END-OF-LIFE PLANNING AND CARE FOR PATIENTS WITH HEART FAILURE AND THEIR FAMILY MEMBERS: WHY NURSES AND OTHER HEALTH CARE PROFESSIONALS’ KNOWLEDGE, WORDS, AND FEELINGS MATTER

by

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Abstract

Heart failure (HF) is a progressive, chronic illness characterized by decompensation episodes and hospitalizations. Life expectancy is only 2 years following HF-related hospitalizations; when complicated by frailty and comorbidities, prognosis worsens. Compared to patients with malignancies, HF patients receive less end-of-life (EOL) planning and specialist palliative care. Patients with HF often die in hospitals, where prolonged dying, inadequately managed symptoms, and worsened suffering for patients/families are commonly reported. Hospital environments have been described as having influence on EOL planning and care. Thus, the purpose of this study was to understand how hospital environments influence healthcare professionals’ (HCPs) thinking about HF-EOL care and structure their approach and practices.

The concept of structure was defined within a theoretical framework and informed the study design and research questions. Ethnographic methods and interpretive description guided data collection and analysis. A sample of twenty-two HCPs from various disciplines experienced in acute care and HF-EOL participated from two study sites; data were collected over 250 observation hours and through eighteen semi-structured individual interviews.

Data analysis produced three main areas of findings: practice knowledge and notions of expertise; uses and meanings of EOL-related words and phrases; and, emotional and value-based dimensions. Participants commonly framed EOL planning and care as the work of clinical experts and framed expertise in relation to perceptions about the knowledge required for clinical
practice in hospitals. Findings about HCPs’ knowledge also related to understandings and interpretations of frequently used EOL-related words such as “palliative.” These EOL-related words were used within interprofessional communications; however, differing interpretations existed. Findings about emotional and value-based dimensions of EOL planning and care work were identified. Emotions and values related to HCPs’ uses of strategies, such as avoiding particular words in order to manage emotion in EOL-related work.

Discussion of the findings in this research highlight several implications including the need to more intentionally situate EOL planning and care for patients with HF-EOL as being within all professionals’ scopes of practice. The need to prioritize development of communication competencies for HCPs is also supported. Overall, this study adds new insights about how EOL practices are structured within hospital environments.
Lay Summary

Heart failure (HF) is a serious chronic illness. After a HF-related hospitalization, a person’s lifespan can be only 2 years. People with HF frequently die in hospitals and the quality of their end of life (EOL) care experiences can be poor. This study examined ways hospitals influence HF and EOL planning and care.

Study findings related to three areas: what clinicians knew, said, and felt. What clinicians thought about the knowledge needed to work in hospitals shaped how they learned about HF and EOL. Clinicians’ HF-EOL knowledge also shaped uses of words such as “palliative.” Feelings also mattered and influenced word uses. For example, sometimes words such as “palliative” were avoided.

To better improve HF-EOL planning and care in hospitals for patients and their family members, developing clinicians’ communication skills and emotions awareness are recommended. Clinicians also need clearer definition of their roles in supporting patients’ HF-EOL issues in hospitals.
Preface

This dissertation is original, unpublished, independent work by the author, J.A. Gibson.

I note the following disclosures:

A. The research design and related methods were approved by the University of British Columbia’s Research Ethics Board [certificate #H15-01648].

B. Figures 2-2, 2-3, and 2-4 are used with permission from applicable sources.

C. Portions of Sections 2.5 were published with modifications as Gibson, J.A. and Crowe, S. (2018). Frailty in critical care: Identifying patients, understanding risks, and examining implications for current clinical practices. Critical Care Nurse, 38(3), 29-35. doi:10.4037/ccn2018336. Crowe and I collaborated equally in the conceptual development and organization of this publication and co-wrote the content. As the lead author, I lead the overall composition, manuscript edits, and publication.

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care: The valuable action of disrupting assumptions about the words we use in clinical practice. Presentation, Canadian Bioethics Society Annual Conference. Banff, AB.


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<tr>
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<td>Advance care planning</td>
</tr>
<tr>
<td>EOL</td>
<td>End of life</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
</tr>
<tr>
<td>HCPs</td>
<td>Health care professionals</td>
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<tr>
<td>HF</td>
<td>Heart failure</td>
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<td>HF-EOL</td>
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<td>VS</td>
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Chapter 1

The HF-EOL Study: Introduction, Purpose, and Overview

In this dissertation, I present and discuss a research study that I carried out which adds new knowledge to the growing body of literature about end-of-life (EOL) planning and care\(^1\) for patients and their families experiencing heart failure (HF). As I will describe over the course of the forthcoming chapters, I examined the problem of reportedly poor quality EOL experiences for patients with HF. As many HF-related EOL experiences are known to occur in hospitals, I focused my inquiry on acute care inpatient settings in hospitals, which included general medical units and cardiac units\(^2\).

As I will show in Chapter Two where I examine and discuss the body of HF and EOL-related literature, other authors have situated the problem of reportedly poor-quality HF-EOL

\(^1\) I use the phrase “EOL planning and care” in a particular way throughout this dissertation. I define this usage below on page 4.

\(^2\) Inpatient units in hospitals are often organized by the nature of the admission and have different names and descriptors. For example, “acute medicine” is a common descriptor for inpatient medical units where patients with many different medical issues are admitted. “Acute surgery” is a descriptor for units where patients are admitted for care after surgical procedures. “Acute cardiology” is a descriptor for units where patients are admitted with cardiac issues. I delve into more detail about the types of acute inpatient units that were involved in this study in Chapters Two and Four.
care experiences in relation to hospital contexts and acute care settings where patients with HF access care. As I will also show, aspects of these contexts have been described as having some problematic influence on the quality of HF-EOL care; however, specific and intentional explication of these influences and interrelationships was not available. As aspects of the context were named but not necessarily well understood, a knowledge gap was apparent. As many HF-related EOL experiences take place in hospitals, I designed my research study with the purpose of better understanding how the contexts and cultures of acute care hospital settings shape or structure health care professionals’ (HCPs’) related beliefs and values, and subsequent decisions and actions about HF and EOL care (HF-EOL care).

