appalled at some of the stories I hear from family members. I remember one time I wanted to go to the emergency department and ask the staff to experience it with me. I remember thinking, "How can we think that *any* of this is okay?" I wonder too how we can reach them. What experience is it that will get them to be more compassionate? Is it when *their* parent is dying of cancer? Is it when *they* have a bad experience and now it matters? How do we shift that so we don't have to have a bad experience to embed compassion in our practice?

Me: It is what changed me. When it became personal and I experienced the behaviour from the other side, I was forced not only to question what happened to us as nurses that led us to becoming so defensive and feeling like we need to protect ourselves, but also examining my own behaviour. It has made me reflect on my own practice on a deeper level. I have been told that I am intimidating and condescending. Neither of those attributes align with compassion.

So, for me, it is that disconnect, like when I pass the charge nurse in the hallway and she avoids eye contact with me. Rather than engaging families, I think we are still marginalizing them. Patient- and family-centred care should be embedded in our practice, yet we need a formal initiative to draw our attention to it.

Noreen: That drives me crazy!

Me: Moving on to the subquestions now, beginning with the question about whether I exploited my dad. The reason I wanted to ask this particular question is that Carolyn Ellis asks it in her autoethnography about her experience of caregiving for her mother. Carolyn is a leading writer and teacher on autoethnography. In this particular autoethnography she talks about how

as a daughter trying to care for her mother they were both vulnerable. Her mother was vulnerable in Ellis' descriptions of her, which is similar to what I am doing with my dad. How I write about him may not always present him in a favourable light, for example, when I write about his refusal to use his walker. Ellis was vulnerable as well in that she risked harming her relationship with her mother and altering the way the readers would view her by the way she talked about her mother.

Noreen: I don't see that you are. There is definitely a potential for that but you have his permission and no doubt you have had lots of deep discussions with him.

Me: Yes, but I also think he would do whatever I asked him to do because he is so proud of me for getting the PhD. He would make himself vulnerable if it helped me in any way. Perhaps that is the part of being my parent. As parents we often do that. Perhaps we never stop doing that.

Noreen: And there is a power structure, an unintended power structure. When I look back at my career and the people I worked with, I think I made decisions and took certain actions because of the power structure. That would not have been my intention but I can see that is really the way our current culture is organized.

Me: What do you think about the decisions and choices I made about my dad's care?

Noreen: I think you made good decisions. I think in a couple of instances it was difficult for the team; it is really about boundaries. It is like, they need to work with you as the daughter of your father, yet you are more than that. You have a different role and passion around it that some of the staff sometimes find hard to manage. That passion is even more evident when it is your parent.

Me: Yes. I'm not making excuses; however, I was so emotional about it all. When the physiotherapist said what he did I jumped all over him. Of course, what he said was not appropriate; however, he really was trying to make a joke. It's tricky. I want to be part of the team, yet I do not want to go along with the status quo either. I believe we need to challenge each other's behaviour in order for change to happen. I want to be careful with my power too and part of that is acknowledging that I have power. I really appreciated what you said about not feeling comfortable challenging me.

Noreen: Yes. The other piece that I don't want to miss is about you going into the emergency department sort of unannounced because you had access. Unfortunately, that puts the team on edge. I don't think you'd mind if I shared that with you because I've done it myself. I think the physiotherapist may have had a fairly good relationship with your dad. Sometimes our behaviours have the potential to risk the relationship between our parents and the team, because of *our* relationship with the team. And that doesn't always serve our parents or loved one in the best possible way. As far as whether I could challenge you, you are the expert in care in this area. I am certainly learning more and more about it, from you and from my own experiences with older family members. I don't think I could have challenged you. I didn't even feel like it was safe enough to say, "You need to decide whether you're a daughter or a caregiver."

Me: That's interesting. Tell me more about that.

Noreen: Probably because I valued our relationship so that would put that at risk too. And I was abundantly aware that the team wasn't 100%. I totally believed they were doing the best they could do, however it made me, as it always does, no matter who the family is, made me question if we missed something. It started in the emergency department and I thought, if we missed it there—and we did, we missed the fracture—what else did we miss? And how did the

team handle it? Were they offhand and rude and awful, which we have all seen at one time.

That's the piece around nursing that really bothers me. There were so many levels to it and I

couldn't say, "Well, you're wrong. I know they didn't miss it." Because I couldn't say for sure

they didn't. I couldn't even say, "Sorry, they did miss it." That's when it gets really complex.

Recognizing that there is a lot of emotion there and I really felt that when I met with you I

needed someone else there, someone besides just you and me, so that we were all clear when we

left.[5]

    Me: Do you mean the patient care quality person?

    Noreen: Yes, that would be the appropriate person or we may have decided on the chief

of staff. I think over the course of our careers we are dealing with far more complex issues than

we ever used to be for several reasons. People are living longer so when they fall and break their

hip they are much more complex. You can describe that far better than I can. These

complexities are much more difficult than they used to be. Family units used to be much closer

together too. As nurses we are potentially dealing with no family that's close by or a split family

and children from each side. This situation is not unique to the elderly but sometimes remarriage

introduces the dynamic of the children disliking the person the parent is remarried to or is in a

new relationship with. So, it is navigating roles and responsibilities. Questions arise for

families, health care providers, and persons about who actually has decision-making power in

these situations. People are living longer and longer and we are faced with ethical dilemmas like

never before. Like an extremely compromised elderly person with very complex issues on a

ventilator in ICU. It is so complex because it isn't black and white. So, I have a nurse leader in

the unit saying to me, "This person needs to get off that vent. They are taking up an ICU bed."

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[5] Noreen is referring to a request from me for a meeting to discuss my concerns about my dad's care. This meeting took place and included Noreen, me, my sister, the emergency department manager and the chief of staff of the hospital.

My question is, who has the right to make that decision? Who has the right to say, "I want you to do everything you can for my dad if he arrests' even though he is 95 and been on a vent with no improvement for three months." I just don't think families understand what that means. For example, that could mean compressions to his chest and breaking every rib in his body, and for what? I think we need to be careful about our own motivations behind these questions. Is it us who can't let go when they are on that trajectory, that part of the journey of life. So, there is risk around absolutely everything.

Me: One of the discourses that I am already seeing in my data is the discourse of trust/mistrust. I remember the email that I sent you when I was at my wits end. I sent it to you because I trusted you. I remember writing that to you the night I spoke to his nurse when dad was delirious. I was so emotional. I drove back the next day but would have driven back that night if my sister-in-law hadn't recognized the state I was in and believed I was in no shape to drive. She handed me a glass of wine saying, "Have this and settle down." and then she said, "Okay you can't drive now." She recognized the risk, she took control, and I trusted her judgement when I couldn't trust my own. My siblings and my dad trust me. I trust you, which is why I felt safe writing what I did and the way I did to you. I didn't trust the staff. Anything you would like to add about this?

Noreen: I guess my question would be, why didn't you trust them? I think generally patients and families trust the staff. Of course not 100%, there are always exceptions. But even putting myself in this cohort of families and patients, we trust the staff because we recognize them as experts and believe they know best. So, staff hold the trust at least from the beginning. My question for you is, did you not trust them from the very beginning? Like right out of the gate you didn't? Because I suspect that you didn't.

Me: You are right. I didn't. The reason I didn't is because I now know what I didn't know as a staff nurse.

Noreen: Yes. And I also think that with your area of expertise, your standards are exceptionally high. Which is awesome, not a criticism. But it can put the staff at a disadvantage.

Me: That is a significant point Noreen because I don't want to disadvantage the team.

Noreen: I think it goes back to your role and position as a daughter. You need to give yourself permission to be emotional. This is very difficult. If we strip away your expertise and being connected to the system, it still wasn't straightforward. You are a daughter who is worried about her dad and you know things aren't right. This is very difficult. Getting the phone call about something you could clearly diagnose would have been troubling. So, it's okay to give yourself permission to say, "I'm emotional about this." Something like, "This is really hard for me," being clear about not wanting to disadvantage team. Then is makes you more real and more like a daughter. If we have to add back in the piece of your expertise and being connected to the system then we can do that. We all know it is hard to deal with family members who are connected to the system, those notations on the chart: 'Son is a neurosurgeon; daughter is a lawyer' or whatever profession it happens to be.

Me: Yes. Well, that is the end of the questions I have for you. Do you have any for me?

Noreen: Yes, actually. You say that autoethnography requires the writer to become vulnerable. How do you feel about laying open your vulnerability in this way?

Me: It is hard. I am in a place where I am established in my career. Not that anyone is 'safe'; however, I am confident in my knowledge. In that way I believe I am 'safer' than perhaps a new graduate would be. I remember just writing something about vulnerability in my analysis. It was about me saying to you that sometimes I felt the staff were attempting to protect my dad

from me. You said, "Well I wouldn't go that far." There was certainly a tug-of-war. I believe for the most part they were trying to give the best care they knew how and part of that was managing me.

Noreen: Oh, absolutely!

Me: The last thing I want to do is make it more difficult for them. Like we have talked about before, it is difficult enough on the front lines already. Tension and distrust makes it more difficult for sure.

Noreen: Yes. Everyone has a parent, or a son or daughter, or spouse or someone. Therefore, the skill set needed to engage in relationship with the family and communicate effectively is so important. Some people are better at it than others.

Me: You asked me earlier what my personal goal, my reason for doing this was. I answered you, and you said, "But those still aren't getting to what I am looking for." You said I was talking about external motivation rather than internal. I think that my personal goal is to improve care, so that when I become an older adult and nurse being cared for by other nurses/health care providers, that the care is more relational rather than adversarial.

Noreen: So, what I hear you saying is that if you were in need of the health care system as an older adult, you would be able to trust the team?

Me: Yes!!! And I want them to be able to trust me!!

Noreen: I appreciate that you thought about this. Again, you have kept the emotion out of it. My question is more about what is it emotionally that you are looking to gain from doing this? In your heart, what is motivating you as well as the things you have talked about?

Me: I want to do the best thing for my dad. I think that is the emotional piece. Even though it could be said that some of those things I did were not appropriate, I would have done anything for him.

Noreen: Of course you would have!!

Me: So, I would have done anything, regardless of protocol or policy or whatever to keep him safe. But now that I am unpacking it with you, perhaps it is more about *how* we do that?

Noreen: Absolutely!!

Me: I just hear about similar stories so often. Everyone has a story about bad care. I don't want to say we are complaining, but it is often the case. We, as nurses, are complaining about the care we receive from other nurses. I hear a lot about how "it is not the way it used to be" meaning it is much worse than it used to be.

Noreen: Yes. We spend far too much energy on making each other wrong instead of making each other right. It is really sad. Hopefully we can change that and this should help!!

5.1.7.3 My sister: Megan

Megan has always done the right thing. She is six years older than me. She was the "good daughter." She never caused my parents any trouble. I am using *always* and *never* on purpose here; while we know nothing ever happens always and never, in this case it did. I, on the other hand, was not so good, causing my parents a lot of worry. When I spoke to her about risk and my research she said, "You were always a risk-taker. I was always afraid." This is the first time I have heard her say this, and I would agree. I believe she is overly cautious, and as a result, has missed many opportunities.

One thing that stood out for me reading my sister's interview was how often she used the word "feel", for example: *"I feel I understand."; "I feel it's a risk worth taking."; "I feel he*

is…" rather than the word "think". I am often annoyed and impatient by language that is heavily weighted on feelings. I reserve feeling language to describe emotions and generally, I am less interested in what people feel than what they think. I want to know what they think and why they think it.

Me: Megan what do you see as the risks to our dad when he was in the hospital? Specifically his last two hospital admissions: the first time when he broke his hip and the second time when he broke both of his arms.

Megan: [Hesitating] Risks of being in hospital. [Silence]

Me: I'll give you an example. As a nurse, I understand the risks of hospitalization for older people because most health care providers in the hospital are trained to manage acute and episodic care that is based on evidence from the middle-aged population. Older people present differently than middle-aged adults and have many other things affecting them than the episode that brought them into the hospital. For example, we (health care providers) have a specific focus on vital signs in the hospital and one of those vital signs that we assess is temperature. Increased temperature is an indication of infection; yet an older person may not have the metabolism to mount the increased temperature response. Therefore, if staff are relying on this specific indicator to signal an infection in an older person, the infection may get missed. Another thing that is often missed is delirium. Delirium is often assumed to be dementia, especially in older people. So, as a health care provider and a nurse with a specialty in geriatrics I see a lot of risks to Dad when he is in the hospital. I'm wondering what you see from your perspective.

Megan: From observing Dad in the hospital, I don't know too much about risk but one thing I understand is increased risk of infection just from the hospital experience. So, why put an older person in a hospital if they don't need to go?

Me: How did you know about the increased risk of infection in hospitals?

Megan: Just from my acquaintances who are nurses. It is common knowledge that there are more germs in a hospital.

Me: You said it is a risk to put an older person in the hospital if they didn't need to go. Would you say that Dad needed to go to the hospital?

Megan: Yes. I believe he needed to be there for the surgery.

Me: Any other risks you see for him?

Megan: It was pretty scary for me on one of his admissions. I don't know if it was the first or second admission, but I was with him for an extended length of time. He was sitting up in a chair beside his hospital bed and he started to drool and he wasn't able to coordinate himself. That was pretty scary for me. I called the nurse and she came to see if he could speak. At first he couldn't speak very well to communicate what was happening to him. To this day I don't know what was going on with him, whether he was having a stroke or what was going on with him. I was probably so scared and maybe in shock myself that I don't know if I processed what was happening or what did happen appropriately, but I believe he did recover from that incident at least a little bit.

Me: Megan this is the first time I am hearing this. Why didn't you tell me?

Megan: I don't remember why. It might not have been convenient. You may have been busy. I was probably in shock myself. I may have told you and you may have dealt with it quickly and forgot.

Me: You say you were scared. What were you scared of?

Megan: I was scared of something bad happening to him.

Me: What else scares you?

Megan: We aren't just talking about Dad here are we? Would you be scared?

Me: No. I don't think I scare easily.

Megan: You sure don't. We are different that way.

Me: So, keeping on the topic of me now, what are your thoughts about risk related to me caring for Dad within the context of double-duty caregiving? Do you see risks to me and/or risks to him when I care for him both as a daughter and a professional specialist in geriatrics?

Megan: At this point I don't see any risks to him or you with your double role of being a caregiver to him and also a daughter. I feel that is probably helpful because of your professional role, you understand the challenges that he has better than me, who is just a daughter with no health care background. We have relied on you in that capacity over the years.

Me: I am not afraid to challenge the health care staff. I think I talked to you about when I came into Dad's room the first day after his surgery and the physiotherapist was helping Dad to mobilize. Dad looked like he was in pain and I said something like, "Dad you need to ask for pain medication before you start to mobilize so that you are more comfortable." I said, "I know you don't like to complain but asking for pain medication or telling them you are in pain is not complaining. It's team communication." And then the physiotherapist said, "Bob, you can complain. Just don't complain too much or you'll be blacklisted." I believe that was not appropriate to say to anyone, let alone an older adult, and I included this incident in my email to the health services administrator. Sometimes when you challenge practice there are

repercussions. Also, it may have not been the best way to address the issue. Do you see any risks to Dad or me because of the way I addressed this?

Megan: Well, I feel holding people accountable is necessary and worth the risk to anybody. Professionals need to realize the need for being held accountable, themselves included. If there is an issue with their behaviour or their language, then they need to know that there is an issue and why. And if they are disgruntled that process needs to be worked through.

Me: In an ideal situation you would work it through. But what if they are silent?

Megan: I suppose potentially it could be a risk. But I feel it's one not only worth taking, it's necessary to take that risk.

Me: Do you see any risks to me, for advocating for him in that situation?

Megan: Possibly.

Me: For example?

Megan: Maybe somebody getting disgruntled and reporting your behaviour to your supervisors.

Me: But I'm in a daughter situation.

Megan: But you're also in a professional situation.

Me: So, that leads into the next question: What are your thoughts about the roles I performed and continue to perform caring for him? Do you see any risks to me in performing these roles? For example, I perform the role of insider. I know how the health care system works. I know who to talk to. I have a relationship with the health service administrator of the hospital where my dad is receiving care. I know the standards that professionals are bound to under their regulatory body and I know the risks to them if they become investigated by their professional college. So, I have particular information that most people don't.

Megan: Yes. I see you as an insider and I consider that beneficial. I guess we are all at risk to some extent.

Me: I think I am at less risk than many people. I am an advanced practice nurse and I have a good reputation within the organization. I am a divorced white female in a privileged position. If I was a less experienced nurse, it may be different.

Another question I have for you is whether you think I exploited my relationship with Dad for my PhD. For example, Carolyn Ellis is one of the leading researchers and writers on autoethnography and it is a question she asked herself about caring for her aging and dying mother. I am using Dad as a subject for my research. Have you thought that perhaps I am using him for an ends to my own means?

Megan: I have thought about that. But I understand that you've talked with Dad about this and he is comfortable with it. So, I'm comfortable with it if he's comfortable with it.

Me: What do you think about the choices and decisions I've made about his care? Do you believe you could challenge me on any of these decisions if you did not believe they were beneficial or appropriate for him?

Megan: I feel I could challenge you on anything. I don't, but I feel I have questioned you. Whenever I question something, I question you, and I can't remember any decision you made that I disagreed with. I think if I did remember I would have some feelings about it and I don't.

Me: That's it for the questions. Anything else you would like to add?

Megan: No. Not at this point.

5.1.7.4 My brother: Brent

Brent is my older brother. He is the only one of my participants who does not live within my health authority. He is retired and of all of us siblings, he sees my dad the most, managing his appointments and finances. I trust him completely. Like the other interviews, I began by asking him if he saw any risks to Dad while he was in the hospital.

Brent: Well, one risk was when the nurse didn't believe me when I told her Dad was going cuckoo. Dad was telling them that his nephew from Sweden was in to visit him, and they were saying," Oh that's good." But it wasn't, it wasn't the way it was. Edgar was never there. They didn't realize something was wrong until he told the nurse there was a dog under his bed. Then she realized, okay…

Me: [Thinking] This makes me very angry. My people—nurses—didn't listen to my family. It's personal, and it draws the lines.

Brent: There is risk in not catching that, that something is going on with his brain and it turned out to be serious. Patients can fool their caregivers into believing they are okay when they're not. They don't know. They don't know what they're like.

Me: What are your thoughts about risk within the context of me in the double-duty caregiving role?

Brent: I think in your case, when you are trying to deal with the nurses and other stuff that they are not as appreciative as they could be. Like when they ask, "Why are you doing that? This is our job not your job."

Me: Do you see any risks to me?

Brent: Not really. Unless that letter goes back to your employer or your supervisor and they see it as you pushing yourself too much.

Me: Do you see any risks to him?

Brent: No. None. I guess there was that one meeting where the nurse got her nose out of joint, but I don't think it had an impact on the outcome of the meeting.

Me: Oh I remember that! The manager told us how the meeting would go and asked if that was okay with us and if we had any questions. I was feeling a bit punchy and I asked when we did the introductions if everyone could give one sentence about what patient- and family-centred care meant to them. The manager said something like, "Absolutely not! We will run this meeting like we do every other meeting." I guess I instigated that a bit. I used the situation to make a point. It just bugs me so much when we hear the rhetoric of patient- and family-centred care and how we are given lip service to it, but not real substance. So kind of along those same lines, do you think I ever exploited Dad? Like did I use his situation for my own gain? I am using him for the subject of my PhD research and I believe he would do whatever I asked him to because he is so proud of me for doing the doctorate. Do you think I am stepping over that moral boundary?

Brent: No. Dad is doing this because he wants to.

Me: What do you think about the decisions I made and continue to make about his care?

Brent: I think they were appropriate. I don't think we would have gotten the action and outcome we did without it. Everything that came out of your decisions was positive.

Me: Do you think you could challenge me if I made a decision that you didn't agree with? Would you feel comfortable doing that?

Brent: Yes.

Me: I think as far as families go we are pretty collaborative.

Brent: Yes. As far as families go we are. Jason does a really good job getting a lot of information from a lot of people and puts it all together. Megan expects a lot of the staff and

questions why they did this or that when we don't know if the staff members tried something and he didn't want it. There is nothing wrong with his mind.

Me: Is there anything else you would like to say about risk?

Brent: Just about the next level of care for him. I think there is a risk in leaving that conversation too long. There will come a time when the ladies at [care facility] will no longer be able to care for him and the accessibility of higher level care homes will be depleted. It is pretty clear to everyone else that he needs help but when they ask him, he says, "I can do it myself." There is a risk in that. He says everything is fine and things aren't fine.

5.1.7.5 My brother: Jason

Jason is my younger brother. Of all of my siblings Jason is the one who understands physiology and medical terminology the most. He was a volunteer firefighter and first aid attendant. As in the other interviews, I began by asking him what he saw as the risks to our dad when he was in the hospital on the last two admissions.

Jason: I think the risks to him were predominantly around the level of care he was getting. When he was discharged home after one of those admissions, I picked him up and he still had a cannula in his hand from the IV. They let him go without taking the cannula out. It makes you wonder what else they missed. The level of care was not what we hoped it would be. He was even sent home with a broken hip once.

Me: What are your thoughts about risk within the context of me caring for Dad. There is a body of research about double-duty caregiving and what it means to be a professional caregiver as well as a family member who provides care.

Jason: I don't think there are any risks to Dad in that situation. I think there may be some risks to you in being emotionally involved, including the fact that you've got a pretty tight

relationship with Dad. I don't want to call it baggage but all that impacts you emotionally. That could be carried over to your professional life.

Me: When you see me challenge health care providers, do you see that as a risk to Dad?

Jason: I may be naïve, but I don't think they would take it out on Dad if they were upset at you. I've never really considered it. I guess it's possible, but I don't see it as a risk.

Me: Do you see any risks to my performing and taking up multiple roles? For example, I am an insider in that I know the system and have clinical expertise, but when I challenge or ask questions I often end up in an outsider position. I feel shut out by the staff. Do you see any risks in that?

Jason: I don't see any risks to Dad. You bring incredible expertise; you can't put a value on that! When I talk to health care professionals it's really hard to know what questions to ask and even the language is difficult to understand sometimes. I'm starting to pick it up though! Like I know what you mean by comorbidities now!

Me: Yes. You sure are. I hear you talk now and I often think, "He sounds like a nurse!"

Jason: I'm starting to pick it up but it can be intimidating, and often we are just trying to deal with the fact that he is back in the hospital. It always crosses my mind whether this is the time that he is not going to make a recovery. The question for me is always how do we ensure that he gets the best care possible?

Me: Yes. That is always the question for me too. Here is another question which you brought up once. It is in the literature too, but you brought it up before I found it there. Carolyn Ellis, who is one of the leading researchers and writers on autoethnography questioned the ethics of writing about her mother. She asked the question whether she was exploiting her mother or using her mother's vulnerability for her own gain. When I talked to you about writing about Dad

for my PhD work you said something similar. I wanted to ask it to you again as well as my other

participants because it's a question I struggle with. There may be times that I don't present him

in the most favourable light, for example, writing about his reluctance to use his walker. What

do you think and how do you feel about this?

Jason: I brought this up once?

Me: Yes. You did, and before I read it in the literature. You said something like,

"Sometimes I wonder if you are using him or his situation for…" I can't remember your exact

words but it was along the lines of using him for my own gain.

Jason: I don't remember doing that. The reality is: his situation is his situation. It is

what it is. Maybe you are taking advantage of the situation, but you're not taking advantage of

the individual. I don't see any exploitation here at all!!

Me: What do you think about the decisions and choices I've made about his care?

Jason: You are a good communicator, Mary and communication is important, both

ways. If you believe you have expertise in the field and you believe something is not right, you

bring it forward. You communicate it. I think your delivery is professional. I don't have any

issues with your conduct or your behaviour whatsoever.

Me: Do you believe you could challenge me if you didn't agree with something I was

telling you? Do you see any risks in questioning me?

Jason: Yes, I believe I can always question you and I don't see any risks at all in doing

that. I mean, I need to listen to what you're telling me and make sure I have a good

understanding of what you are saying or doing. If it's not making sense to me, I just need to

keep asking questions and listening to answers. I don't think I have any problem challenging

you but it's not a challenge, it's so I have a better understanding, because it's not my area of expertise. It's yours.

Me: But you have a different lens where I'm embedded in it. You have fresh eyes, which is very helpful. I'm embedded in this culture of safety and the perspective of health care providers and professionals and what we think the patient needs.

Jason: Yes. I wouldn't have any problem asking those questions because maybe it would help you with the decision or you may even reconsider your position. But as far as challenging you, Mary, I just can't see those circumstances arising.

Me: I think our family, we and our siblings, with Dad, is a great team.

Jason: And you are leading. You are a leader and that's appropriate. I think with you steering the ship the risks are mitigated as much as they can be. I think Dad is subjected to a lot less risk than somebody who didn't have an insider in his corner.

5.1.7.6 My Dad

My dad grew up in Saskatchewan on a farm and became a teacher. He received his Bachelors of Education from the University of Saskatchewan and his Master's in Education from the University of North Dakota. He taught industrial arts in the junior high school that I attended in grade eight and nine. In those days, boys took industrial arts ('shop' as he used to call it) and girls took home economics. Therefore, I never had him as a formal teacher.

My dad is not a conversationalist. He enjoys the company of others; however, he is not a talker; he prefers to listen. I find it interesting that most often when he does talk, everyone listens. He is frail, has a number of comorbidities, yet no significant cognitive impairment.

Dad's interview lasted 20 minutes and his answers to most of my questions about risk and whether he saw any risks were short responses of *"No."* and *"Not really."* Reading his

interview makes me nostalgic. The way he responds to me is the way teenage Mary would have responded to him years ago. The roles are reversed. He appears passive; however, it would be a mistake to assume his silence indicates he has relinquished control.

Me: Dad, what do you see as the risks to you when you were in the hospital?

Dad: Well, not very much.

Me: Was there anything?

Dad: Not really.

Me: As a nurse I know that hospitals are not necessarily safe places. So, I see a lot of risks, for example, risks of hospital-acquired infections and those sorts of things. Are you aware of these types of things?

Dad: Oh, yes.

Me: Do you think about that when you are admitted to the hospital?

Dad: Not really.

Me: No? I know you don't like going to the hospital. In fact, you seem to try anything to avoid it! Does that have anything to do with risk?

Dad: No.

Me: What is it then? Why is it that you don't want to go to the hospital?

Dad: I think I can recover just as well at home.

Me: The last time you fell, you didn't go to the hospital. However, you had trouble getting out of bed for three days. Do you remember that?

Dad: Not exactly. Not very well anyway.

Me: I think one of the reasons you didn't get out of bed was because you were in so much pain. Do you see that as a risk?

Dad: No.

Me: Staying in bed too long is a significant risk factor for deconditioning. We use the saying, "Stay in bed and you will end up dead." We have learned how important regular mobilization is to healing and staying healthy. That's why [the physiotherapist] won't let you stay in bed, because if you do you will decondition and end up worse.

Dad: I was surprised how much!

Me: It's even more of a risk for older people. So, when you said you were surprised how much you deconditioned from staying in bed and not mobilizing, you didn't see that as a risk?

Dad: Not really.

Me: From my health care perspective and most likely from Jack's, we see that as a big risk.

Dad: Exactly.

Me: Do you have any thoughts about risk within the context of me caring for you?

Dad: No.

Me: When I question the nurses or the physicians or the physiotherapist for example, you don't feel there are repercussions to you? You haven't experienced that at all?

Dad: No.

Me: Have you experienced it the other way? When I ask questions do you think maybe you receive better care or more attention?

Dad: Maybe.

Me: I'm thinking about Jack joking with you. He's said to you, "Bob, if you don't get out of bed your daughter is going to be on my case." You and he have a great relationship and he is joking, but I think we all know there is some truth to it too.

Dad: Right.

Me: Do you see any risks for me?

Dad: I don't think so.

Me: What are your thoughts about the roles I perform or continue to perform in your care? For example, following up on your care plan, talking to your care providers, reviewing your medical records, arranging the family meeting with the team in the hospital, do you believe that I am inserting myself where I don't really need to be?

Dad: No.

Me: Do you see me as an insider in the health care system?

Dad: Yes. You are an insider.

Me: What does that mean to you, that I am an insider?

Dad: Well, you understand the health care system and you know how it works.

Me: Dad, I need to ask you a very frank question. It is a question that another researcher asked when she was providing care to her mother. I'm asking it to you, and I need you to be very honest. If you have had any of these feelings, I want you to let me know. Do you think that I exploited you in any way?

Dad: No!

Me: No? I am using you for the subject of my research…

Dad: That's not exploiting me. That's taking advantage of a situation.

Me: That is the way I look at it and for the purpose of making change.

Dad: Yes.

Me: Do you see any risks to our relationship for talking about this or doing this research?

Dad: No.

Me: I don't either. What do you think about the decisions or the choices I made about your care? For example, when I encouraged you to go to [inpatient rehab facility] for strengthening after you were discharged from the hospital instead of going straight home and advocated to the staff at the hospital for you to go there?

Dad: Well, I guess I needed to go there because I was in a lot poorer shape than I thought I was.

Me: It is hard for all of us to understand what shape you are in. You never complain.

Dad: Well, it doesn't do much good.

Me: Well, maybe I shouldn't have said complain. You definitely are not a complainer. Sometimes though, it would be helpful to understand the reasons why you do or do not like to do things. For example, if it is pain that is keeping you in bed, we can often manage that pain if you let us know. Telling us you are in pain is not complaining. I understand that you are independent and believe you can look after yourself.

Dad: Well, I do.

Me: Yes. However, we are here to help you do that. Do you remember when the physiotherapist in the hospital told you that it is okay to complain, but not complain too much or you will be blacklisted?

Dad: No.

Me: He laughed when he was saying it, like it was a joke.

Dad: Well, are you saying it was?

Me: Yes. At least half joking. I think there is danger in what he said because it might make people afraid.

Dad: But I wasn't.

Me: So, you feel you could challenge me if I was making a decision about your care that you didn't agree with?

Dad: Yes. If I thought you were doing what was not recommended, I would challenge you.

Me: You would question me? And you wouldn't have a problem questioning me?

Dad: No.

Me: I didn't think you would. I know we've talked about risk before. Do you have any other thoughts you would like to add about risk?

Dad: Not really.

Me: What's it like having a nurse for a daughter?

Dad: Well, I suppose it's quite similar to you having me for a teacher.

Me: That's a good point. I liked having you as a teacher when I was in junior high. If I forgot my lunch, I could just borrow money from you.

Dad: [laughs]

Me: And you gave me a ride home. I liked that. It was similar to our situation now actually. You didn't provide me direct teaching because at that time girls didn't take industrial arts. Although there was one girl I met who said you taught her. This was after I graduated. Did they open it up to girls before you retired?

Dad: I don't remember a girl in the class at all. I wonder if it was a real teaching class. Every Wednesday there was something special. I remember taking kids to the range to practice with rifles.

Me: That would have been fun.

Dad: I was teaching them about hunting.

Me: Anything else you would like to add about risk and having a daughter who is a nurse interfering in your…

Dad: Well, you aren't interfering. You are passing along knowledge that you happen to have. I have actually thought a number of times that it is kind of handy to have a daughter who is a nurse and in the health care system, especially since I am using it a lot!

5.1.7.1 Summary of participant responses

Besides the difference in time between the interviews with my family and the interview with Noreen, there were a couple of other differences and surprises. While every member of my family agreed that they would not have a problem challenging me if they did not agree with my decisions or actions around Dad's care, Noreen stated she was not comfortable doing that. That surprised me and I asked her to talk more about that:

> Mary at that time no one in the health authority had the expertise around older adults that
> you did and most likely still do. I certainly didn't. You are recognized as the expert, and
> rightly so. There was no way I was going to challenge you. (line 738)

At another point, Noreen and I were talking about my difficulty navigating my roles of geriatric expert and daughter. She stated, "I didn't even feel like it was safe enough to say, 'You need to decide whether you are a daughter or a caregiver'" (line 772-773). Her statement remains

troubling for me. Drawing on poststructural perspectives, I am reluctant and resistant to choose.
It is also troubling that she did not feel safe to raise the discussion with me.

While she was not comfortable challenging me during my dad's hospital stay, she was
the only one of my participants who challenged me during the research process. She pressed me
to a deeper analysis on many levels: during the interview; in follow-up, member-checking
conversations; and, in reflective emails and conversations after reading my writing.

As part of the member-checking process, I provided my participants with not only a
transcript of their interviews, but an early draft of the dissertation including the autoethnography
in the findings chapter. Noreen and Brent were the only participants who commented on my
analogy of war. Brent provided feedback that he believed the analogy of war was harsh. "Mary,
war is…serious." Noreen sent an email:

> As I read your dissertation and learned a lot from the research there were several things
> and thoughts that came up for me. As we've had several deep discussions about your
> experience, I'm comfortable sharing these with you and [I'm] happy to discuss if you
> wish. Please know they come from a place of deep respect and compassion for you. The
> framework of war as in you feeling like you went to war or were at war is an interesting
> one and may have impacted both your actions and those who interacted with you. It is
> quite an aggressive approach to life. Is there a space available to you to work in a more
> neutral place? Not as it relates to this as the experience is past; however, as you move
> forward. If I may, I'd like you to take a moment to think about when you feel a
> relationship at work or at a presentation or interaction has been the most effective. Is it
> when it is collaborative? When you are at war?

Megan responded with a number of emails. She commented that she found the interviews "illuminating and at times hilarious (entertaining)." She elaborated that she would like to travel together as siblings again to get to know each other better now that we "are all grown up." She added, "Mary, yes I know my "feeling" too much bugs you, and I think I've made it clear to you that your "thinking" too much bugs me!! :)."