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3 I am using the word context in a way that aligns with general understandings of the word. For example, the dictionary describes context as “the circumstances that form the setting for an event, statement, or idea, and in terms of which it can be fully understood and assessed” (Oxford Reference, 2019, para. 1). This definition distinguishes the notion of context from setting in that context is capturing a broader thinking about circumstances while setting is referring to the more physical and observable aspects of context.

4 As I will return to in Chapter Three, Sewell (1992) defined culture simply as “what people know.” He states, “after all, the usual social scientific term for ‘what people know’ is ‘culture’” (p. 7). I build from this simple definition and explore culture in more detail in Chapter Three.

5 I used Sewell’s (1992) Theory of structure to define “structure.” As is explained in the coming chapters and particularly in Chapter Three, there are different conceptualizations of the term. According to Sewell, “structure” explains why social conditions are reproduced even when the agents who are affected by them do not desire them (or acknowledge them). I explicate this idea more fully where I discuss the theoretical framework informing my research in Chapter Three.
Given my study purpose, I was seeking to address an important knowledge gap that existed about the relationships between HF, hospitalizations, and EOL experiences. Using a qualitative design and ethnographic methods, I collected and analyzed data with the aim of producing greater understandings about relationships between acute care contexts and HF-EOL experiences. Overall, I aimed to identify ways the quality of HF-EOL experiences might be improved for patients with HF and their family members. In the chapters forthcoming, I explain and discuss how I designed and carried out my study and I present what I learned about HF-EOL planning and care in acute care settings in hospitals.

1.1. Overview of Chapter One

Chapter One is an introduction and overview of my research study, which I called: “The Heart Failure End of Life (HF-EOL) Study” (see Appendix A). This first chapter opens with an introduction and background to HF, chronic illness, and mortality followed by a discussion about my research problem and the reportedly poor-quality HF-EOL in acute care. I briefly explain HF in relation to reported EOL and dying experiences, discuss characteristics of acute care hospitalization encounters, and summarize what is already known about the cultural and contextual features that structure EOL planning and care for patients with HF and their families in hospitals.

Following my initial presentation of the research problem I investigated, I outline my study purpose and define the three research questions that guided my inquiry. I also touch on
the methodological approach that I used to collect and analyze my study data. I close with a
general overview and layout of what follows in this dissertation.

1.1.2. Defining my uses of EOL-related terms. As I proceed, it is important that I
clarify my use of EOL-related terms including “EOL planning and care.” “EOL care” describes
the care provided during the final stage of life, usually referring to the weeks and days
immediately preceding death. This definition aligns with a joint position statement from the
Canadian Nurses Association, Canadian Hospice Palliative Care Association, and the Canadian
Hospice Palliative Care Nurses Group: “EOL care begins when a person is actively dying, and
then continues until death and into family bereavement and care of the body” (Canadian Nurses
Association, Canadian Hospice Palliative Care Association, & Canadian Hospice Palliative Care
Nurses, 2015, p. 7). The aim of EOL care should be to relieve suffering and improve the quality
of living in all care settings and is broadly applicable to many illnesses, including HF (Canadian
Nurses Association, Canadian Hospice Palliative Care Association, & Canadian Hospice
Palliative Care Nurses).

6 The words and phrases used by clinicians to talk about advanced illness stages including
active dying and death (i.e. “EOL-related words”) were identified as a predominant feature of
acute care with considerable influence on HCPs’ thinking, decisions, and clinical care activities.
I explain this study finding in detail in Chapter Six where I also reflect on the strengths and
drawbacks that I encountered with how I used the phrase “EOL planning and care.”
As is evident in the literature, end-of-life care experiences should be shaped by *upstream* EOL planning activities including EOL-oriented communication (e.g. HF illness education, goals of care), and integration of palliative care principles (e.g. interdisciplinary approach, optimization of QOL, symptom management, holistic approach). For some patients, EOL planning and care should also involve the inclusion of palliative care specialist HCPs (Howlett et al., 2010). To encompass this upstream relationship, Howlett et al. used the phrase “EOL planning and care” to include the activities (or the lack thereof) that have influence on EOL care experiences. I similarly use the encompassing phrase “EOL planning and care” to reflect the relationship between upstream efforts and downstream EOL care experiences. As Howlett et al. emphasize, communication about illness and EOL issues is foundational to EOL planning and care. And as I will explain in Chapter Two, with HF specifically, “EOL planning” should also include conversations about HF-specific illness issues such as *self-management*. Self-management is important in HF-EOL planning because it creates opportunities for patients to recognize early signs of deterioration and prevent acute decompensation events, which are associated with increased morbidity and mortality. Throughout my study I focused on understanding how HCPs in hospitals approached the *planning* aspects of EOL as well as EOL care.
1.2. Background: Heart Failure, Chronic Illness, and Mortality

Heart failure is a chronic, progressive, and life-limiting disease with multiple etiological causes (Beattie, 2015; Butler & Kalogeropoulos, 2008; Johansen, Strauss, Arnold, Moe, & Liu, 2003; Kheirbek et al., 2013; Strachan et al.). Heart failure is also a disease that deteriorates towards death along a variable and largely unpredictable trajectory (Goebel et al., 2009; Goldfinger & Adler, 2010; Goldstein & Lynn, 2006; Goodlin et al., 2004; Goodlin, 2009; Gott et al., 2007; Howlett et al., 2010; Jaarsma et al., 2009; Lynn & Adamson, 2003; Murray et al., 2005; Ryder et al., 2011; Strachan et al., 2009; Wotton et al., 2005). In Canada, an estimated 600,000 people are living with HF; an additional 50,000 are newly diagnosed annually (Butrous & Hummel, 2016; Heart and Stroke Foundation, 2016; Public Health Agency of Canada, 2009).

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7 According to the British Columbia Ministry of Health (2013) the term “life-limiting” describes: “illnesses that can be reasonably expected to cause the death of the individual within a foreseeable future. This definition is inclusive of both malignant and non-malignant illnesses that are expected to shorten an individual’s life” (p. 2).

8 Helman (1981) distinguished the terms “disease” and “illness.” According to Helman, “disease” is based in the medical model and describes pathological aspects; disease can be distinguished by biological or chemical evidence. In contrast, “illness” is based within the individuals experience of the disease; illness includes both the experiences of illness and the meaning given to the experience (Helman). I recognize the value in this conceptual distinction, particularly with respect to discussions about each. However, in practice (and in much of the writing cited through this dissertation), the terms are used synonymously and thus I do not distinguish between the two.
Heart failure is associated with significant morbidity and mortality. In many cases, mortality outcomes for patients with HF surpass those related to many cancers (Howlett et al., 2010; Jessup & Brozena, 2003; Ko et al., 2008; Mamas et al., 2017). At five years, the mortality rate of HF is approximately 50 percent (Beattie, 2015; Cacciatore et al., 2005; Ho, Anderson, Kannel, Grossman, & Levy, 1993; Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). Following a HF-related hospitalization, a person’s life expectancy declines to only two years (Howlett, 2011). When complicated by frailty, comorbidities, and other-organ dysfunction, prognosis deteriorates considerably (Afilalo, 2009; Afilalo, 2011; Cacciatore et al., 2005; Lee et al., 2003; Mosterd et al., 2001).

Heart failure is also a *chronic* illness and this chronicity characteristic is associated with unique health care and EOL planning and care needs (Holman & Lorig, 2004; Thorne, Roberts, & Sawatzky, 2016). In acute pathologies, the illness usually manifests suddenly from a distinguishable origin and efforts to diagnose, treat, and cure are beneficial. In contrast, chronic illness and disease processes are less linear and often appear gradually, progress over time, and originate from multivariate etiological causes (Holman & Lorig, 2004; Penning, 2002; Wagner et al., 1996). The diagnose, treat, and cure goals for acute-pathologies are not necessarily applicable or beneficial in chronic pathologies; instead, goals such as slowing the illness progression and supporting symptom self-management may be more relevant for patients with HF (Bergethon et al., 2015; Howlett et al., 2016). In HF specifically, slowing the
illness progression and preventing decompensation events are key goals. Despite various therapy options, the HF illness course is unpredictable, uncertain, and ultimately terminal.

1.3. Research Problem: Heart Failure, Hospitalizations, and Reportedly Poor-Quality Experiences at End of Life

Patients and their families with HF reportedly experience poor-quality EOL. This patient/family member group also characteristically endures multiple hospitalization encounters over the course of their illness(es). As I proceed, I explore and discuss both the reported quality issues of HF-EOL as well as HF-related hospitalizations. The introductory content serves as a background for the research problem and highlights what is known, and where there are gaps in understandings about the relationships between HF, EOL experiences, and hospitalizations.

1.3.1. Poor quality HF-EOL experiences. Patients with HF have reportedly poor-quality EOL experiences. In the final month of life, more than half of the people who die from HF experience uncontrolled pain (Alemzadeh-Ansari, Ansari-Ramandi & Naderi, 2017; Godfrey et al., 2006; Goebel et al., 2009; Setoguchi et al., 2010; Zambroski, 2004). Many patients also experience a wide range of other poorly controlled symptoms associated with dying including anxiety, breathlessness, pruritus, and delirium (Goldfinger & Adler, 2010; Howlett, 2011; Jaarsma et al., 2009; LeMond & Goodlin, 2015; Setoguchi et al., 2010; Walthall & Floegel, 2019). Family members may also be affected; depression and anxiety are more common when patients' EOL experiences are poor (Coombs, 2010; Cypress, 2010; Hwang et al., 2014; Kavalieratos, Mitchell, Carey et al., 2014; Wright et al., 2008). Compared to patient groups with
similar morbidity and mortality outcomes, including patients with cancer, patients with HF also have less access to specialist palliative services (Beattie, 2015; Cunningham, Hanley, & Morgan, 2011; Howlett et al., 2010; Howlett, 2011; Meyers & Goodlin, 2016; Strachan et al., 2009). As palliative care specialist clinicians have expertise in symptom management, this lowered referral rate and access to palliative services may relate to the symptom issues (e.g. uncontrolled pain) associated with advanced HF and HF-EOL experiences.

Communication and planning about EOL is also reportedly poor for patients with HF and their family members (Beattie, 2015; Dunlay, Swetz, Mueller, & Roger, 2012; Howlett et al., 2010; Howlett, 2011; Meyers & Goodlin, 2016; Strachan, Ross, Rocker, Dodek, & Heyland, 2009). Heyland et al. (2013) have established relatedness between upstream EOL-related planning activities and downstream EOL care experiences. Quality upstream EOL planning involves effective and ongoing communication between HCPs and patients and their families about EOL issues such as HF disease progression and illness expectations, the individual’s goals of care, and emergent intervention preferences (e.g. resuscitation)—such communications promote alignment between what patients want and what is provided (Goodlin et al., 2004; Kelley & Morrison, 2015; World Health Organization, 2017). According to Heyland et al. (2013), a lack of EOL-related planning communication, for example, can lead to intensification of medical treatments before death, which may be unwanted by patients and may also diminish the quality of EOL experiences. In the absence of previously expressed wishes for advanced-illness and EOL care preferences, hospitalization and acute care experiences
become default (Goldstein & Lynn, 2006). Another consequence of this under-emphasis on EOL-related conversations and planning is that death from HF can seem sudden, which can be difficult for both patients and families and may diminish the quality of HF-EOL experiences (Mamas et al., 2017; Flynn, Connolly, & Booth, 2008).