Jason responded this way, "Nice work, Mary! Unfortunately, I haven't been able to plow through all 184 pages, but I did skim through some of it and I also reviewed Jason's interview. All good there…Good luck with this."

When I asked my Dad for feedback and if he had anything to add he responded with "No, not really. When will you be done?"

5.2   Part Two: Discourses at Work within the Data

In this section I discuss the findings of discourses at work within the data (my autoethnography and artifacts, including my father's chart and conversations with my participants). It is important to note that these discourses are not discrete entities. Although they are listed separately they were interdependent, integrally related, interwoven and mutually informing, producing, reproducing, and resisting one another. In congruence with other poststructural health research focusing on discourse (Hole, 2004; Neville, 2006; Kjorven, Rush, & Hole, 2011), I have incorporated some theoretical discussion within this section in order to provide a foundation and explanation for these findings. My analysis includes how the culture of risk within my workplace contributed to my performance of double-duty caregiving and identification of discourses that produced this culture. I illustrate how these discourses were at work to produce subject positions that were either available or unavailable to me and discuss what it means to perform multiple aspects of identities simultaneously. I illuminate how taking

up and performing multiple and mobile subjectivities was manifested within interactions with others, including how my taking up and performing specific discourses led to the way I positioned others and how others positioned me. I begin this section with an illustration of the culture of risk where these discourses were at play, which was the health authority where I work, including the hospital where my father received care.

5.2.1 Culture

To an [auto]ethnographer, 'culture' is anything that binds a group of people together, for example, shared values and interests, a common birthright, or allegiance to a particular code (Denzin & Lincoln, 2005; Savage, 2006; Wolcott, 2008). Autoethnography is embedded in the concept of culture, and while culture remains "linked to colonialism, essentialism, typologies, generalizations, labels and so on" (Mayan, 2009, p.38), poststructural perspectives provide opportunities to deconstruct and "take apart and expose the underlying meanings, biases, and perceptions that structure the way a text conceptualizes its relation to what it describes" (Denzin, 1994, p. 185). Arguably, the centrality of culture has waned with the changing nature of ethnographic work; however, Wolcott (2008) maintained that "there is no [auto]ethnography until culture makes an entrance, no matter how tenuously" (p. 70). He went on to define culture as "an abstraction, a perspective for studying human behaviour that gives particular attention to acquired social behaviour" (p. 72). It consists of what people do (behaviours), what they say (language), what they believe (and the potential tension between what they do and ought to do), what they value, and what they make and use (symbols, artifacts) (Creswell, 2007; Mayan, 2009). This may include a holistic perspective of the group's history, religion, politics, economy, and environment (Creswell, 2007) and, within this description, cultural concepts such as "social structure, kinship, the political structure, and the social relations or functions among

members of the group" (Creswell, 2007, p. 71). Ethnographers (and therefore *auto*ethnographers) put great value on understanding the cultural value we put on things, as well as the practices that define us as part of a particular cultural group.

5.2.2   Risk culture in health care

The discourses identified in my data worked to produce a culture of risk in my health authority, where risk is viewed as a threat to be identified and mitigated. 'Patient safety' is commonplace language within this risk culture. One of the tensions that emerged for me in applying poststructural lenses to autoethnography was that while interrogating culture is a necessary component of autoethnography, 'risk culture' is also a discourse in and of itself. I chose to reconcile this tension with an acknowledgment that both poststructural perspectives and autoethnography allow for multiple ways of representing reality and for the purposes of this dissertation this representation proved to be the most useful.

Nurses have long held the moral imperative to keep patients safe. I take ownership and responsibility attached to this imperative. Nurses, including me, often refer to patients assigned to their care as "my patient" and there is an underlying implied risk to them personally and professionally should harm come to one of their patients.

I believe it is significant that the chair of the board of directors for my health authority has a strong background in safety and quality, currently holding both chair and provincial patient safety and quality officer positions within the BC Patient Safety and Quality Council. Previously, this individual was a member of the Board of the Canadian Patient Safety Institute where he also held the position of Chair of the BC Patient Safety Taskforce. These organizations list patient-centred care, transparency, innovation, and an inclusive approach as essential to improving quality of care (BC Patient Safety and Quality Council, 2018; Canadian Patient Safety

Institute, 2018).

Organizations are placing more importance on enterprise risk management (ERM) programs to understand how risks might impact the organization's strategy and objectives. ERM programs have enabled a process to identify, assess, and mitigate a broader range of risks across all organizational units (Interior Health, 2016). My organization's ERM program has continued to evolve, developing ways to support and strengthen the management of risk within the organization. One of these ways is through the Quality, Risk and Accreditation Department where patient safety is a key priority and the mission is "[to create] a culture where quality and patient safety is everyone's responsibility every day, [thereby achieving] the best possible outcomes through patient centred care, teamwork, innovation and learning" (Interior Health, n.d.-c).

The Privacy, Policy and Risk Management Department is one of 13 other departments within the Quality, Risk and Accreditation Corporate Department. The purpose of this department is to provide strategic direction, guidance, and leadership regarding privacy, policy development, and risk management; comply with laws, regulations, and organizational policies; audit electronic clinical systems; and manage freedom of information requests. Policies from this department are developed to protect the privacy and security of staff, patient, and client information. My organization requires all staff to complete an annual privacy education and training module and sign a Data Access Confidentiality Agreement each year as part of the process to govern employees' access to health information. Inappropriate access and/or redistribution of patients' information may result in termination of the employee.

[The organization] considers intentional viewing (accessing) of personal and confidential information that is not required to carry out work-related responsibilities or the misuse of

such information to be a breach of policy. Failure to comply with this policy may lead to termination of access, termination of employment, termination of contract, withdrawal of privileges and/or professional sanctions. (Interior Health, n.d.-b)

Professional health care providers are also bound by the standard of confidentiality from their regulatory college, which outlines appropriate/inappropriate reasons for accessing and sharing patients' information. Failure to adhere to this standard places professionals at risk of losing their license to practice. I am embedded in this culture of risk and safety that extends from the board chair and is reinforced throughout all levels of my organization including espoused vision, mission, goals, values and principles (Interior Health, 2012).

While the message is loud and clear that health care professionals do not have an automatic right to access patient information, most people (professionals and lay persons) do not understand that a person (patient/client) has a right to their own medical information, including the information in their hospital chart. This information includes (but is not limited to): physicians' orders and progress notes, admission forms, diagnostic laboratory reports, emergency room forms, nursing assessment records and nursing notes, allied health consent forms and notes, medication records, care plans, consent forms, vital sign sheets, bowel and bladder records, ambulance records, discharge summaries, and all other documents related to their care. Historically, paternalism, protectionist practices, and obscurantism (the practice of keeping knowledge or understanding about something from people) of health care providers has prevented patients and families from engaging in their care or care of their loved ones (Stempniak, 2014; Tzeng, Yin, & Fitzgerald, 2014). Health care providers often respond defensively when their practice is questioned and patients feel they lack control over their care process (Siegal, Bonnie, & Applebaum, 2012). Reasons for the secrecy are steeped in risk

culture and include fear of litigation, fear of harm to clinician's reputation, and emotional distress (Russell, 2018). In other words, transparency and full disclosure involves vulnerability on the part of health care providers and resisting the dominant discourse of risk. Transparency and fully involving patients in their care is a "not-so-secret tactic to transform [health]care" (Stempniak, 2014, p. 57), which may lead to fewer preventable rehospitalizations and improve patients' health literacy and their satisfaction with the care they receive (Agency for Healthcare Research and Quality, 2013; Carlson, Patterson, & Holm 2014; National Alliance for Quality Care, 2012; Stempniak, 2014).

Updated processes such as electronic medical records and patient portals are enabling patients to gain unprecedented access to their personal health information (Bell et al., 2017; Fossa, Bell, & DesRoches, 2018; Interior Health, n.d.-a). Still, most people (health care professionals, patients, and families) do not understand that not only is the chart a legal document, there is a process for patients to access and retain all of the information contained in it. Through this appropriate process they can receive copies of this information, share it, and even publish the information in it. Appendix E and F are copies of the requests from my dad for access to his personal records through the Freedom of Information and Protection of Privacy Act (FIPPA) (Government of British Columbia, 2019).

It was within this culture that I, Noreen, and the health care providers who cared for my dad resisted and performed discursive practices that competed, overlapped, and coexisted with other discourses. My siblings and my dad were on the periphery of this culture, which became evident in their interviews: they had difficulty talking about risk in health care. Historically, patients and families have been passive recipients of care (Stempniak, 2014), content to let the 'experts' identify and manage the risks.

From the data, I identified safety as a prominent discourse that I, my participants, and the health care providers who cared for my dad took up and performed in my experience of double-duty caregiving for my dad. Within the safety discourse are subdiscourses of competency/incompetency, surveillance, trust/mistrust, fear, and control.

5.2.3 Discourses of safety

It is not surprising that discourses of safety were prominent in my findings. The culture of risk in health care centres on risk avoidance and preventing mistakes. Generally, I believe the more you know, the more you anticipate, recognize, and appreciate the implications of those mistakes. Still, in my professional clinical experience mistakes often go unnoticed and potential mistakes or 'near misses' are only recently being brought to light, valued, and treated as learning opportunities In health care, mistakes are rated on the degree of patient harm. My memory of my experience of double-duty caregiving for my dad began with a mistake: *They made a mistake. Mistakes happen and will continue to happen, despite all of our quality improvement measures. I've made some myself, and some of those have affected my patients.*

The first page of my dad's combined medical records also began with a mistake. It is important to note that not all physicians were as diligent with accurate documentation as the anesthesiologist. Figure 4 illustrates the first page of my dad's chart: the discharge summary of his hospital stay, written by a physician (who I don't know and have never met), which contains a number of mistakes.

Discharge Summary
Signed

I will be discharging ████████████ today, July 12, 2013, with a final diagnosis of a slow recovery post total knee replacement on the right side. He was admitted for the same reason by the surgeons, has had a slow recovery and as he is an elderly gentleman, the feeling was that he needed a little bit longer to recuperate and we will be discharging him to the Short Stay Unit.

Of note, is that we are querying a slight UTI at the moment and have sent off a urine culture which should be back within the next day or two, to be followed by his family doctor in case he needs antibiotics. Due to the fact that there is not any signs of sepsis, I have opted not to start him on any medication immediately. Otherwise, he is doing well, other than the fact that he had a bit of a sore neck in hospital as well from the hospital bed, which recuperated well. He will be followed in the community by his family doctor as well as the orthopedic surgeons for follow up for the knee replacement.

Dictated by: ████████   Dictated Date: 12/07/13 0959
Transcribed/Edited by: ████   Transcribed Date: 12/07/13 1105

Copies: ████████████████████
Report: 1207-0060

Figure 4. Discharge Summary

My dad had a percutaneous pinning of his right hip fracture, not a total knee replacement. His slow recovery was not solely because he is an elderly gentleman. A significant cause of his slow recovery was because he had delirium. Delirium is a sign of sepsis. I would not have known these mistakes were made if I hadn't, with my father's signed permission, requested and received his chart. I would not have requested and received his chart if I hadn't known my right and the process to do so. I would not have known my right and the process to do so without my education and experience in health care.

Noreen spoke about missing things, which can also be interpreted as mistakes: "The way I see it, there was a lot of risk for your dad in his initial visit to the emergency room around missing the original injury or break" (line 87). She also talked about her personal angst and sense of responsibility about missing things: "It always makes me think, no matter who the family is, what if we missed something?" (line 787-788). "Then I think, my gosh, if we missed it

there, what else did we miss? And how did the team handle it? Were they offhand and rude and awful, which we know we've all seen" (lines 793-795), "and what else is going on in the emergency department at that time" (lines 92-93).

Brent talked about the staff missing the change in Dad's cognition when he became delirious:

> The nurse didn't believe me when I told her Dad was going cuckoo. Dad was telling them that his nephew from Sweden was in to visit him, and they were saying, "Oh that's good." But it wasn't, it wasn't the way it was. Edgar was never there. They didn't realize something was wrong until he told the nurse there was a dog under his bed. Then she realized, okay… There is risk in not catching that, that something is going on with his brain and it turned out to be serious. Patients can fool their caregivers into believing they are okay when they're not. They don't know. They don't know what they're like. (lines 13-33)

Jason talked about missing things too:

> I think the risks to him were predominantly around the level of care he was getting. When he was discharged home after one of those admissions I picked him up and he still had a cannula in his hand from the IV. They let him go without taking the cannula out. It makes you wonder what else they missed. The level of care was not what we hoped it would be. He was even sent home with a broken hip once. (lines 9-18)

There was another level of safety that was evident in the findings: safety in relationships. Noreen stated that she wanted to say things to me; however, she did not feel entirely safe to do so:

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There were so many levels to it and I couldn't say, "Well, you're wrong. I know they didn't miss it." Because I couldn't say for sure they didn't. I couldn't even say, "Sorry, they did miss it." That's when it gets really complex. Recognizing that there is a lot of emotion there and I really felt that when I met with you I needed someone else there, someone besides just you and me, so that we were all clear when we left. (lines 799-813)

When I asked her to talk more about that she stated, "Because I valued our relationship" (line 775). I believe Noreen was in a difficult position. She was tasked with protecting everyone: her staff, the organization, my dad, other patients, and me. She was careful not to declare alliances but to remain objective and neutral. I believe it is difficult to be neutral in war as the expectation is to choose sides and remain loyal to that side. Straying from that side is considered risky and dangerous. This was evidenced when the nurse pulled me aside privately in the ED and spoke softly about her feelings about discharging my dad the day before. I wondered if she felt she was breaking solidarity as it could be interpreted that she was talking to the enemy: *I feel she has given me clandestine information, and she did not feel entirely safe doing so.* Intricately tied to discourses of safety were discourses of competency/incompetency.

5.2.4 Discourses of competency/incompetency

A subdiscourse of competency strongly supported the dominant discourses of safety. I took up this binary discourse and used it to position the nursing staff as incompetent, even imposing these discourses of staff incompetency on my siblings. For example, I doubt that my siblings would have recognized the lack of gerontological expertise in hospital staff without me pointing it out for them. My siblings and I took up this binary discourse by positioning me as the expert and clearly competent against the staff, who I positioned as incompetent.

My brothers and Noreen questioned both implicitly and explicitly the knowledge and skill level of the staff as contributing factors to missing things. Discourses of competency/incompetency produce power and powerlessness, in so far as positioning risk in one way or another. In other words, the more competent a nurse, the less the chance of mistakes, therefore the less of a risk. The language of competency was not mentioned in the data, yet an unspoken and unnamed discourse of competency exercised power in directing the actors in this discourse. Because of my experience working in acute care, my understanding of the research evidence, and my advanced education and clinical specialization in gerontology, I understand that it is essential that health care professionals are equipped with the appropriate knowledge and skills to meet the needs of older people.

There was much talk in the narratives about knowing and doing. I know that when "[health care professionals] fail to recognize geriatric syndromes, they resort to practices that undermine patient functioning, thereby putting them at risk for functional decline and iatrogenic complications" (Fox et al., 2016, p.71). Not only did I believe the nurses' general knowledge about older adults as a population was lacking, I also did not trust their assessment skills. This was apparent in my memory from my conversation with my dad's nurse when I spoke to her about Dad's delirium: *She doesn't know what the Confusion Assessment Method (CAM) is, or that it is the tool we use within the organization to prevent, assess, and intervene for delirium.* This is evidenced repeatedly in my dad's chart. Nurses, including LPNs, RNs, and nursing students did not recognize my dad's confusion as delirium: a medical emergency. Because they did not recognize it, they did not respond appropriately with specific assessment, intervention and follow up. Figure 5 illustrates nursing notes that begin with documentation that my dad is [slightly] confused. Confusion should produce the same degree of emergency as the symptom of

chest pain. One may be signalling a brain attack; the other may be signalling a heart attack

(Kjorven, 2009; Kjorven, Rush, & Hole, 2011). Yet, nursing notes indicate that the nurses were

not responding this way.