1.3.2. Hospitalizations and HF. Patients with HF and their family members commonly endure multiple hospitalizations over the course of a HF illness trajectory, including at EOL. Acute care settings such as medical units, cardiology units, and critical care areas are frequently utilized to provide the complex care needs for patients with HF who experience acute decompensation events, advanced illness stages, dying, and death (Chan, 2014; Cook & Rocker, 2014; Fowler & Hammer, 2013; Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Heyland et al., 2013; Hopkinson, Hallett, & Luker, 2003; Kheirbek et al., 2013; Kelley & Morrison, 2015; Komajda et al., 2007; Komajda et al., 2009; van Diepen et al., 2014). Acute HF decompensations that require hospitalization are significant because they may indicate a deteriorating prognosis and nearness to death (Dharmarajan et al., 2015; van Diepen, 2014).

As I will explore further in Chapter Two, HF-related hospitalizations are also significant because they can contribute to poor-quality EOL care. Acute care areas in hospitals are not necessarily equipped to support patients with HF and their family members plan or experience EOL; this mismatch in what is needed versus what is offered has an impact on how EOL planning and care is delivered and experienced (Andresen et al., 2015; Gries et al., 2010; Hopkinson, Hallett, & Luker, 2003; Safavi et al., 2013; Thorne, Roberts, & Sawatzky, 2016). For
example, patients’ HF-EOL experiences in hospitals have been reported as including inadequately managed symptoms (e.g. pain, dyspnea), inappropriate (i.e. unwanted) escalation of medical interventions at EOL, prolonged dying, and worsened suffering for patients and their families (Godfrey et al., 2006; Goebel et al., 2009; Goldfinger & Adler, 2010; Howlett et al., 2010; Kavalieratos, Mitchell, Carey et al., 2014; Setoguchi et al., 2010; Strachan et al., 2009; Zambroski, 2004). In many cases, the acute treatment focus of hospitals and related acute care approaches misalign with what patients actually want and need to prepare for and experience EOL (Andresen et al., 2015; Baggs et al., 2007; Thome, Roberts, & Sawatzky, 2016; Wright et al., 2008).

The mismatch in services—that is, between what hospitals provide and what patients actually want and need to plan for and endure EOL—makes up an important aspect of the context of hospitals and structures HF-EOL planning and care experiences. Other structural aspects of hospital contexts have been identified and described including a dominant “cure” culture in both general acute care and cardiac care (Hauptman & Havranek; Howlett et al., 2010; Tucker, 2009). The care for patients with HF in hospitals can also be technologically-focused; unlike some other life-limiting chronic illnesses, in HF there is a range of biomedical technologies and pharmacological management options that can effectively improve patients’ prognoses (Hauptman & Havranek, 2005; Howlett et al., 2010; Howlett, 2011). While these technologies and pharmacology options can improve HF prognosis, they can also add complexity and uncertainty to the overall illness trajectory.
Though HF prognosis improves with effective illness management, uncertainty and chronicity remain. Such uncertainty can obscure HCPs’ sense of the “right” timing for EOL planning (Goebel et al., 2009; Goldfinger & Adler, 2010; Goldstein & Lynn, 2006; Goodlin, 2009; Gott et al., 2007; Howlett et al., 2010; Jaarsma et al., 2009; Kavalieratos, Mitchell, Carey et al., 2014; Ryder, Beattie, O'Hanlon, & McDonald, 2011; Strachan et al., 2009; Wotton, Borbasi, & Redden, 2005), which shapes EOL planning and care experiences. As Hauptman and Havranek (2005) have noted, “the array of treatment options is particularly broad in HF and includes a number of technologically invasive therapies. Because there is frequently ‘one more thing to try’, shifting the focus of care from life extension to symptom relief can be particularly difficult” (p. 375).

The interrelated issues of reportedly poor-quality HF-EOL experiences, limited access to EOL planning activities (e.g. EOL-related communication) and palliative specialists, frequent hospitalization experiences, and the influence of hospital contexts on HF-EOL planning and care, are significant and is an important problem. This problem of reportedly poor-quality HF-EOL experience is important because it effects a large number of people who currently have HF and will continue to be important as the prevalence of HF is expected to rise (Bleumink et al., 2004; Boutrous & Hummel, 2016; Heart and Stroke Foundation, 2016; Public Health Agency of Canada, 2009; Strachan et al., 2009; van Diepen et al., 2014). Poor-quality HF-EOL experiences should also be a concern for nurses and all HCPs.
1.4. Research Purpose: Understanding how acute care contexts shape HCPs’ approaches to HF-EOL planning and care

Given the challenges noted above, the purpose of this study was to examine the problem of reportedly poor-quality EOL planning and care for patients with HF and their families by producing new knowledge about how acute care settings in hospital contexts shape or structures HCPs’ approaches to HF-EOL planning and care. As I presented in the section above, when I began my study, there was some evolving understandings within the existing literature where other researchers had described structured relationships and impacts of hospital contexts and EOL planning and care experiences. For example, the dominant “cure culture” shapes the care in hospitals by driving health service focus on diagnosing, treating, and curing (Hauptman & Havranek; Howlett et al., 2010; Tucker, 2009). However, to my knowledge, no researcher had undertaken a purposeful and intentional study of these contexts and the relationships regarding HF-EOL planning and care experiences. Further, significant knowledge gaps were apparent in the literature regarding HF-EOL planning and care. I therefore designed my research study with a theoretical framework and methodological approach that enabled me to examine aspects of hospital contexts and acute care settings where patients with HF and their family members access EOL planning and care with the goal of explicating, interpreting, and understanding structured HF-EOL planning and care practices.

1.4.1. A brief explanation of “structure.” The terms “structure”, “structural”, and “structuring” are commonly used in nursing discourse and scholarship and the idea of structure
as a concept exists with a range of theoretical roots. Structure is often used to describe ways in which elements of complex socio-political-historical contexts shape, pattern, or influence people’s lives—contexts also include, for example, aspects or features within the settings/environments of acute care hospitals and influences on EOL and death experiences.

Sewell’s (1992) *Theory of structure* aligns well within the broader theoretical and philosophical commitments in this study; thus, I used Sewell’s work for definitional support and to build a theoretical framework for this dissertation.

Sewell (1992) described structures as composed simultaneously of the *schemas* (i.e. things that exist virtually but may not be objectively observable) and *resources* (i.e. things that are actual and are usually observable), which are influential in shaping and reproducing social relations. The notion of “schema”—that is, preconceptions and patterned ways of thinking—describes virtual social features (e.g. constructs of culture, etiquette rules, aesthetic norms). Schemas encompass notions such as collective beliefs⁹ (e.g. the biomedical model), discourse (e.g. “evidence-based medicine”, “patient-centered care”), and values (e.g. professional values

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⁹ Jiwani (2017) describes beliefs as having two dimensions: the stories consciously developed from subconscious experiences; and, the actions or consequences that these beliefs are thought to bring. According to Jiwani, beliefs inform how we perceive the world and how we think. Beliefs can also change as a result from different experiences, including interaction with others.
and biomedical ethical principles). Importantly, schemas belong to agents—that is, schemas exist exclusively in the human experience. Sewell also described structures as composed of resources; that is, in most cases, features that are actual and observable\(^{10}\). Resources are used to enhance or maintain power\(^{11}\) within social contexts (Sewell, p. 9). For example, in hospitals and in acute care settings, professional designations are resources that are associated with considerable power and influence in how patient care decisions and actions unfold.

In general, resources make up the observable and discernable constituents of health care environments. For instance, a cardiac program in a tertiary hospital with components including cardiac specialty wards and critical care services; extensive cardiac imaging, intervention services, and biomedical technologies; as well as cardiac specialty physicians, nurses, surgeons and allied HCPs; is a compilation of appreciable, observable, actual, resources. Using Sewell’s (1992) notion of resources and schemas, I found that hospitals, acute medical units, and cardiac specialty units, can be understood as having structured practice

\(^{10}\) In Chapter Three, I more fully explicate the definitional issues of structure. In that discussion I will also argue that resources may be both actual and virtual (e.g. coping, resilience, knowledge, words).

\(^{11}\) Giddens (1984) also wrote about the concept of structure and indeed, Sewell (1992) builds on Giddens’ work. According to Giddens, power should be defined in relation to agents’ intent or will and their capacity to achieve desired and intended outcomes (p. 15). Sewell called this aspect of power the “capacity” of agency—meaning, the efficacy of human action.
conditions because the actual resources—such as medications and biomedical equipment—are continually interfacing with multiple, simultaneously functioning schemas such as “cure culture” which influence actions. Berwick (2002) has argued that understanding structuring can be difficult because structural relationships are complicated; to untangle such complexity, Sewell’s development on the theory of structure formed an integral part of the overall theoretical framework.

As I discovered from reviewing the body of HF and EOL-related literature, there was limited explanation of hospital and acute care contexts and culture regarding HF-EOL planning and care, and no explicit and intentional study of their structured relationships. The research purpose for my study was therefore to address this knowledge gap and add new insights towards understanding how micro, meso, and macro-level\textsuperscript{12} hospital contexts and acute care settings interrelate to shape or \textit{structure} actions and HF-EOL planning and care. Indeed,

\begin{footnote}
\textsuperscript{12} I am using the terms micro-, meso-, and macro- to describe different levels of social organization. For example, Rodney, Buckley, Street, Serrano, and Martin (2013) describe micro- as the individual and interpersonal level; meso- refers to the organizational or regional influence; and macro- applies at the societal level (p. 201). Micro-level can refer to individual HCPs; meso-level encompasses hospital- and organizational-level; and macro-level captures influences at societal level.
\end{footnote}
consistent with my theoretical framing, this emphasis on interrelations points not only to greater understandings of how context shapes practice but also to how agents shape contexts.

1.5. Research Questions

In order to address my research problem and achieve my study purpose, my inquiry was informed by my theoretical framing and guided by three research questions:

1) What are the relationships between agents, schemas, and resources within acute care practice contexts where patients with HF and their family members experience care and how can such relationships be said to structure HCPs’ clinical practices specifically concerning EOL planning and care?

2) How is power operating within these practice contexts to preserve (or sustain) some structural configurations, and limit (or constrain) others?

3) What are the implications for nursing and interprofessional practice, research, and policy?