Figure 5. Nursing Documentation B

Competency/competencies is language that is increasingly used within health care as

providers attempt to describe the values, skills, knowledge, and attitudes required to provide

optimal care to general and specific populations. The BC Centre for Palliative Care (2018) uses

a Competency Triangle to illustrate that not everyone requires expert skills. I adapted this

triangle (Figure 6) to illustrate required competencies for appropriate care of older adults.
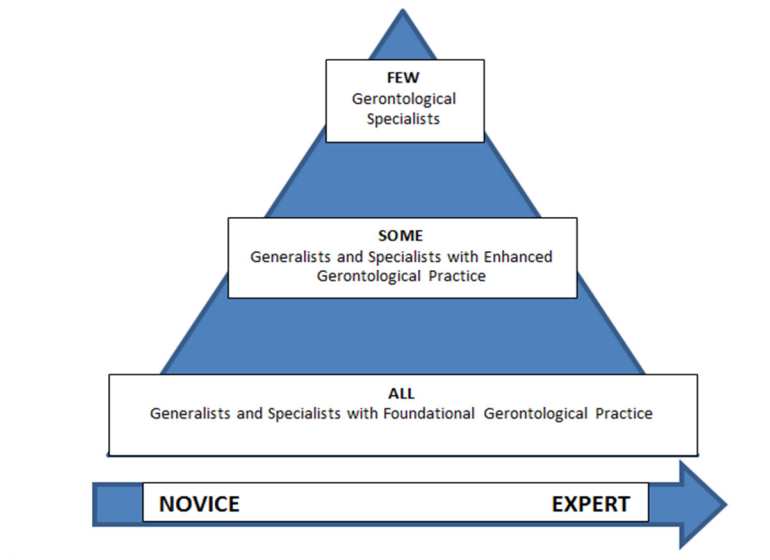
Figure 6. Competency Triangle for Care of Older Adults

There appeared to be very few nurses who had even the foundational gerontological competencies and/or were able to use them. As a result, nurses did not provide appropriate assessments, did not question or follow through on the practice of other nurses, and did not mentor new nurses (student nurses and new graduate nurses) in this practice. Rather than a problem isolated to nurses, I believe this is a symptom of a larger system problem. Noreen alluded to this when she wondered what else was impacting the ED on the day that my dad's fracture was missed. Her response was consistent with Bradley, Webster, Schlesinger, Baker, and Inouye's (2006) identification of the role of senior management in improving hospital experiences for older adults. I suspected a deficit with the system when the nurse in the ED informed me that the ED nurses knew there was a problem discharging my dad on the day that he was discharged with a fractured hip, yet they were unable to prevent it.

Perpetuation of discourses of competency/incompetency are illustrated in nursing notes (Figure 7) from a student nurse who 'taught' my dad postoperative hip precaution procedures. I

remember this incident well because I was in the room when the student approached me and my

brother to explain that she was going to give Dad some teaching. I responded to her that Dad

was delirious; therefore, it was not a good time to provide teaching. It is interesting that her

notes indicate that she went ahead and gave Dad the required teaching before she assessed his

delirium. I assume that the student was required to complete a teaching component integrated

into her assignment of caring for my dad. Flexibility and integration of clinical skills into patient

assessment takes time and practice to become an expert; therefore, I am not surprised the student

was not able to adapt. I have done as much in my own practice as I moved through the stages of

novice to expert. What is more disappointing is that there is no follow-up documentation from

the nurses who were assigned to this student and my dad's care, nor from the student's clinical

supervisor who was on the ward at the time. The student's charting about my dad's

confusion follows the practice of the nurses: there is no indication that it is serious, no specific

assessment for delirium, no investigation, and no follow up.

1240	aas	Teaching	D	Pt was taught how to properly roll onto side when attempting to sit up. Successful as per repeat demonstration. Pt was taught hip precautions, could repeat that he wasn't allowed to cross legs only. Pt left c̄ handouts, teaching needs to be reinforced. Son and daughter aware of the teaching
1300	apls	Neuro	D	Pt states "there is an ant problem here," pointing to the cupboard he said "can you see all the ants? Pt getting increasingly confused, not remembering who or where he was for breakfast ————
			O	Now alert to person only ————
			A	Pt reorientated to place and time reassured pt that there were no ants. Pt sitting at bedside ————

Figure 7. Nursing Documentation C

Nursing documentation also reflects that the nurses did not understand or apply the basic

principles of bowel and bladder health, let alone appreciate implications of age and person-

specific changes to my dad's bladder health. Again, while evidence-informed practice and

clinical practice standards indicate clear guidelines for avoiding indwelling catheters and require

specific indicators for insertion, Figure 8 illustrates that the nursing student inserted an

indwelling catheter (Foley) with no application of clinical practice guidelines and no

documentation of assessment and reasoning that accompanied her decision. Indwelling catheters

pose significant risks to patients and should only be used in exceptional situations (Clayton,

2017; Gould, 2015).

Figure 8. Nursing Documentation D

I remember wanting to talk to the nursing instructor and the nurses about the student's practice,

but feeling hesitant after my previous less-than-optimal interactions with the nurses. I did not

want to be punitive; however, I also believed this was an excellent learning opportunity for the

student. Weighing the risks of further damaging my relationship with the health care team, I remained silent. I also didn't think they would listen to me.

5.2.5   Competency: Listening

My younger brother Jason spoke about the importance of listening to me (the expert). It is evident he trusts me and values what I have to say. It is interesting that none of my participants spoke about my own listening skills: how I listen to others. When my nursing colleagues did not listen to my older brother when he told them my dad was not acting like himself it evoked in me a sense of combat. It is also interesting that my dad is a listener; yet, when he does talk, everyone listens.

During the member-checking process, Noreen challenged my listening experience stating, "People don't necessarily listen to us because of our position or education. [Rather] it is because of who we are and how we show up with that expertise" (personal communication, March 2019).

5.2.6   Competency: Biomedical

Noreen talked a lot about knowledge and skills, implying a deficit in health care providers' skills specific to older adults: "From a cultural perspective it's the risk around the older adult and risk around skill level" (line 95). "I was abundantly aware that the team wasn't 100%" (line 781-782). She also identifies me as an expert on the competency triangle: "Mary, what you bring to the table is exceptional and I believe unusual. You have a heightened sense of risk. Your standards and your level of advocacy for your father are exceptionally high" (lines 168-170 & 942-943). I used this high position of expert to attach judgement to nurses as either competent or incompetent with no in-between. This is evidenced by my use of judgemental language that permeates throughout my autoethnography, which I chose to leave in because it

reflects my thoughts and feelings at that time from my social standpoint. Noreen cautioned me on this social standpoint:

> As you are coming to the end of this part of your educational experience and will be adding an additional degree, please think about who you identify with. A PhD can distance you further from the nurses at the front line. It is as they say, "lonely at the top". (personal communication, March 2019)

This top-down position of expert and heightened level of awareness led to me taking up and performing discourses of surveillance.

5.2.7   Discourses of surveillance

Working intimately with discourses of safety and discourses of competency were discourses of surveillance. There was much talk in the narratives about watching. *I call my brother and we set up a schedule for one of us to be with him at the hospital every day for the next week. Together we will watch over him and keep him safe.*

It wasn't only that we were watching Dad. We were also watching and evaluating the care that was provided to Dad. At first, the health care providers may have been indifferent to our watching. Once I responded offensively by questioning their practice they responded defensively and offensively, adding surveillance of me in return, as evidenced in identification of 'daughter' as the focus in their documentation. The RN who attempted covert surveillance of me by standing next to the sharps disposal container did so because I "appeared confrontational towards [the LPN, her colleague]. She pretended to do something else; however, she was watching me. It became clear to me that the health care team, primarily the nursing component of this team (that didn't include me), were on the defensive against me. From defending others to defending their own practice, the team appeared to be mobilizing on the defensive.

Once they understood how I was able to use power, they retreated and things changed. This change remains reflected in the care my dad continues to receive at this hospital. Whether I am watching or not, he now receives excellent care. Foucault (1995) provides the analogy of the panopticon, where surveillance becomes self-regulated. The panopticon of a prison is designed so that all prisoners' cells face the guard tower, which is located in the centre. This allows for constant observation of the prisoners by the guards. The panopticon was specifically designed so that the prisoners could never be sure if they were being watched or not. In this way, this surveillance method caused the prisoners to self-regulate. In other words, the possibility of surveillance "caused the internalization of disciplinary individuality and the docile body required of inmates" (p. 46).

The effects of surveillance may be evident in the nursing notes (Figure 9) that reflect appropriate interventions from a urinary assessment. The RN used a bladder scanner to identify 415 mls of urine in my dad's bladder. They then indicated that they would monitor and they followed through with that monitoring. Although Dad was voiding, he was voiding small amounts; therefore, they repeated the bladder scan, which showed the amount of urine had increased to 630 mls and an in-and-out catheterization resulted in 575 mls of urine removed from his bladder. This is what I would expect from a nurse who has foundational clinical knowledge of the urinary system. It is interesting that this care was provided after documentation that I was not only watching, but speaking to leaders: the patient care coordinator (PCC) and the manager of the patient care area where my dad was receiving care.

Figure 9. Nursing Documentation E

It is not clear if the staff were more diligent because they knew they were being watched or if this particular registered nurse (RN, documenting above) would have intervened in this way regardless. It is also not known what else was going on the patient care unit that day as Noreen talked about in her interview. Was this a relatively quiet day? Or, did staff make my dad a priority over other patient needs because of my position and influence? In other words, would another older adult who did not have a fierce advocate have received the same quality care on this given day? What is clear is that this nurse had the knowledge and skills and applied them. Discourses of surveillance are closely tied to discourses of trust.

5.2.8 Discourses of trust/mistrust

Discourses of trust and mistrust were woven through all discourses of safety, including discourses of competency/incompetency and discourses of surveillance. My siblings and my dad easily took up discourses of trust as they trusted me to manage Dad's care. I remember my brother-in-law telling me that when my sister attempted a request and was denied by the staff she responded, "Oh well, my sister will take care of it."

I struggled in taking up the trust discourse, which was evident in constant contradictions within my sense of self that inclined toward distrust. My chronic view of self as expert and lack

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of reflexivity prevented me from engaging relationally with the nurses. I wanted to trust my dad's care providers; yet I didn't, and the act of not trusting them made me feel guilty. *I don't trust them. There. I've said it, even though by saying it, I feel guilty, like I am betraying my profession.* I trusted my siblings though: *I am fortunate. I have siblings who I trust and who trust me.* I took up these discourses of trust and used them to discredit the nurses to my family. I engaged in constant judgement of them with an arrogance that served to further set me apart from them. Noreen pressed me on this point during our interview:

> **Me**: One of the discourses that I am already seeing in my data is the discourse of trust/mistrust. I remember the email that I sent you when I was at my wits end. I sent it to you because I trusted you.
>
> **Noreen:** I guess my question would be why didn't you trust them? I think generally patients and families trust the staff. Of course not 100%, there are always exceptions. But even putting myself in this cohort of families and patients, we trust the staff because we recognize them as experts and believe they know best. So, staff hold the trust at least from the beginning. My question for you is, did you not trust them from the very beginning? Like right out of the gate you didn't? Because I suspect that you didn't.
>
> **Me:** You are right. I didn't. The reason I didn't is because I now know what I didn't know as a staff nurse.
>
> **Noreen:** Yes. And I also think that with your area of expertise, your standards are exceptionally high. Which is awesome, not a criticism. But it can put the staff at a disadvantage. (Lines 924-946)

It has been said that nursing is the most trusted of all professions (Milton, 2018). Yet, trust is not always shared between nurses themselves. In her feedback after reading the draft

dissertation, Noreen reflected on her career and moving from novice to expert and the people along the way who supported that growth understanding the shades of grey. She stated:

> Thank goodness [they were there] as I made mistakes, certainly in leadership I've probably made them all. The tolerance, support and guidance of others helped me along the way. Where have we been given the benefit of the doubt? Do we as nursing leaders have an opportunity to support nurses along the journey from novice to expert? Do you have any ability/thoughts about trusting nurses who are moving through that journey even when they are not expert? (personal communication, March 2019)

These are questions I invite you, the reader, to help me explore. I too have made and continue to make my share of mistakes. I am fortunate to have nursing leaders and colleagues support me to manage those mistakes and I believe I return this support by mentoring other nurses in this process. Part of this process is applying the professional standard of responsibility and accountability (British Columbia College of Nursing Professionals, 2018a). This is where ethical concepts such as obligation, responsibility and 'good' action work in partnership with what Hartrick Doane and Varcoe (2007) described as " familiar relationship concepts such as trust, empathy and respect" (p. 193). This is also where relationship has potential to break through the historical culture of bullying and horizontal violence (Townsend, 2016) that has afflicted oppressed groups, such as nurses. My alliance with the physicians and my animosity towards the nurses was a classic illustration of oppressed group behaviour. This behavior is not new. How can we negotiate our worldviews with the understandings of others and open opportunities to think and perform differently? How can we switch our reference from surveillance to support and in doing so shift the discourse of trust? Surveillance and trust

discourses produce and reproduce each other. We watch, or 'stand guard' because we don't trust.

Taking up the surveillance discourse because we don't trust produces powerful effects. Noreen talked about how knowing they are being watched creates more stress on the health care team: "It's like, 'Oh my goodness, now I have to look at absolutely everything I'm doing because now I've got someone looking over my shoulder,' so before you even meet the team it will change their response to you" (line 231-234). Knowing you are watched contributes to discourses of fear.

5.2.9 Discourses of fear

Although fear was not often mentioned explicitly, discourses of fear permeated within and throughout discourses of safety, discourses of competency/incompetency and discourses of trust/mistrust. It is interesting that my brothers and my dad did not talk about fear and I would question if it was even implicit in their interviews. I believe this reflects the discourses of male gender that were available to them. The nurses' defensive behavior may have been a result of taking up the discourse of fear as they were faced with explaining the pain medication that my dad did not receive. Although I attempt to position myself as fearless (and have been told I instil fear in others), it was fear for my dad's well-being that drove my actions toward the staff. This is another contradiction that I wrestle with.

Megan referred to fear as being scared during an incident that happened when she was alone with Dad:

It was pretty scary for me on one of his admissions. I don't know if it was the first or second admission, but I was with him for an extended length of time. He was sitting up in a chair beside his hospital bed and he started to drool and he wasn't able to

coordinate himself. That was pretty scary for me. I called the nurse and she came to see if he could speak. At first he couldn't speak very well to communicate what was happening to him. To this day, I don't know what was going on with him, whether he was having a stroke or what was going on with him. I was probably so scared and maybe in shock myself that I don't know if I processed what was happening or what did happen appropriately, but I believe he did recover from that incident at least a little bit. (lines 39-50)

She also spoke about her general tendency toward fear and my lack of it in relation to risk: "You were always a risk-taker; in fact you still are! I was always afraid" (line 3) (and I would add still is). Noreen talked about how acting in my position of expert caused the health care team to be afraid, which then placed me in a position of risk:

Oh, it's absolutely fear. So, I think that for you, it put you at risk as well because you are the expert in this field. Like, we had no other expert in the health authority that comes with the same level of expertise as you. And now you're a caregiver and adversarial relationship or not, that is very scary. That's possibly perceived as threatening, whether you intend that or not. And I know you didn't. (Lines 205-229)

I'm not so sure I didn't. Noreen is very gracious in this last sentence; however, I wonder how I took up and performed discourses of control using the discourse of fear for my own advantage.

5.2.10 Discourses of control

Discourses of control were threaded through all of the other discourses and were another subdiscourse of discourses of safety. I tend to rely heavily on research and evidence in the literature to defend my practice and actions. I also used this evidence to maintain my position of control. For example, being skilled as a researcher and privy to current evidence-informed

practice gives me a significant advantage over other health care providers who do not have these skills. As evidenced in other literature focused on families providing care for their loved ones in the hospital (Lindhardt, Bolmsjo, & Hallberg, 2006), I responded to the relational tensions by taking up the tug-of-war of control (Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001) in the care my dad received.

Brent alluded to discourses of control when he talked about roles, responsibilities, and expectations:

> I think in your case, when you are trying to deal with the nurses and other stuff that they are not as appreciative as they could be. Like when they ask, "Why are you doing that? This is our job not your job." (Lines 43-47)

In spite of all of my efforts, taking up the safety and surveillance discourses, I was still unable to control the care of my dad in acute care and prevent him from harm as evidenced in my memory when he became delirious: *My dad is delirious. I have spent my nursing career teaching health care providers that delirium is a medical emergency that can often be prevented and I couldn't prevent it from happening to my own dad in my own health authority.*

Being forced to choose the subject position of daughter over expert contributed to the risk of losing control over his care. The subject position available to me as 'daughter' was a passive one. When I tried to take up the active position of 'geriatric expert' by asking questions and sharing knowledge and providing information, I was shut out. This only served to increase the threat of me losing control and becoming a "raging lunatic" as I described in my email to Noreen and correspondence with Belinda Parke. I use the language of 'raging lunatic' and 'the crazy daughter' with caution. These labels or subject positions were in the data; therefore, I believe it is important to include them. I acknowledge the historical negative contribution this language

has had on persons with mental illness. My intention in using them is to be transparent, provide opportunity for critique from the reader and create a new discourse.

In her interview with me, Noreen and I referred to the implications of performing the subject position of 'the crazy daughter':

Noreen: Your exceptional advocacy for your father may have presented some risks in terms of…I hate to use this label, but we have talked about it…the crazy daughter. It may set up the person who is unwell to be…targeted? That's not the right word…

Me: Would [the right word] be stigmatized?

Noreen: Yes! It might create a situation where your dad…I'm not condoning anyone's behaviour but in the current environment it's just that sometimes things are too hard, and there isn't enough time…and now I've got a crazy daughter looking over my shoulder…

Me: …making me nervous. Like, "I'll never be able to please her."