To answer these three research questions, I used a qualitative ethnographic methodological approach with complementary interpretive description methods. As I explain in Chapter Four, this combined methodological approach provided a way to answer my three research questions because it created access to relevant types of data within particular practice contexts. In Chapter Four, I more fully discuss methodological considerations including data collection methods, study sample design, and the analytical process.
1.6. Significance to Nursing and Patient/Family Outcomes

The problem of poor-quality HF-EOL planning and care constitutes an important clinical issue for nurses and all HCPs. As Strachan, Kryworuchko, Nouvet et al. (2018) have argued, “nurses [have] a key role in advocating that patient wishes and preferences remain at the center of serious illness communication, especially in goals of care\textsuperscript{13} discussions and decision-making” (p. 29). Thus, the findings and implications described in this dissertation are aimed largely at nursing practices and systems-levels issues that influence nursing and interprofessional practices.

Structural relationships are important to understand because they can create and reinforce ways of being; as Waitzkin (1989) stated, “structures of society help generate the specific context in which patients and doctors find themselves…” (p. 221). The aim of studies such as mine is to reveal implicit schemas (e.g. assumptions, principles), which are usually tacit, unquestioned, and taken-for-granted. The aim is also to understand how schemas interface with resources (e.g. cardiac biomedical technologies, patient education materials) to shape decisions

\textsuperscript{13} Strachan, Kryworuchko, Nouvet et al. (2018) defined “goals of care” conversations as what is important for patients and their families to accomplish. Simply, “goals of care communication refer to the process of discussion that ideally informs and occurs prior to shared decision-making processes about EOL care options” (p. 27).
and actions and to make recommendations for changes in structures and practices. This type of structural inquiry addresses HCPs’ collective ethical, professional, and disciplinary responsibilities to understand and act on inequitable social relations via research and policy development at the micro-, meso-, and macro-levels (Reimer-Kirkham & Anderson, 2010). As Anderson and Reimer-Kirkham (1998) have cautioned, “unless we recognize and unmask the unquestioned and taken-for-granted notions that are embedded in our institutions, health reform may build on the ideological structures that form the substratum of our current theorizing, policy decisions, and health care practices” (p. 250). Ideological structures, for example, may include implicit and taken-for-granted schemas that can undermine professional, ethical, and disciplinary imperatives such as health, fairness, social justice, and the common good (Rodney & Varcoe, 2012; Peter, 2013). As I will present in Chapters Five, Six, and Seven, I uncovered implicit schemas that would not necessarily reflect these professional and disciplinary imperatives and thus should be reconsidered.

Pursuing explication of the implicit is also foundational in ethical practice. As Jiwani (2017) has argued, the process of undergoing ethical justification of any health care decision depends in part in how “accurately and comprehensively contexts are understood and how carefully relevant values have been thought through” (p. ix). As such, identifying and understanding these implicit schemas within the context of HF-EOL care in hospitals, were central aims in this research. Indeed, as I will show as I present my findings in subsequent chapters, the structures in acute care hospitals do have influence on patients and their families’
HF-EOL planning and care experiences. As I will also show, there are opportunities to alter these structures through supporting HCPs to develop communication skills, which may improve HF-EOL care.

1.7. Overview of Dissertation Chapters

The research study carried out for this dissertation is presented in nine chapters. In this first chapter, existing problems with EOL planning and care for patients with HF and their families were introduced. The research problem and purpose were explained with a short description of the supporting theoretical framework. Sewell’s (1992) theory of structure was introduced with definitional explanations for how I am using the word “structure” throughout this dissertation. Three research questions were laid out with an overview to my methodological approach.

Chapter Two contains a discussion about the literature I reviewed to substantiate my research focus. I discuss four related substantive areas: HF-related hospitalization and mortality; dying in hospitals and care needs at EOL; chronic illness management concepts and HF; and, the complex issue of heterogeneity in the HF-patient population. Building on the introductory content above, I begin Chapter Two by more fully delving into the linkage between HF-related hospitalizations and mortality. I review literature about experiences of dying in Canada more generally; I also look more specifically at the care needs of patients and their families at EOL and explain and discuss both the palliative care philosophy and the palliative approach to care. Following this general discussion about dying in Canada and about quality-
EOL care and palliative principles, I shift focus and explore concepts in the management of chronic, life-limiting conditions. I emphasize illness education and self-management as aspects that should be considered within how I have defined “EOL planning and care” in the HF patient population. To close Chapter Two, I explicate the complex issue of heterogeneity in the HF patient population and illuminate the substantial amount of clinical knowledge that clinicians utilize to support this patient population.

In Chapter Three, I elaborate on the theoretical framework, which supported all aspects of my study. I present and discuss Sewell’s (1992) *Theory of structure* and Kincheloe and McLaren’s (2011) *Reconceptualized critical theory*\textsuperscript{14} in detail. In doing so, I articulate how Sewell’s particular conceptualization of structure emphasizes two key strengths: the foregrounding and presentation of agency, and social transformation (i.e. change) as possible. Sewell points to issues of power within social relations (for example, when explaining why some structures remain and others do not); however, he does not explicitly identify a theoretical underpinning for power. Thus, after introducing Sewell’s work, I also address ideas of power in social structures in relation to Kincheloe and McLaren’s (2005) writings on critical theory.

\textsuperscript{14} Kincheloe and McLaren’s work was first published in 1994. I reviewed a 2005 (Kincheloe & McLaren, 2005) version and a 2011 version. The 2011 version is cited through this dissertation.
explain how I addressed philosophical congruence throughout the study design with these two theories. I close Chapter Three by discussing implications of research and knowledge production within the theoretical framework described.

In Chapter Four, I open with a brief review of key philosophical issues concerning methodology. I situate qualitative research within what has been called the “emerging” paradigm. I then explain how my research questions, the implications of such questions, and the purpose of this inquiry, required a qualitative methodology. I locate this study within a particular methodological style called critical ethnography. I describe my complementary use of ethnographic methods and interpretive description and how they informed my study sample design and data collection methods (observations, interviewing, fieldnotes, and reflexive journaling). I close Chapter Four by explicating my analytic processes and described how I maintained quality and integrity throughout the study process.

I present my study findings in Chapters Five, Six, and Seven. Each of these three chapters are focused around a particular area of findings. In Chapter Five, I explore the area of findings about what HCPs saw and knew, which addresses issues of practice knowledge and notions of expertise, as well as acute care clinicians’ perceptions of knowledge needs and competencies in acute care. In Chapter Six, I examine the area of findings about what HCPs said and heard. This second major area of findings illuminates uses and meanings of particular EOL-related phrases. I explore how EOL-related words were used beyond their definitions and instead, reflected what I interpreted as narrative. Chapter Seven is a presentation of the third
major areas of findings, *how HCPs felt and acted*. Here, I focus on what I recognized as the emotional and value-base dimensions of EOL planning and care. I explore aspects of how EOL planning and care work can be emotionally difficult for HCPs; for example, when HCPs’ own values are misaligned with what a HCP perceives the patient/family wants.

In Chapter Eight, I discuss all three areas of my dissertation findings in relation to the current literature and related concepts. For example, in the first section of discussion, I examine my findings about *What HCPs saw and knew* and explore the topic of knowledge, skills, and competencies in acute care. I also examine and discuss other areas including the use of language in practice, and emotions in health care work.

Chapter Nine is my final chapter; in it, I discuss the micro-, meso-, and macro-level implications of the findings from Chapter Five, Six, and Seven. I also highlight limitations in the study design and opportunities for future research. I close this last chapter with an overall summary of this dissertation and some concluding remarks. I emphasize how my study adds new knowledge to the growing body of literature about HF-EOL care for patients and their family members. I also discuss how my findings may improve EOL planning and care experiences for this patient population and other similar patient groups and inform future policy and research.
Chapter 2
Living and Dying with Heart Failure: Chronicity, Heterogeneity, Comorbidity, Uncertainty, and Mortality

Throughout my own experiences working in diverse clinical roles, and being involved in countless HF-EOL planning and care experiences with patients with HF and their families, I have been cognizant of the complexity of this patient/family population. The complexity of this patient population is in part related to the prevalence of HF and the pathophysiological heterogeneity, which results in significant prognostic differences from one person with HF to another. Though HF is an illness that impacts many patients in hospitals, individuals’ outcomes differ, as do etiologies, treatments, illness trajectories, and so on. In practice, this means it can be hard to identify what any one individual might need because while there are guidelines, there is no single treatment and care approach for this patient population. Patients’ individual illness journeys are unique.

The complexity of the HF patient population, the diversity and uncertainty of the illness trajectory, and the multitude of treatment and care options relates, in part, to the array and availability of therapeutic options in cardiac care. Cardiac therapies are sophisticated and continually evolving. These therapies further complicate and confound prognostic differences and also underpin some of the challenges both HCPs and patients/families can have understanding illness expectations. For example, even though HF is a life-limiting illness, therapies can be effective at both prolonging life and improving symptoms, which can obscure
the therapies aims (e.g. to prolong life versus to control and manage symptoms). Complexity is also related to differences in care settings where patients with HF access hospital services. Indeed, thinking about HF-EOL planning and care involves explicating aspects of complexity in this particular patient population. Thus, my overall purpose in this empirical review is to summarize what is currently known about the significance of these complex HF patient characteristics and to situate my research problem, purpose, and research questions.

As the HF patient population is growing, I also discuss the importance of understanding EOL care experiences. Unlike any other cardiovascular disease (CVD), HF prevalence continues to rise (Bleumink et al., 2004; Boutrous & Hummel, 2016; Heart and Stroke Foundation, 2016; Public Health Agency of Canada, 2009; Strachan et al., 2009; van Diepen et al., 2014). The prevalence of HF is increasing in part due to improved treatment and survival of precedent etiological causes including coronary artery disease (CAD) and hypertension (HTN) (Beattie, 2015; Butler & Kalogeropoulos, 2008; Johansen, Strauss, Arnold, Moe, & Liu, 2003; Kheirbek et al., 2013; Strachan et al.). As Kheirbek et al. (2013) have explained: “survival rates of patients with myocardial infarction (MI) continue to improve, but with that advance [in MI survival,] comes a rise in disabling heart failure; within 6 years of a MI 22% of men and 46% of women are disabled with HF” (p. 478).

Growth in the HF patient population is also expanding because HF prevalence increases with age (Butrous & Hummel, 2016). The population incidence of HF approaches 10 per 1000 by 65 years of age (Jessup & Brozena, 2003; Mozaffarian et al., 2016). By 80 years of age,
approximately 10 to 20 (meaning 100-200 per 1000) percent of people are affected (Campbell & McMurray, 2014; Chow et al., 2005; Howlett, 2011; Komajda et al., 2009; Lloyd-Jones et al., 2002; Mahjoub et al., 2008; Mozaffarian et al., 2014; Rutten, Grobbee, & Hoes, 2003). In Canada, older adults make up the fastest growing age demographic (Pesut et al., 2014); 2.2% of the population is aged 85 and older and about 13% are aged 65 and older (Statistics Canada, 2017). Together, the improved survival of CVDs, coupled with aging population trends, are expected to lead to continued increases in the prevalence of HF (Butler & Kalogeropoulos, 2008; Dunlay & Roger, 2014; Mosterd et al., 2001). These continued increases undergird why it is critical to understand more about the problem of reportedly poor-quality HF-EOL planning and care—indeed, many more people will be affected by HF and EOL planning and care issues will become increasingly important to this growing patient/family group.