Noreen: Right. And I think that does set up some risk for your dad because then it's like, what's the easy route out? I just won't go see him enough times a day. And when I was thinking more about this, it's like, how sad is that? That we've set that culture up. I don't want to say that we have set it up that that's okay, but as a human nature kind of thing… (Lines 168-192)

In taking up the subject position of 'raging lunatic' and 'crazy daughter' I risked losing my expert *competent* status. Yet, as Belinda explained to me, she believes there is an advantage to or a time to "become a 'raging lunatic'" (Parke, personal communication, August 2013). In other words when being patient, acting rationale and following the rules did not prevent my dad from delirium. I crossed the tipping point and was willing to resort to extreme behavior. These subject positions point to discourses of control, specifically that health care providers may have

difficulty controlling the subject because they (the subject: in this case me) are not acting as a rational being. Therefore, while historically there is risk in these subject positions, there is also power.

5.3   Subject Positions

In addition to the subject positions previously mentioned, there were others that were either available or unavailable to me, depending on the discourse.

5.3.1   Insider/outsider

While I consider myself a full member in the social/cultural world that identifies as "nurses," the staff did not position me in this way. At the time of our initial interactions, they would have had no warrant to position in me in any other way than as a daughter. Although the hospital where Dad was receiving care is one that I cover within my nursing role, it is not one that I frequent on a regular basis and the staff most likely would not recognize me as they may in other hospitals. I am not easily identified as a nurse. I do not wear a type of uniform that would signify me as a member of the nursing community. On the day I entered the ED to see my dad, I was dressed in business clothes and was identified as 'the daughter/family member.' Although I wore my identification badge that signifies me as a nurse, no one seemed to notice or inquire about my position. 'Daughter' was the only subject position available to me. This annoyed me because the pacifist discourse that produced the subject position of daughter was limiting. Power relations are quite different when I am positioned as *'just the daughter'* vs *'the daughter who is a nurse'* vs *'the daughter who is the CNS in gerontology within Interior Health'* vs *'the daughter who is the CNS in gerontology within Interior Health, and the Chair of CRNBC.'* Noreen talked about this:

Even the part about how you were able to access the emergency department. You were able to get into the "inner sanctum" because you had access. It's like, I've got my [security] card that will give me access. I don't have to wait for somebody to press me in. The other thing that sets us up and you up a little bit is that you have a personal relationship with me. So, you can send a note to [the manager and the patient care coordinator of the unit where my dad was cared for] and they see that I am copied on it. And they see that you are speaking quite personally to me. Which is quite appropriate…but it adds another level of, "Oh my God! Not only do I have an expert whose father is unwell on my floor, she knows our boss really well!" So, I can only imagine what is playing out in their minds. (Lines 280-305)

My dad and siblings positioned me as an insider and from their vantage point I held that position, even when I felt it was no longer available to me. All of my participants either implicitly or explicitly talked about me as leader. Jason put it this way:

You are leading. You are a leader and that's appropriate. I think with you steering the ship the risks are mitigated as much as they can be. I think Dad is subjected to a lot less risk than somebody who didn't have an insider in his corner.

Challenging the pacifist discourse the way that I did may have set the tone for an adversarial relationship within the team and created subject positions of 'us' vs 'them', alienating myself from the team, which hadn't even had a chance to begin operating. Troublemakers can be problematic on teams.

5.3.2 Troublemaker

> I'm really attracted to anti-heroes
>
> and I'm a little bit of a troublemaker myself,
>
> and a little bit of a rule-breaker,
>
> and I like spies.
>
> Doug Liman

As a nurse working on the front lines providing direct patient care, I have engaged in the process of interpellation[6] (Butler, 2015; Fomiatti, Moore, & Fraser, 2017) by performing the 'trouble-making family' discourse, going as far as using the discourse to produce the family/patient as "a pain in the ass" (Kjorven, 2009, p.55). For example, I have rolled my eyes and declared to my colleagues, "Oh, that *family*." I have performed the exclusionary discourse binary of us/them. And then I found myself on the other side of the tension: the excluded edge of the binary.

The power of the 'trouble-making daughter' is illustrated in my dad's medication record (Figure 10) with the notation, "daughter requesting prune juice in the [morning]." I find this documentation problematic for a number of reasons: 1) prune juice is not a medication, therefore it does not belong on a medication record; 2) medications are highly valued in health care, therefore perhaps recording it on the medication record produces value; 3) the use of "daughter requesting" points to the power I have to direct care simply as the daughter versus collaborative decisions on sound assessment. In other words, the power of the 'daughter' should not have been used to justify/document the prune juice. Rather, a sound bowel and bladder assessment and follow up should have been the power that was used to direct (or not) interventions.

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[6] Interpellation expresses the idea that an idea is not simply yours alone, but rather, an idea that has been presented for you to accept.

	NEW MEDICATIONS	Transcr-ibed By	Nurse Check	Initials/ Comments
	Bowel care			1200 lactulose
	Daughter requesting prune juice in am			

Figure 10. Medication Record

Performing the troublemaking daughter subject position to ensure my dad received the care I believed he needed was not where I wanted to be either. I was caught in the contradictions and tensions between subject positions.

5.3.3 Contradictions and tensions

At one point during the writing of my autoethnography, as I was unveiling who *I am,* I identified myself as a poststructuralist. This brought a smile to one of my committee members who questioned whether a poststructuralist would identify as a poststructuralist.

There were many contradictions that were evident in my findings including:

- While I believed I leaned toward a poststructural perspective of risk, what became clear in my findings was that my actions reflected my valuing of the realist/positivist position. Noreen remarked on this in feedback to me after reading the draft dissertation. "You kind of touch on things in a black and white way where there doesn't seem much opportunity for grey."

- While I understood the value of relational practice to mitigate risk, I actually put the nurses at risk by taking up the discourses of safety in particular ways, including: 1) taking up discourses of surveillance, making it clear that I did not trust them, and putting them on the defensive; 2) using my power and position to send an inflammatory

message to their boss; and 3) positioning us as adversaries and adding to what may have been their already stressful work environment.

- While I espoused to a value of shared power, I desperately performed discourses of control for the purpose of holding onto power rather than looking for innovative ways to use it, including sharing it.

- The word 'team' was mentioned numerous times by both Noreen and me in her interview and it was implicit in our language that *the team* was distinctly separate from me: "before you even meet *the team* it will change their response to you" (Noreen interview line 233); "that puts *the team* on edge" (Noreen interview line 756); "I was abundantly aware that *the team* wasn't 100%" (Noreen interview lines 781-782); "I didn't want to disadvantage *the team*" (Me interview line 949). In my interview with my dad I talked about "arranging a family meeting with *the team* in the hospital" (Line 116), reproducing the distinction between *family* and *team*. Yet, I desperately wanted to be included as an equal member of the team as a daughter with expertise, a recognition I believe should be offered to any family member. The problem is, the more I asserted myself on the team, the more I felt shut out. Because I didn't feel valued as a daughter with expertise I pulled the biomedical trump card: the clinical nurse specialist in geriatrics. While we (the organization) espouse to move toward a culture of patient-and family-centered care and team-based care it is not clear what that means, how these roles are defined and where patients and families fit within the team. The two terms are in some ways conflated. If family were considered a vital part of the team and actually made a part of the team is that not promoting patient- and family centered care? This

leads to a fundamental question, one I struggle against and one that I invite you, the reader to ponder with me: we call it a team, but is it truly a team?

- The greatest tension for me was attempting to reconcile the positions of daughter and nurse. In the follow up interview with Noreen, I asked her to elaborate on her previous comment, "You need to decide whether you are a daughter or a caregiver" (line 772-773). It was a very troubling assertion from her and a positioning with which I was not comfortable. I asked her, "Why can't I be both a daughter *and* a nurse expert?" She replied, "Because you can't." During the member-checking process she sent me this feedback:

As you note about my comment that you can't be both I probably didn't explain it well enough. As a daughter you bring a whole different dynamic to the relationship and the emotional side of it cannot be ignored or minimized. It is what comes with being a daughter.

The problem was, I desperately wanted to be a daughter and relinquish being a caregiver. I wanted to trust. I wanted to believe my dad would get appropriate care. However I didn't and I couldn't trust that he would. Therefore my response would be the same back to Noreen when she stated that I needed to choose between being a daughter or a caregiver, "I can't".

Noreen gave me two other points of feedback from the member-checking process. First, she stated, "The other thing that is clear in your writing is that you want recognition for what you bring/brought. Please spend some time considering why that is important to you." It wasn't that I wanted to be recognized for being a nurse expert in geriatrics. I wanted to be acknowledged and recognized as a daughter with expertise about who my dad was as a person, as any family member should be. This is important to me because if we (health care professionals) are

espousing to value and practice person-centered care then we need our actions to reflect those

values. These actions include listening to families, assuming families have expertise and inviting

families input on their loved ones. Second, she comments that "The frame of your paper is

consistent with the theme of lack and limitation. Is there a way to shift your own frame of

reference forward that may begin to shift others? We can only start with, and be responsible for,

ourselves." This is another tension and contradiction for me. In my CNS role I spend much of

my time building gerontological capacity. In other words, I teach, mentor and support health

care providers to better care for older adults. The reason I do this is because of the lack of

expertise in providing this care for this population. This does not however negate the importance

of being respectful of those who are not at the knowledge and skill level I want them to be.

Practicing as a poststructuralist requires me to shift my frame as reference as Noreen

encouraged. I will provide a further discussion on these tensions and contradictions within the

liminality section of Chapter Six.

5.4   Chapter Summary

In part one of this chapter, I presented the findings from my research woven into my

autoethnography. I used the process described by Bochner and Ellis (2016) as "systematic

sociological introspection" (p. 67): actively recalling thoughts and feelings from a social

standpoint. In recalling these thoughts and feelings I used various artifacts: data from my

father's charts, conversations from interviews with research participants, emails, and memory.

In part two of this chapter, I presented the most prominent discourses at work within the

data (autoethnography and artifacts) and an analysis of how these discourses were at play, both

informing and being informed by the culture of risk. First, I provided a description of the culture

of risk within my workplace and how that culture contributed to my experience of double-duty

caregiving for my dad. Next, I identified safety as the most prominent discourse that produced

this risk culture. Within the safety discourse I unveiled subdiscourses of

competency/incompetency, surveillance, trust/mistrust, fear, and control.

Within this analysis I described how these discourses were at work to produce subject

positions that were either available or unavailable to me. Moreover, I explored what it means to

perform multiple aspects of identities simultaneously and how taking up and performing multiple

and mobile subjectivities were manifested within interactions with others. I concluded this

chapter with an acknowledgment of the tensions and contradictions within my autoethnography.

Chapter Six: Discussion of Findings, Implications, and Conclusions

This chapter provides a discussion of the findings from my study specific to the aim and objectives. The aim of this study was to evoke a response in readers by drawing on my own subjective experience of double-duty caregiving in the context of risk culture while caring for my hospitalized, frail, older adult father. I welcomed readers into this experience and encouraged comparison and interrogation of their own perceptions with mine. I became vulnerable and revealed the challenges and opportunities I faced. I negotiated my worldview with the understandings of others for the purpose of opening opportunities to think and perform differently. The objectives for this study were:

1. To illuminate how risk culture influences my engagement in the health care system, within the context of double-duty caregiving for my frail older adult parent.

2. To become vulnerable and acknowledge the inevitable privilege I experience as an *insider* and *expert* within this system and take responsibility for my subjective lens through reflexivity.

3. To explore how my multiple identities (nurse; daughter; expert; white, middle-aged, middle-class, divorced woman; etc.) are manifested within interactions with myself and others, and how I take up discourses that produce cultural identities/subject positions.

4. To add to the body of knowledge about nurse family member/caregivers of older adults through writing/sharing my autoethnography.

To begin, using a poststructural theoretical lens, I present the revelation of how biomedical discourses were unveiled as the most dominant discourses that produced the culture of risk within the context of double-duty caregiving for my frail older adult parent. Next, I provide a discussion of my privileged position within this culture and an overall analysis of the

power networks that were operating within my autoethnography. Next, I discuss how I navigated multiple identities while dwelling in the liminality between subject positions of daughter and nurse expert. Lastly, I identify the implications, significance, and contributions of this study and how it may be integrated into existing research in the field of double-duty caregiving within the culture of risk. Within this section, I will identify the strengths and limitations of this research, discuss the potential applications and recommendations from the findings, and provide an analysis of possible future research directions drawing on the work from this study.

6.1   Revelation of Biomedical Discourses

Historically, biomedical discourses have held great power in hospital settings and the pervasiveness of these discourses is well documented in the literature (Brown & Sedden, 1996; Frank, 1991; Grant, Giddings, & Beale, 2005; Neville, 2006). In this section, I present the revelation of how biomedical discourses were unveiled as the most dominant discourses in the data and how all other discourses relate to these overriding biomedical discourses. Through the process of discourse analysis, it became evident that all other discourses identified in this study pointed to discourses of biomedicine. This analysis also revealed the tension between biomedical discourses (including evidence-informed practice) and person-and family-centred care within the context of risk. Cheek (2000) talked about how "within the biomedical discursive field, as in any discursive field, there are many, often competing discourses" (p. 33). "Some will account for and justify the appropriateness of the status quo. Others will give rise to challenge existing…organization and the selective interests which it represents" (Weedon, 1987, p. 35).

6.1.1 Privileging and resisting biomedical discourses

The biomedical discourse has its origins in the nursing profession's close relationship with Western medical practice in which biomedical knowledge and practices have been the most privileged. While I espouse a poststructural perspective of risk - a position that integrates aspects from both the realist/positivist and the strong constructionist positions - the findings from this study showed otherwise. I privileged the biomedical discourse that supports the realist/positivist position of risk. The biomedical discourse continues to dominate my nursing practice of caring for older adults. It is well documented in the literature that there are significant educational needs of nursing staff caring for hospitalized older people (Baumbush, Leblanc, Shaw & Kjorven, 2015; Dahlke, Hunter, Negrin, Reshef Kalogirou, Fox & Wagg, 2019) and a lack of gerontological expertise. For me, clinical credibility and competency is based on evidence informed practice and I expect nurses to be able to defend their practice based on current evidence.

Marshall, West, and Aitken (2013) identified clinical credibility and approachability as key characteristics to building trust between nurses as they sought information from each other for making clinical decisions. For me, there was significant tension between these two characteristics. Clinical credibility is strongly connected to my attachment to credentialing. If I had my way, every nurse would have a certification in gerontology. I believe it provides the foundation for the knowledge and skills required to provide appropriate and safe care for this population. I was acutely aware that the nurses who cared for my dad did not have this credential and I judged them for it, which negatively impacted approachability and ultimately trust. Noreen addressed this issue with me when she asked me to reflect on why I was doing my

PhD and cautioned me that it would further separate me from the bedside nurse. My credentialing and they not being credentialed reinforced mistrust.

Many of my friends are nurses and I consider them 'good' nurses; I have 'good' relationships with them and I fully trust them. I consult them when I have questions related to their area of expertise. I also know their knowledge and skill base, including their credentials and their limitations. Tarlier (2004) outlines that "good" relationships are founded on respect, trust, and mutuality. Hartrick Doane and Varcoe (2007) describe trust as an essential element in relational practice where "trust rests on the patient's belief that the nurse will assist [them] in achieving a good outcome" (p. 193). Baumbusch (2010), in her study documenting her experiences as both a nurse and novice researcher in long-term care, described the complexities of enacting trust when "we are not only positioning ourselves in relation to these multiple selves but we are constantly being positioned by those we are engaging with in the research process" (p. 187).

As nursing leaders we have an additional responsibility to develop relationships "before heading into the difficult stuff" (Noreen, personal communication, March 2019). This 'difficult stuff' includes sharing what historically we (health care providers) have been afraid to disclose: information, mistakes, and choices. Perhaps the reason we have traditionally been afraid to disclose is because we haven't, as Noreen cautioned, developed relationships. I believe having a relationship would make it easier to disclose. In their book, *After the Error: Speaking out About Patient Safety to Save Lives,* McIver and Wyndham (2013) talk about the value of giving information and that 'silence isn't golden.' Unfortunately, when a doctor, nurse, or other health professional makes a mistake, the tendency has been to hide the mistake and drop the 'cone of silence' in fear that if a patient is told a mistake was made in their care, they will be more likely

to file a lawsuit. In actual fact, the exact opposite has happened. For example, in 2001, the University of Michigan Health System adopted a mandatory policy of disclosing medical errors and offering apologies. As a result, the malpractice lawsuits filed against the hospital dropped by a stunning 65% (p. 240).

Foucault explains that in Western industrial society, the medical discourse dominates, often to the exclusion of other types of knowledge that are dismissed as non-objective, irrational, and unable to be verified by measurement of some kind (Foucault, 1995). What I valued in the documentation in the anesthesiologist report was that it was succinct, objective, thorough, accurate, included the reference to "all questions were answered", and paralleled what the British Columbia College of Nursing Professionals (2018b) outlines for nursing documentation standards. This standard directs that documentation is "clear, concise, factual, objective, timely and legible" (p. 2).

While I took up and performed the truth of the biomedical discourse as it related to older adults, what was revealed in my study was that what made the difference in my experience was not biomedical competency but *being listened to.* This was evidenced in my conversation with my dad's nurse on the day I discovered he was delirious. Listening is a key component of both patient- and family-centred and team-based care. Yet, it is often dismissed as a 'soft' skill. In Gregory David Roberts' novel, *Shantaram* (2003), the protagonist (Lin) learns about power and being listened to, not necessarily in that order:

Karla: "Being listened to – really listened to – is the second-best thing in the world."

Lin: "What's the first best thing?"

Karla: "Everybody knows that. The best thing in the world is power."

6.1.2 Power and listening

Listening is powerful. As professionals in geriatric medicine and social work, Kaiser and Kaiser (2017) described how their experience of caring for their aged mother during one hospitalization quickly repositioned them from insiders to outsiders in a system where "the patient and family are not consistently listened to, or integrated, into the clinical team" (p. 46). In my experience of double-duty caregiving, it was being listened to by the physicians that created in me a sense of safety. In contrast, the feeling of not being listened to by the nurses or integrated into the clinical team left me on the other side of the binary: I did not trust them. I did not believe they were competent and I did not believe my dad was safe in their care. It is important to note here that the quantity of time I spent with the physicians was very short compared to the daily front-line contact with the nurses. Perhaps if I had led the way by listening to the nurses instead of attacking them I may have been able to build a relationship of trust and I might have received more of the information I was seeking.

From a poststructural perspective, it is not about choosing a biomedical discourse (knowledge and skills) over a relational (listening and being present) discourse. Rather, it is acknowledging the power and usefulness of both and understanding how and when to take them up for a particular purpose, in this case better outcomes for my dad.

Powerlessness is present when relationship is absent. When relationship is absent, doing something technical is, at times, the only possible response. The narrow focus on technical care, body systems, and laboratory tests, in the face of human suffering of the whole patient, eventually dehumanized both the patient and the caregivers; these people forget who they are. (Bergum & Dossetor, 2005, p. 95)

6.2   Power: Where is it?

It is well documented in the findings that I held significant positional power. The discourses available to me because of my expert position were significant, although, not unlike other powerful discourses, they were not invincible. Following the ideas and writings of Foucault and others who have expanded on his work, I too "do not offer the possibility of a power-less situation either in health care or elsewhere" (Cheek, 2000, p. 31). As Smart (1991) explained:

> It is clear therefore in Foucault's terms there can be no power-free or power-less society, no millennial end of history towards which oppressed, exploited or dominated subjects may be led or guided, for relations of power, that is ways of acting upon the actions of (other) acting subjects, are endemic in society. (p.169-70)

The nurses in my story were not powerless. They had and used power to shut me out, demonstrating what Cheek (2000) described as "resistance at the very edges of these power networks in the hospital ward or in the home" (p. 32). I also believe the nurses held power in the ED the day that my dad was discharged with his broken hip. However, because they were working in a system driven by economics and efficiencies, they were not able to use that power on that day to prevent/protect my dad from assuming the subject position of a 'bounce back'. Instead of fighting against power or "working to overcome or eliminate power entirely, it may be possible to work with it at different sites of the capillary relations of power that pervade any context, including the health care setting" (Cheek, p. 32).

6.3   Dwelling in the Liminality

Rush, Kjorven, and Hole (2016) describe the "rupture between the binaries" (p. 499) in their study with older adults who resisted the subject positions of 'disabled' and 'impaired'

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because they didn't see themselves as either abled or disabled. In this case, the older adults "constructed new subject positions – a liminal, 'in between' that resisted a devalued disabled/impaired subject position while holding onto the highly valued abled subject position" (p. 499). In my case, I saw myself as *both* daughter and nurse expert and I was frustrated, feeling that I was forced to choose one or the other. In other words, my struggle was moving from what I experienced as a nurse/daughter to a nurse-daughter position. This struggle is reflected in Olge and Glass's (2006) description of mobile subjectivities and how "the notion of the unified rational author appears to be expected for credible scholarly work and dominates other conceptions of subjectivity and identity even in articles arguing for different conceptions of subjectivity" (p. 170).

Over a quarter of a century ago, Butler (1990) challenged the taken-for-granted sex-gender binary. Drawing on poststructural insights, Butler deconstructed the notion that gender was an essential quality or inherent identity arising from biological sex, where human beings were divided into two groups, women and men (Hole, 2007). Butler successfully argued that gender "is an act that grows out of, reinforced and is reinforced by societal norms and creates the illusion of binary sex" (Morgenroth & Ryan, 2018). This reified sex/gender binary limits and closes down identity options (Hole, 2007). At the time, it was considered common sense that the biomedical subject positions of male/female were concrete categories and, therefore, the only options available to persons. Butler highlighted the instability of these identity categories and today conversations that serve to disrupt this binary are mainstream.

Although gender was not necessarily a focus of this study, I believe it deserves a mention. I am a daughter and a caregiver, both gendered positions and I wonder how the experience would have been different if I had been a male nurse, a son, and/or a male caregiver? Anjos, Ward-

Griffin and Leipert (2012) drew on relational theory of gender in their study of men who were double-duty caregivers. Their findings indicated that professional affiliation complicated men's family care-giving in different ways than it did mine. Where double-duty caregivers who were men were at times expected to take on more of a personal care role, they were able to exempt themselves of these responsibilities by appealing to gender norms, where these tasks were traditionally viewed as "women's work". These gender norms enabled them to adopt a more managerial role.   What was similar to my experience was that "although their nursing background afforded advantages with regard to resources and skills, they were disadvantaged in terms of conflicting expectations, which ultimately caused them to lose their sense of control" (Anjos, Ward-Griffin, & Leipert, 2012, p. 120).

Ward-Griffin and colleagues have placed a significant focus on gender in their studies (St. Amant, et al., 2015; Ward-Griffin, St. Amant & Brown, 2011) and identified compassion fatigue as a significant risk for nurse-daughters who were "unable to escape from the 24/7 responsibilities of caregiving" (Ward-Griffin, 2013, p. 15) and who were taking on the "bulk of care" (p. 15) providing care "around the clock". This was not my experience. I have not provided this type of continuous personal care to my dad. I have not felt fatigued or "at risk for mental exhaustion and/or physical illness such as hypertension" (p. 15). My older brother, while not providing this care himself, manages the day-to-day aspects of dad's care. What was similar to my experience was that I was:

> positioned [both by my family and myself] within [my family] as having specific inside
>
> knowledge that was derived from [my] professional role, and often selected by [my] family
>
> to be "in charge" of care. As a result, [I was] expected to interact with the health care

team, to keep [my] family informed of what is happening, to interpret meaning for them and to assure that "proper" care [was] administered. (Ward-Griffin, et al. 2015, p. 60)

Hole (2007) discussed how poststructural analysis revealed that participants in her study performed multiple and complex identities based on their hearing status. This was my experience as I resisted choosing between the binary positions of daughter and nursing expert in gerontology. My status of CNS in geriatrics was steeped in power imbued by biomedical discourses. My position of daughter was assumed to be passive because of the historical culture of patients and families being passive recipients of care (Stempniak, 2014). I wanted to be recognized as an expert solely because I was a *daughter* and knew my dad; however, I felt I was forced to take up the position of 'crazy daughter' and/or the 'trouble-making daughter' (or nurse expert to gain expert status) for my dad to receive quality care. Although I wanted my position as daughter to provide me equal status on the health care team, it was never enough.

I shifted around in the liminality between daughter and nurse expert taking up subject positions of acquiescer, adversary, aggressor, ally, colleague, contrarian, informant, insider, outsider, researcher, resistor, and troublemaker (to name a few). In the Rush, Kjorven, and Hole (2016) study, "older adults resolved the contradictory identities (of being both abled and disabled) by shifting their subject positioning between overcomer and complier" (p. 499). I shifted my subject positions for the purpose of mitigating biomedical risks to my dad. Bochner and Ellis (2016) state that "ultimately liminality ends in recognition" (p. 67). For me, this recognition was resolving what I saw as my contradictory identities (nurse/daughter) to complimentary positions (nurse-daughter) that served different purposes at different times during my dad's hospitalization. Like Olge and Glass (2006) who resisted the notion of a "unitary subject occupying a sole, rational, and unified position" (p. 170), the first step for me was

revealing and 'troubling' the taken-for-granted assumptions that underpin discourse. Troubling

involves a certain way of thinking about texts and a certain way of reading them, not to find 'the'

meaning of that text but to uncover the assumptions that support the discourse (Cheek, 2000;

Olge & Glass, 2006). Cheek (2000) illustrates the possibilities afforded by this approach by

shifting or reversing the terms in binary positions. For example, what would be the effect in the

practice setting of the following reversals: practice-theory; nurse-doctor; *daughter-nurse*?

Other double-duty care providers and gerontological experts have experienced similar

shifting identities. Kaiser and Kaiser (2017) were positioned as insiders in the health care system

as professionals in geriatric medicine and social work. They too became outsiders as they

attempted to care for their mother of 90 years when she was admitted to hospital. Like me, their

"training and experience gave them a solid understanding of the hazards of hospitalizing an

elderly person and the need to be present, engaged, attentive, active and vigilant" (p. 46). Like

me, they caught and corrected major mistakes, and like me, their experience was that as family

caregivers they were not formally and consistently integrated into the health care team. While

organizations espouse transformative change that shifts the patient and family to the center of the

team, it appears patients and families are still feeling shoved to the periphery.

6.3.1   Team-based care

Recently my organization has developed directives (Interior Health, 2018) for 'team-

based care' as an approach to person- and family-centred care within my workplace. This

approach is defined in a policy direction overview as:

> …care that promotes the person voice, person safety, and acceptability in care delivery,
>
> thereby creating better experiences for individuals, their families and caregivers, and

providers in the health system. Interdisciplinary teams and all team members are called to:

- Provide person-centred care

- Improve information and understanding

- Ensure informed decision making

- Enhance understanding of self-management strategies for individuals, families and caregivers, and

- Apply principles of dignity, respect, information sharing, participation and collaboration. (p.1))

The assumption is that the person and family are at the centre of this team. This is problematic for a number of reasons. This is a significant change in culture where the person and family have traditionally been on the periphery of the team, if acknowledged to be a member of the team at all (Fry, Gallagher, Chenowith, & Stein-Parbury, 2014; Hanson, 2016; Kaiser & Kaiser, 2017; Olivet & Harris, 1991; Ward-Griffin, 2004). Teams and the roles of team members need to be clearly defined. Teams take time to build and go through several forming stages before reaching a stage of productivity (Farrell, Schmitt, & Heinemann, 2001). In acute care hospitals, health care teams often consist of a group of disparate individuals. In my case, this group included me, my dad, my family, the staff (that often changed from shift to shift), and the physicians.

The critical body of literature on who serves as 'expert' and who holds 'expertise' within patient-and family and team-based care is growing (Fox & Reeves, 2015; Larson, Sharma, Bohren & Tuncalp, 2019; Sidani et al., 2018). A study by Fox and Reeves (2015) found that rather than putting the patient at the centre of the care team, the discourse of interprofessional

collaboration and patient-centred care reinforced a patient compliance model supported by deeply embedded interprofessional and professional–patient hierarchies. Delivering patient-centred care through an interprofessional team faces the challenges of needing to define not only how the knowledge, skills and effort of each member of the team centres around the patient, but also how the health care professionals relate to one another, the patient and the family (Gachoud, Albert, Kuper, Stroud & Reeves, 2012; Kim et al., 2017).

My attachment to credentialing and judgement of nurses who do not have it promotes hierarchy and impedes collaboration, one of the key principles of team-based care. Chinn (1995) talks about 'the power of integration' (p.10) as viewing "all aspects of a situation in context without value-laden judgments" (p. 10). While I espouse to a poststructural perspective and looking at power differently I acknowledge that it doesn't come easily. I am attached to a system of privilege that operates in society and supports the discourse of competency/incompetency by self identifying as 'expert'. Rothenberg (2005) explains that the first step to dismantle this system of privilege is to name it, and the second step is for those of us with privilege to use our privileges to speak out and create change. I believe the first step for me is to share my autoethnography, to reveal my struggles and contradictions, to expose my vulnerabilities and invite critique and feedback to speak out against this system as a whole. While I remain curious about credentials because it helps me understand (acknowledging only to a certain 'level') what people know and how they know it, I have stopped identifying as an expert in geriatrics. For now, I choose to identify as a specialist because it reflects my knowledge while at the same time collapses the power-over (Chinn, 1995) of hierarchy.

This leads to one of the key implications from this work: autoethnography connects the personal to the social (Adams, Holman Jones & Ellis 2015; Chang, 2008; Ellis, Adams, &

Bochner, 2011; Holman Jones, Adams, & Ellis, 2013; Reed-Danahay, 1997). This research acknowledges that the self, the subject or focal point of the study, is a member of certain cultural groups connected to other cultural groups. As Chang (2016) explains:

> individual selves are shaped by their sociocultural environments or the "historical, cultural, and biographical conditions" (Denzin, 2014, p. 124). This also means that the researchers' personal experiences of social phenomena are not idiosyncratic (peculiar) but sociocultural (shared). With this understanding, personal experiences are explored as a window to the understanding of others in society. The ethno-component of this research method expects autoethnographers to move beyond merely "narrating" their personal experiences toward "analyzing," "interpreting," and sometimes "theorizing" the sociocultural meanings of their personal experiences. Sociocultural interpretation would also require researchers to understand their sociocultural context beyond their lived boundaries. (p. 445)

6.4   Implications of this Study

This study is unique in using autoethnography to look at double-duty caregiving for an older adult parent within the context and culture of risk. Autoethnography informed by poststructural perspectives offers novel insights that may not be gained from other qualitative research methodologies. By examining my subjective experience in relation to the cultural context of risk and acknowledging that there is no single truth readers are able to become engaged both emotionally and cognitively (Peterson, 2015). This gives readers the opportunity to connect with my story through their own experiences. By engaging readers to think, feel, reflect and critique, autoethnography offers great potential to connect with a broad audience who may not access traditional nursing research (Bochner & Ellis, 2016; Peterson, 2015).

6.4.1 Implications for health services research

By becoming vulnerable, exposing my personal story to both the academic and clinical practice audience and inviting public scrutiny, I opened possibilities for further investigation into sociocultural interpretation of my experience. Lohr and Steinwachs (2002) provide a definition for health serves research as:

> the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being. Its research domains are individuals, families, organizations, institutions, communities, and populations. (p. 16)

Autoethnography allowed the telling of the "subjugated knowledge" or what Denshire (2010) referred to as previously untold, often oppressively silenced stories in order to bring the previously silenced knowledge to light so that others gain a new understanding about the health care experience. As a clinical nurse specialist, researcher and insider in the health care system I was able to publicly share the process of accessing my dad's medical information, a process that traditionally has not been disclosed or encouraged for patients and families. Autoethnography allowed me to convey aspects of my experience and analysis of myself that otherwise may be inaccessible due to power dynamics, embarrassment, or lack of trust (Peterson, 2015). My intent was not to disclose that nurses were incompetent, did not want to partner and/or did not engage in patient and family centered care. Rather my intent was to draw on my own experience to examine the interplay between self and culture. In doing so I needed to unveil my own secrets and position myself as the vulnerable person to achieve a new understanding of reality, the self

and truth (Peterson, 2015; Tierney, 1998). Perhaps the most vulnerable question remains: was I ever vulnerable?

Whenever I tell my story I often hear from other nurse-care-givers that "it happened to me to". Most often these nurses are in similar positions of power as me. We are privileged and we often tell the same stories. Peterson (2015) explains that autoethnography's greatest potential in nursing lies in allowing nurses' voices to be heard in a new way. This offers the opportunity to break barriers of silence and challenge dominant forms of repression, allowing nurses to promote social action or social justice.

Chang (2016) proposes five standards for judging the quality of autoethnography in health research:

1. *Authentic and Trustworthy Data:* Does the autoethnography use authentic and trustworthy data?

2. *Accountable Research Process:* Does the autoethnography follow a reliable research process and show the process clearly?

3. *Ethics toward Others and Self:* Does the autoethnography follow ethical steps to protect the rights of self and others presented and implicated in the autoethnography?

4. *Sociocultural Analysis and Interpretation:* Does the autoethnography analyze and interpret the sociocultural meaning of the author's personal experiences?

5. *Scholarly Contribution:* Does the autoethnography attempt to make a scholarly contribution with its conclusion and engagement of the existing literature?

    (p. 448)

6.4.2 Authentic and trustworthy data

Personal memory is central to autobiographic data. However, it has been argued that "memory can wane and become distorted over time" (Chang, 2016); therefore, autoethnographers can increase the possibility of collecting rich, authentic and trustworthy data by engaging in other data collection techniques such as self-observation, self-reflection, self-analysis, document and artifact collection and interviews with others. In addition to collecting such data I documented my data sources, collection and analysis processes in this dissertation.

Rather than moving the interview data to an appendix I included vignettes of the interviews with my participants within the findings section in part to engage the reader to interact with the data and critique my analysis of the data. I encourage my readers to "hold the measuring stick" (Chang, 2016) for the accountability and/or trustworthiness of my research.

6.4.3 Accountable research process

I followed research processes used and taught by leading researchers and writers of autoethnography including Anderson (2016), Chang (2008), Ellis, (1995, 1996) and Ellis and Bochner (2016). I was systematic and explicit in outlining my methods within this dissertation.

6.4.4 Ethics towards others and self

Bochner and Ellis (2016) talk about the ethical challenges that present when writing about others, including family members. Like many of their students, I struggled with what to write about my dad and how to write it. Like many of the family members of Bochner's and Ellis' students', Dad told me to write whatever I wanted, however I wanted to write it. He even gave me consent to use his own name, something that goes against traditional research principles, not that autoethnography would ever be described as traditional research. Yet, I need to meet academic requirements for the PhD and satisfy expectations from the academy and my

research committee. In order to meet the REB (Research Ethics Board) requirements, I specified in my proposal that I would use pseudonyms for my participants. Now I wonder whose interests I was really serving. I think my dad would be proud to have me use his real name. At the same time, I believe my dad is so proud of me he would do anything I asked to help me get my PhD.

In her book, *Giving an Account of Oneself,* Butler (2013) explores whether it is possible to truly give an account of oneself:

there is no "I" that can fully stand apart from the social conditions of its emergence, no "I" that is not implicated in a set of conditioning moral norms, which being norms, have a social character that exceeds a purely personal or idiosyncratic meaning. (p. 7)

She then talks about rethinking responsibility in relation to the limits of self-understanding that make us human. There are limitations to this work, including limitations to my self-understanding and the understanding of others. I acknowledge that my choice of research methods was limiting. I performed discourses of control by using semi-structured research questions because I anticipated my family may have difficulty talking about risk, as evidenced in the limited data I obtained from my family participants compared to data from the one nurse participant. What is also evidenced is that I led my family in these discussions where I did not perform the same way in my interview with the health service administrator. I acknowledge that the questions and subquestions I asked, including the examples I provided to draw data out of my family participants, reflected where I stood: as *the expert.* Although there was no intent to lead them to affirmative answers to my questions or to validate my actions, their struggle to understand the meaning of risk led me to coach and lead them in particular ways). This difference also reveals the glaring gap between health care providers' and families' control of care. As Ellis explained, "As is true with the rest of life, sometimes we do it right and

sometimes we make mistakes or in hindsight see a better way of doing things" (Bochner and

Ellis, 2016, p. 149-150. Perhaps the most significant limitation is that the voice of the health

care providers who cared for my dad while he was in hospital is missing.

6.4.5   Sociocultural analysis and interpretation

Keeping in mind that "autoethnography is not about focusing on self alone, but about

searching for understanding of others (culture/society) through self" (Chang, 2008, p. 48-49), I

invited readers to use my story and experiences for their own sense-making. I unveiled and

critiqued sociocultural structures, including historical perspectives of risk and the influence of

risk culture on in-the-moment caregiving.

6.4.6   Scholarly contribution

My study supports previous studies that have shown that patients and families can

provide important safety information to health care providers that reduce adverse events and

positively impact their health outcomes (Vincent and Davis (2012). However, "establishing a

proper and fruitful role for patients [and families] to play in their own [and loved one's] safety is

not straightforward, and many issues remain to be resolved" (p. 16). As evidenced in my study,

challenging staff or being contentious can be risky. Engaging in relationship and valuing family

members as care experts and a source of support may better equip the health care team to address

this perceived 'lack' of gerontological expertise in acute care.

This is a distinct contribution to the body of knowledge regarding double-duty caregiving

for older adult relatives. This study serves to uncover how biomedical discourses serve to hinder

the evolution of patient- and family-centred care. I believe this study will add to existing

knowledge on this topic and open possibilities for effective change in the way we operate as

subjects within a system of health care.

6.5   Recommendations

There is an unlimited scope for future research in the areas of risk, double-duty caregiving, person- and family-centred care, team-based care, and relational practice. New research on patient- and family-centred care is exploding (Park, Giap, Lee, Jeong, Jeong, & Go, 2018). Future research into how best to shift the focus of risk imbued by biomedical discourses to a patient- and family-centred and team-based approach is essential, including:

1. A need to re-evaluate the culture of risk when caring for older adults. It is uncommon to acknowledge the positive effects of risk, especially in an acute care setting. Managing risk and maintaining safety for an older person within a person- and family-centered approach requires healthcare providers to think differently and challenge previously held assumptions. For example, dad's nurse told me that he hadn't had anything for pain because he "denied pain for the entire shift"; she believed she was doing the right thing within a patient-centred approach. I responded with arrogance based on my nursing knowledge that pain is also evident in verbal cues: holding one's breath and wincing. We could have managed this tug-of war better with a relational approach which is founded on three essential elements: respect, trust and mutuality (Hartrick Doane & Varcoe, 2007). I could have used the opportunity to share what I knew about my dad (that he will always respond verbally that he is not in pain) and what I have learned about his non-verbal responses to pain (reluctance to mobilize). Together, his nurse and I could have provided teaching to dad about safe ways to manage his pain. If, after this collaborative approach, dad chose not to receive pain medication, then I

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needed to respect that choice, including respecting both him and his nurse.

Hartrick Doane and Varcoe (2007) highlight the way in which "familiar

relationship concepts such as trust, empathy, and respect work in concert with

ethical concepts such as obligation, responsibility, and "good" action (p. 193).

What I consider good action (assuming and treating pain in a postoperative

older adult) may interfere with the older adult's choice of risk: maintaining

control by choosing to live with pain.

2. A need to re-evaluate risks not only to older adults, but also to double-duty

caregivers who provide familial and professional care. There are many ways

that double-duty caregivers provide care, from 24/7 care including personal

care to episodic, specialist care. The risks are just as varied, including

compassion fatigue and risks in working and familial relationships. There is a

need for health care providers, managers and policy makers to consider the

unique subject positions of double-duty caregivers and to validate their

positions within the interprofessional team. Although

multidisciplinary/interprofessional team approaches to care are not new, there

is a need for a critical analysis of the processes of integrating team-based care

and person- and family-centred care. It is not as simplistic as adding the two

together and expecting better outcomes. Health care policies need to be

revised to support family caregivers as an integral component of team-based

care. Ward-Griffin and colleagues (n.d.) developed a policy brief that outlines

recommendations that can support double-duty caregivers to balance

professional and familial obligations including:

a. Employers should converse with double-duty caregivers in their workforce about familial care expectations, resources that are being used and missing, and how caregiving roles are impacting labour force participation and health status.

b. Health care administrators, human resource managers, researchers, policy makers, health provider associations and union officials should collaborate to conduct a comprehensive review of the current supports and strategies that are relevant to double-duty caregivers.

c. Government officials, employers, union representatives and researchers should continue to work collaboratively to enhance workplace supports and human resources policies that recognize and support double-duty caregivers and create care-giver-friendly workplaces.

d. A specific amount of the government transfer of health care dollars should be targeted to achieve measurable outcomes in the improvements to family and friend caregivers.

e. Governments should adopt a caregiver recognition act to acknowledge the social and economic contributions of family caregivers.

f. Professional associations should lobby government to institute caregiver's rights that recognize the value of caregivers' unpaid labour.

(Ward-Griffin, et al. n.d.)

3. An urgent need to address the knowledge and practice gaps in front line staff specific to caring for older adults. Acute care health care providers require better knowledge about the older adult population in order to mitigate risks and promote patient- and family-centred care. It is time to recognize geriatrics for the specialty that it is and to admit that the majority of our acute care hospital population consists of geriatric patients. There is a need for managers to examine the processes within their care areas that promote function for older people and interprofessional collaboration that includes the patient and family and addresses system issues that contribute to gaps

4. An urgent need for the nursing profession to engage in renewed critical analysis on power within our profession. Other nursing researchers (Baumbusch, 2008) have identified the need for nursing to advocate not only for patients and families, but also for our colleagues; yet movement has been slow. Nursing needs to use power as a capillary network of power relations, rather than a top-down approach between nurses. Nursing researchers, specialists, managers, administrators, and direct care providers need to co-create innovative ways to use our power, constructing opportunities to build and maintain trust in the process. Leaders need to self-examine their use of legitimate power that comes from their professional positions.

6.6   Conclusions

In this study I found that powerful discourses were at work in offering/withdrawing subject positions that were available to me within the culture of risk and double-duty caregiving for my older adult parent. These discourses included discourses of biomedicine, discourses of

safety, discourses of competency/incompetency, discourses of surveillance, discourses of trust/mistrust, discourses of fear, discourses of competition/collaboration, and discourses of control. This study illustrates the value of a poststructural methodology to expose and unveil the hegemonic influences that serve to direct the way health care is provided in certain ways. By exposing these influences through a process of discourse analysis, it is possible to challenge, resist, and reshape powerful discourses with a purpose to inform new practice. By illuminating and exposing existing discourses, not as good or bad, but rather as how they are used to direct the way we engage in risk within the context of person- and family-centred care and caring for older adults, it is possible not only to imagine, but to realize new possibilities. These possibilities have great potential to create positive changes not only in improved outcomes for hospitalized older adults, but also in improved satisfaction for families who are double-duty caregiving for these older adult relatives.

A thought in closing:

I have discussed this work with many people including academics, friends, family, colleagues, and others. Bochner and Ellis, 2016 support that "the reader be conceived as a co-participant, not a spectator, and given the opportunities to think with (not just about) the research story (or findings)" (p. 56). Therefore I invite you, the reader, to compare and interrogate your own perceptions with mine and explore opportunities to think and perform differently. I welcome your feedback and the meaning that this autoethnography created for you. I echo Bochner's thoughts:

> I want to remind you that this is my version of these events. Other people might tell it differently. I lived through this period. Now I'm looking back, remembering and trying to make sense of it. That's often what autoethnographers do. We frame and cast our

vision over experiences through which we've lived, and we invite others into

conversations about meanings of these events. (Bochner & Ellis, 2016, p. 46)

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Appendices

Appendix A: Glossary of Terms

Ableism: Discourses of ableism produce the able, strong, and productive self/body as normal and its binary (disabled, dependent, and unproductive) as abnormal.

Cognitive Science/Psychology: The study of mental processes such as thinking, attention, language use, memory, perception, problem solving, and creativity that is used to explain human attitudes, behaviours, and actions.

Compulsory Abledness: The need to appear and identify as able and normal.

Critical Realist Perspective of Risk: An approach which adopts a weak *social constructionist* perspective by arguing in relation to risk that harmful phenomena exist outside of human perception and understanding and that historical, social, cultural, and political processes produce the ways in which these phenomena are identified, named, and treated as risks.

Cultural/Symbolic Perspective of Risk: An approach built upon the writings of Mary Douglas, which looks at notions of risk as used to establish and maintain conceptual boundaries between Self and *Other*.

Discourse: A way of representing and discussing people, events, ideas, or things, as expressed in a range of forums, from every day, to the popular media and the internet, to expert talk and text; a discourse is also a social boundary defining what can be said and what cannot be said.

Edgework: A term used to describe voluntary risk-taking activities that challenge and test sociocultural boundaries.

Governmentality: A theoretical concept drawn from the work of Michel Foucault that addresses the rationalities and strategies by which subjects are governed and rendered productive in *neo-liberal* societies.

Governmentality Perspective of Risk: A theoretical approach that uses the *governmentality* literature to understand the role played by risk in the organization and management of societies.

Ideology: A collection of doctrines or beliefs shared by members of a group. It can be described as a set of conscious and unconscious ideas that make up one's beliefs, goals, ideas, and motivations.

Interpellation: A process in which we encounter the values of our culture and internalize them. Interpellation expresses the idea that an idea is not simply yours alone but rather an idea that has been presented to you for you to accept.

Older Adults: A population greater than 65 years of age and heterogeneous (not only different from younger people but different from each other in a variety of ways).

Other: An individual or member of a social group who is considered radically different from the Self.

Poststructuralism: A theoretical perspective that looks at the constitution of bodies, selves, and knowledges via language and *discourse* and that emphasises the pleural, contingent, hybrid, and performative nature of these phenomena.

Realism/Positivism: The belief that we see reality objectively and without bias.

Risk Society: The term used by Ulrich Beck to describe a transitional period in late modern societies, incorporating the concept that the processes of modernization have not only produced 'good' things such as wealth and employment, but also 'bad' things such as risks.

Risk Society Perspective of Risk: A sociological approach to risk based on Ulrich Beck's writings on *risk society* that draws attention to the macro-sociological processes that are characteristic of late modern societies, including *reflexive modernization* and *individualization.*

Social Constructionism: A perspective that looks at phenomena such as risks as always knowable and mediated via social and cultural processes rather than as pre-existing objective realities.

Structuralism: An approach in social theory that concentrated on identifying the underlying structures, hierarchies, and cultural categories shaping peoples' experiences, behaviours, and beliefs.

Technico-Scientific Perspective of Risk: Risks common to technical and scientific approaches, which sees risks as objective hazards, threats, or dangers that exist and can be measured independently of social and cultural measures

Uncertainty: In the governmentality and 'risk society' literature, uncertainty refers to situations in which risk cannot be deployed and where reliance is placed on other subjective techniques of estimating the future. However, this distinction is not rigidly adhered to and in some governmentality accounts uncertainty is used to refer to both risk and uncertainty in the narrower sense.

World Risk Society: An outcome of globalization, in which nation-states are inextricably interconnected with each other and therefore risks cross borders and are shared. Responses to risk must therefore take place at a global rather than national or local level, involving new alliances and strategies.

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Appendix B: Information and Consent Form: Father

INFORMATION and CONSENT FORM: FATHER

Title of Research Project:	Keeping dad safe: An autoethnography of double-duty caregiving in the context of risk as an Advanced Practice Nurse in geriatrics caring for a hospitalized frail older adult parent
Principal Investigator and Supervisor:	Kathy Rush, PhD, RN, Associate Professor, Faculty of Nursing, University of British Columbia Okanagan. Email: Kathy.Rush@ubc.ca
Co-Investigator:	Mary Kjorven, RN, MsN, Clinical Nurse Specialist, PhD Candidate, University of British Columbia Okanagan. Phone (250) 826-0671 Email: Mary.Kjorven@interiorhealth.ca

Purpose of the Study: The purpose of this study is to create opportunities for change. By asking and answering questions about my experience of caring for you during your hospital admissions, I as a researcher/daughter/nurse/expert, and those who read my story might better understand these experiences and the emotions they cause. This study is part of Doctoral studies in the Faculty of Interdisciplinary Graduate Studies at the University of British Columbia Okanagan.

Background: Canada's population is aging and older adults use a lot of health care. Older adults like you are often seen to be at risk of harm in daily life and if you end up in the hospital some of your risks can increase. Family members, especially those who are nurses, often feel the need to protect their older adult relative from these risks. Family member caregivers who are also nurses and hospital staff may not always agree on your care. This can make it difficult for everyone.

Who Can Participate?

I will be the main participant in this study. Four other people are invited to participate: you, my sister, my brothers, and the (since retired) Registered Nurse who was the Health Service Administrator at the hospital where you were admitted. I am inviting you to participate because my research will focus on my involvement in your care when you were in the hospital.

What Does the Study Involve?

I will write my story of caring for you during your two admissions to hospital (July 2013 and June 2016). I will write this story using my memory, my notes and, should you choose to participate, information from you including your medical charts. I will interview you (approximately one hour) at a location that is convenient for you and where your privacy can be respected and ask you a few questions about your thoughts and feelings specific to me caring for

you during your admissions to hospital. After I interpret your medical charts and your interview I will ask you to validate my interpretations within a short interview (approximately one hour). With your consent, these interviews will be digitally recorded. If you agree to participate in the study, I will ask you to sign a consent form. No study procedures or data collection will begin prior to this consent form being signed.

Risks

As you know, there are always relationship risks when providing feedback. For example, your feedback to me may change the way I provide care for you and/or the way you relate to me and/or my brothers and sister (either positively or negatively) in the future. If you notice this causing strain in our relationship I will provide time to talk about these concerns with you at a time that is convenient for you.

Benefits

One of the benefits of participating in the study is that it will provide you the opportunity to add your thoughts and feelings about me while I was caring for you when you were in the hospital. The information you provide may not contribute to any immediate changes for you but may help people understand how risk impacts people like you and me. There will be no monetary payment and/or expense to you for participating in this study.

Confidentiality

Because of the nature of the study, it will not be possible to keep your identity entirely confidential. Unless you choose otherwise, I will use a made up name for you. However, most people who know us will be able to identify you. Research documents, including consent forms, electronic files and transcriptions will be securely stored on the University of British Columbia Okanagan Campus by my PhD supervisor, Kathy Rush, for five years after publication, after which they will be destroyed. After that time, any paper copies will be shredded and audio recordings will be erased.

The information you provide will be shared with others who study and work with older adults and be communicated in written papers, including medical and nursing journals and/or oral presentations. This information will also be included in my PhD dissertation which is considered a public document and will be available on the Internet via cIRcle.

It is anticipated that results from the study will be used to guide future research in this area. I will provide you with a report of the findings and all publications related to the study. You will also be provided with a copy of the signed consent form.

Contact for information about the study:

If you have any concerns, questions or would like further information about the study, you may contact either the Principal Investigator Dr. Kathy L. Rush at 250-807-9561, or me, the Co-Investigator Mary Kjorven at (250) 826-0671. Signing this consent form in no way limits your legal rights against the investigator. Once the study is complete I will deliver a copy of the results to you.

Contact for Concerns about the Rights of Research Subjects:

You have the right to ask questions, and have those questions answered. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Participant Complaint Line by email (RSIL@ors.ubc.ca). You may also contact the Chair of the Interior Health Research Ethics Board through the Research Office at (250) 870-4602 or researchethics@interiorhealth.ca.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time during the course of this study without jeopardy to you or our relationship. Up until the point of publication, if you choose to withdraw, the information you provide will be removed from the data.

□ **Yes** □ **No** Your signature below indicates that you have agreed to participate in this study.

 □ **Yes** □ **No** Your signature below indicates that have you have received a copy of this consent form for your own records.

□ **Yes** □ **No** Your signature below indicates that that you consent to the digital recording of all interviews.

Participant Signature _____Date _____

Printed Name of the Participant _____

Witness Signature _____ Date _____

Appendix C: Information and Consent Form: Siblings

INFORMATION and CONSENT FORM: SIBLINGS

Title of Research Project: Keeping dad safe: An autoethnography of double-duty caregiving in the context of risk as an Advanced Practice Nurse in geriatrics caring for a hospitalized frail older adult parent

Principal Investigator and Supervisor: Kathy Rush, PhD, RN, Associate Professor, Faculty of Nursing, University of British Columbia Okanagan.
Email: Kathy.Rush@ubc.ca

Co-Investigator: Mary Kjorven, RN, MsN, Clinical Nurse Specialist, PhD Candidate, University of British Columbia Okanagan. Phone (250) 826-0671
Email: Mary.Kjorven@interiorhealth.ca

Purpose of the Study: The purpose of this study is to create opportunities for change. By asking and answering questions about my experience of caring for our dad during his hospital admissions, I as a researcher/daughter/nurse/expert, and those who read my story might better understand these experiences and the emotions they cause. This study is part of Doctoral studies in the Faculty of Interdisciplinary Graduate Studies at the University of British Columbia Okanagan.

Background: Canada's population is aging and older adults use a lot of health care. Older adults like our dad are often seen to be at risk of harm in daily life and if he ends up in the hospital some of his risks can increase. Family members, especially those who are nurses, often feel the need to protect their older adult relative from these risks. Family member caregivers who are also nurses and hospital staff may not always agree on ways to provide care. This can make it difficult for everyone.

Who Can Participate?

I will be the main participant in this study. Four other people are invited to participate: our dad, you and my other 2 siblings, and the (since retired) Registered Nurse who was the Health Service Administrator at the hospital where our dad was admitted. I am inviting you to participate because I believe you will be able to provide insight into my involvement in our dad's care when he was in the hospital.

What Does the Study Involve?

I will write my story of caring for our dad during his two admissions (June 2013 and June 2016) to hospital. I will write this story using his medical charts, my memory, my notes and, should you choose to participate, information from you. I will interview you (approximately one hour) at a location that is convenient for you and where your privacy will be respected and ask you a few

questions about your thoughts and feelings specific to me caring for dad during his admissions to hospital. After I interpret your interview I will ask you to validate my interpretations within a short interview (approximately one hour). With your consent, these interviews will be digitally recorded. If you agree to participate in the study, I will ask you to sign a consent form. No study procedures or data collection will begin prior to this consent form being signed.

Risks

As you know, there are always relationship risks when providing feedback. For example, your feedback to me may change the way we relate (either positively or negatively) to each other and/or to our dad in the future. If you notice a strain in relationships related to providing this feedback to me I will provide time to talk about these concerns with you at a time that is convenient for you.

Benefits

One of the benefits of participating in the study is that it will provide you the opportunity to add your thoughts and feelings concerning the care I provided to dad when he was in the hospital. The information you provide may not contribute to any immediate changes, but may help people understand how risk impacts people like dad and me. There will be no monetary payment and/or expense to you for participating in this study.

Confidentiality

Because of the nature of the study, it will not be possible to keep your identity entirely confidential. Unless you choose otherwise, I will use a made up name for you. However, most people who know us will be able to identify you. Research documents, including consent forms, electronic files and transcriptions will be securely stored in the University of British Columbia Okanagan Campus by my PhD supervisor, Kathy Rush for five years after publication after which they will be destroyed. After that time any paper copies will be shredded and audio recordings will be erased.

The information you provide will be shared with others who study and work with older adults and be communicated in written papers, including medical and nursing journals and/ or oral presentations. This information will also be included in my PhD dissertation which is considered a public document and will be available on the Internet via cIRcle.

It is anticipated that results from the study will be used to guide future research in this area. I will provide you with a report of the findings and all publications related to the study. You will also be provided with a copy of the signed consent form.

Contact for information about the study:

If you have any concerns, questions or would like further information about the study, you may contact either the Principal Investigator Dr. Kathy L. Rush at 250-807-9561 or me, the Co-Investigator Mary Kjorven at (250) 826-0671. Signing this consent form in no way limits your legal rights against the investigator. Once the study is complete I will deliver a copy of the results to you.

Contact for Concerns about the Rights of Research Subjects:

You have the right to ask questions, and have those questions answered. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Participant Complaint Line by email (RSIL@ors.ubc.ca). You may also contact the Chair of the Interior Health Research Ethics Board through the Research Office at (250) 870-4602 or researchethics@interiorhealth.ca.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time during the course of this study without jeopardy to you or our relationship. Up until the point of publication, if you choose to withdraw, the information you provide will be removed from the data.

□ **Yes** □ **No** Your signature below indicates that you have agreed to participate in this study.

□ **Yes** □ **No** Your signature below indicates that you have received a copy of this consent form for your own records.

□ **Yes** □ **No** Your signature below indicates that that you consent to the digital recording of all interviews.

Participant Signature _____Date _____

Printed Name of the Participant _____

Witness Signature _____ Date _____

Appendix D: Information and Consent Form: Key Informant

INFORMATION and CONSENT FORM: KEY INFORMANT

Title of Research Project:	Keeping dad safe: An autoethnography of double-duty caregiving in the context of risk as an Advanced Practice Nurse in geriatrics caring for a hospitalized frail older adult parent
Principal Investigator and Supervisor:	Kathy Rush, PhD, RN, Associate Professor, Faculty of Nursing, University of British Columbia Okanagan. Email: Kathy.Rush@ubc.ca
Co-Investigator:	Mary Kjorven, RN, MsN, Clinical Nurse Specialist, PhD Candidate, University of British Columbia Okanagan. Phone (250) 826-0671 Email: <u>Mary.Kjorven@interiorhealth.ca</u>

Purpose of the Study: The purpose of this study is to create opportunities for change. By asking and answering questions about my experience of caring for my dad during his hospital admissions, I as a researcher/daughter/nurse/expert, and those who read my story might better understand these experiences and the emotions they cause. This study is part of Doctoral studies in the Faculty of Interdisciplinary Graduate Studies at the University of British Columbia Okanagan.

Background: Canada's population is aging and older adults use a lot of health care. Older adults like my dad are often seen to be at risk of harm in daily life and if they end up in the hospital some of their risks can increase. Family members, especially those who are nurses, often feel the need to protect their older adult relative from these risks. Family member caregivers who are also nurses and hospital staff may not always agree on care. This can make it difficult for everyone.

Who Can Participate?

I will be the main participant in this study. Four other people are invited to participate: you, my sister, my brothers, and my dad. I am inviting you to participate because I believe you will be able to provide insight into my involvement in my dad's care when he was in the hospital.

What Does the Study Involve?

I will write my story of caring for my dad during his two admissions to hospital (July 2013 and June 2016). I will write this story using his medical charts, my memory, my notes and, should you choose to participate, information from you. I will interview you (approximately one hour) at a location that is convenient for you and where your privacy can be respected and ask you a few questions about your thoughts and feelings specific to me caring for my dad during his admissions to hospital.   After I interpret your interview I will ask you to validate my

interpretations within a short interview (approximately one hour). With your consent, these interviews will be digitally recorded. If you agree to participate in the study, I will ask you to sign a consent form. No study procedures or data collection will begin prior to this consent form being signed.

Risks

As you know, there are always relationship risks when providing feedback. For example, your feedback to me may change the way we relate (either positively or negatively) and the way I relate to my dad and siblings in the future. If you notice a strain in our relationship related to this feedback, I will provide time to talk about these concerns with you at time that is convenient for you.

Benefits

One of the benefits of participating in the study is that it will provide you the opportunity to add your thoughts and feelings concerning the care I provided to my dad when he was in the hospital. The information you provide may not contribute to any immediate changes for him but may help people understand how risk impacts people like him and me. There will be no monetary payment and/or expense to you for participating in this study.

Confidentiality

Because of the nature of the study, it will not be possible to keep your identity entirely confidential.   Unless you choose otherwise, I will use a made up name for you. Research documents, including consent forms, electronic files and transcriptions will be securely stored on the University of British Columbia Okanagan Campus by my PhD supervisor, Kathy Rush, for five years after publication, after which they will be destroyed.   After that time any paper copies will be shredded and audio recordings will be erased.

The information you provide will be shared with others who study and work with older adults and be communicated in written papers or oral presentations.

It is anticipated that results from the study will be used to guide future research in this area. I will provide you with a report of the findings and all publications related to the study. You will also be provided with a copy of the signed consent form.

Contact for information about the study:

If you have any concerns, questions or would like further information about the study, you may contact either the Principal Investigator Dr. Kathy L. Rush at 250-807-9561 or me, the Co-Investigator Mary Kjorven at 250-826-0671. Signing this consent form in no way limits your legal rights against the investigator. Once the study is complete I will deliver a copy of the results to you.

Contact for Concerns about the Rights of Research Subjects:

You have the right to ask questions, and have those questions answered. If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of

Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It is also possible to contact the Research Participant Complaint Line by email (RSIL@ors.ubc.ca). You may also contact the Chair of the Interior Health Research Ethics Board through the Research Office at (250) 870-4602 or researchethics@interiorhealth.ca.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time during the course of this study without jeopardy to you or our relationship. Up until the point of publication, if you choose to withdraw, the information you provide will be removed from the data.

□ **Yes** □ **No** Your signature below indicates that you have agreed to participate in this study.

□ **Yes** □ **No** Your signature below indicates that you have received a copy of this consent form for your own records .

□ **Yes** □ **No** Your signature below indicates that that you consent to the digital recording of all interviews.

Participant Signature _____Date _____

Printed Name of the Participant _____

Witness Signature _____ Date _____

Appendix E: Request for Medical Records for my Dad July 2013

Interior Health — Freedom of Information and Protection of Privacy

Request for Access to Personal Health Records

You may make a request for access to records without using this form, provided you do so in writing.
Please Note: The Act allows for 30 business days to provide the requested records
Personal information contained on this form is collected under the Freedom of Information and Protection of Privacy Act and will be used only for the purpose of responding to your request.

Name *(First/Middle/Last)*

Date of Birth *(dd/mm/yyyy)*
09/07/1929

PHN *(Personal Health Number/Care Card Number)*

Day Time Phone Number

Complete Mailing Address *(City/Town/Province/Country/Postal Code)*

Alternate Phone Number

Information Requested Pre Operative Xrays R12
Please describe the records you are requesting. Be Specific. Attach a separate sheet if required.

All medical records from hospital stay @ VJH from June 28 2013 until discharge to Gateby on Friday July 12, 2013. Including ED admission + discharge June 28 + readmission June 29. This request includes (but is not limited to) physician orders + progress notes, admission forms, diagnostic laboratory reports, emergency room forms, nursing assessment records + nursing notes, allied health (OT, PT) assessment forms and notes, medication records, care plans, anesthesia reports, consent forms, vital sign sheets, bowel + bladder care records, ambulance record discharge summary + any other documents related my care during time

Are you requesting access to another person's personal information? ☐ Yes ☑ No
If Yes please attach
☐ That person's signed consent for disclosure OR
☐ Proof of authority to act on that person's behalf

Preferred Method of Delivery
☐ Mail
☑ Pick Up

Requestor's Signature

Information provided to:
Name: Mary Kjorven
Complete Mailing Address *(City/Town/Province/Country/Postal Code)*
5943 Victoria Street
Peachland, B.C
V0H-1K4
Contact #:

Date Signed *(dd/mm/yyyy)*
05/08/2013

Please Mail or Fax Completed Form to   Fax: 250-558-1208

The facility/program where you received your care/treatment.
Please go to the following link for a list of our facilities/programs

http://www.interiorhealth.ca/AboutUs/InformationRequests/Documents/FOI%20Facility_Site%20List.pdf

Interior Health Use ONLY

Request Number	Date Received	☐ Picture ID	☐ ID Checked By:

827025 May 28-13

Appendix F: Request for Medical Records for my Dad June 2016

Interior Health — Freedom of Information and Protection of Privacy
Request for Access to Personal Health Records

You may make a request for access to records without using this form, provided you do so in writing.
Please Note: The Act allows for 30 business days to provide the requested records
Personal information contained on this form is collected under the Freedom of Information and Protection of Privacy Act and will be used only for the purpose of responding to your request.

Name (First/Middle/Last): Robert James Magnum

Date of Birth: 09/07/1929

PHN (Personal Health Number/Care Card Number): ~~...~~

Complete Mailing Address (City/Town/Province/Country/Postal Code): ~~...~~

Day Time Phone Number: 250 309-7544

Alternate Phone Number:

Information Requested

Please describe the records you are requesting. Be Specific. Attach a separate sheet if required.

All medical records from hospital emergency visit June 14 2016. Including ED admission to discharge that day. This request includes (but is not limited to) physician orders + progress notes, admission forms, diagnostic laboratory reports, emergency room forms, nursing assessment records + nursing notes, allied health (OT, PT) assessment forms and notes, medication records, care plans, consent forms, vital sign sheets, bowel and bladder records, ambulance record + discharge summary as well all other documents related to my care during this time

Are you requesting access to another person's personal information? ☐ Yes ☑ No
If Yes please attach
☐ That person's signed consent for disclosure OR
☐ Proof of authority to act on that person's behalf

Preferred Method of Delivery
☐ Mail
☑ Pick Up

Information provided to:
Name: Mary Kjorven
Complete Mailing Address (City/Town/Province/Country/Postal Code): 5943 Victoria Street Peachland, B.C V0H - 1X4
Contact #: 250 826-0671

Requestor's Signature: X ~~...~~

Date Signed: July 25 2016

I authorize my daughter: Mary Kjorven to pick up these documents + have access to these reports that are provided by Interior Health

Please Mail or Fax Completed Form to Fax: 250-558-1208

The facility/program where you received your care/treatment. Please go to the following link for a list of our facilities/programs

http://www.interiorhealth.ca/AboutUs/InformationRequests/Documents/FOI%20Facility_Site%20List.pdf

Interior Health Use ONLY

Request Number	Date Received	☐ Picture ID	☐ ID Checked By:

827025 May 29-13

Appendix G: Legal Letter of Consent from my Dad

Robert Magowan
~~800 3011 Gateby Place~~
~~Vernon, B.C.~~
~~V1T 9S4~~
~~July 22, 2016~~

Mary Kjorven
5943 Victoria Street
Peachland, B.C.
V0H 1X4
250 826-0671

Dear Mary,

This letter provides documentation of my consent for you to use my medical records (provided to you from Interior Health with my consent) for the purposes of your research and teaching in geriatrics. These medical records include (but are not limited to) my stay at Vernon Jubilee Hospital from June 28 2013 until my discharge to Gateby Care Centre on Friday July 12, 2013, as well as my admission to the Emergency Department at Vernon Jubilee Hospital and discharge on June 14, 2016.

These medical records include (but are not limited to) physician's orders and progress notes, admission forms, diagnostic laboratory reports, emergency room forms, nursing notes, medication records, care plans, surgical and anesthesia reports, consent forms, vital sign sheets, do-not-resuscitate orders, bowel care records, ambulance reports and discharge summaries. Your research and teaching in geriatrics includes (but is not limited to) your research specific to your PhD studies, including dissemination of research findings and publications.

I also consent to use of my full legal name as you see fit.

Signed on this day _____ July 25, 2016 _____

Robert Magowan _____

WITNESS: _____

KENNETH W. ~~SMITH~~
Barrister and Solicitor
Glenmore Place
201 - 401 Glenmore Road
Kelowna, BC V1V 1Z6

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Appendix H: Visual of Interview Analysis