2.1. Overview of Chapter Two

The linkage between acute HF exacerbations, hospitalization, and mortality is important. As others have suggested, HF-exacerbation-related hospitalization and mortality outcomes indicate HCPs should be considering EOL planning and care—that is, HCPs working in acute settings should have a role in EOL planning and care. Thus, at the outset of this chapter, I review literature where HCPs roles in HF-related hospitalizations are explained.

The majority of deaths from most illnesses, including HF, take place in hospitals. Hence, in the second section of this chapter I discuss literature about dying and death in hospitals. I also explain EOL-related concepts including palliative care philosophy and the palliative
approach to care. In hospitals and elsewhere, palliative philosophy has had considerable influence on what is presently known about how best to care for patients with HF and their families facing life-limiting illnesses and EOL. Following this discussion about hospitals, mortality, and care for the dying in this chapter, I shift to the broader topic of chronic illnesses.

Chronic illness management strategies are important in the care of many chronic illnesses; in the setting of HF in particular however, I argue that these strategies are critically important. This critical importance relates to a linkage between self-management and acute exacerbation events that may require hospitalizations (Booth, Fallon, & Hollis, 2016). And as HF hospitalizations relate to increased mortality, these management strategies also matter in the “EOL planning” domain of EOL planning and care. To fully explicate and understand this linkage, I present and discuss literature about chronic illness theory generally and HF-self-management concepts more specifically.

To close this chapter, I examine the especially complex issue of heterogeneity in the HF patient population. Heterogeneity relates to several factors including multiple etiological causes, illness stage and symptom burden, comorbidity and frailty burden, and therapy options. While I recognize much of this content is medically-focused and technically-oriented, my purpose is to bring to light to two ideas: the nuances of “knowing” this patient population; and, the inherent difficulties that clinicians face as they navigate the heterogeneity.
2.2. Hospitalization and Mortality: Prognostic Implications of Acute Decompensation Events and Current Dying Experiences

Hospitalizations for acute HF decompensation are indicative of poor prognoses (Howlett et al. 2010; Scrutinio et al., 2015; van Diepen et al., 2014). van Diepen et al. examined outcomes for n=5094 patients admitted to 224 hospitals and reported a 30% 1-year mortality for patients with HF who survive to discharge following admission for acute exacerbation. Scrutinio et al. reported similarly poor survival outcomes: “approximately 12-15% of the patients hospitalized for acute HF die within 12 weeks, and 30% within 12 months of admission” (p. 1076).

The association of HF-related hospitalization and mortality should be significant for HCPs working in acute care settings and indeed, may indicate the need to think about engaging patients in conversations about their wishes in relation to possible shifts their care goals and aims. For example, Howlett et al. (2010) argued that admissions to hospital (for decompensated HF) may signify the need to transition from “Stage I” management to “Stage II” (p. 137). In Stage I, Howlett et al. proposed that HCPs should offer patients with HF and their family members opportunities to participate in goals-of-care conversations, discuss expectations about their disease, and learn how to self-manage their chronic disease(s). In Stage 2, HCPs should engage patients and their family members in opportunities to re-visit and possibly renegotiate goals of care, discuss changes in their illness stage and prognosis, and support patients and their families prepare for subsequent deteriorations. In Stage II, patients and their family
members may also benefit from consultation and inclusion of specialty services when needed (e.g. specialist palliative care clinicians and teams). Recognizing that patients with HF commonly die in hospitals, Howlett et al. (2010) illuminate the role HCPs in acute hospital settings have in HF-EOL planning and care and transitions from Stage I to Stage II. Hospitals are complex settings that encompass a range of acute inpatient services and have influence on dying experiences and the care of patients with HF and their families with life-limiting illnesses at EOL.

2.3. Dying in Hospitals and the Care at End of Life: What is Known about Caring for Patients and their Families with Life-limiting Illnesses

In Canada, most people die in hospitals (Chan, 2014; Heyland, Lavery, Tranmer, Shortt, & Taylor, 2000; Kelley & Morrison, 2015; Komajda et al., 2007; Komajda et al., 2009; Wilson, Hewitt, Thomas, & Woytowich, 2014; Statistics Canada, 2019). Acute care settings (e.g. general medical units, cardiac units) are frequent locations for these in-hospital deaths (Chan, Macdonald, Carnevale & Cohen, 2017; Chan, 2014; Cross, 2013; Heyland et al., 2000). Critical care admissions are also common settings where patients receive EOL care (e.g. medical

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15 “Critical care” refers to hospital units that specialize in the provision of intensive, often invasive, treatment-focused care (Andresen, Guic, Orellana, Diaz, & Castro, 2015; Huynh et al., 2013). I explain these settings in more detail in section 2.3.1. below.
intensive care units (ICU), cardiothoracic ICU, cardiac care unit (CCU). For example, between one-fifth and one-third of people who die in hospitals receive some treatment and care in a critical care area (Bach, Ploeg, & Black, 2009; Canadian Institute for Health Information, 2016; Cook & Rocker, 2014; Cypress, 2010; Fowler & Hammer, 2013; Heyland et al., 2013; Kheirbek et al., 2013). As I will discuss in Chapter Four where I explain methodological considerations including study sites and sample, the diversity of the locations where patients and their family members access EOL planning and care (i.e. medical units, cardiac units, critical care) underscored why I aimed to include a range of perspectives that reflected the care in these locations and how this goal was supported by the design of my sample and study participant recruitment.

2.3.1. Dying in acute care settings: General and specialty areas/units in hospitals.

In hospitals, acute care practice areas (also called “units”) include both general settings such as general medicine and general surgery units, as well as specialty practice settings such as cardiac units, critical care units, and palliative care units. Conceptually, both general and
specialty settings are situated within broader, macro-level societal contexts, as I illustrated below (see Figure 2-1).

![Figure 2-1: Acute care practice areas, general and specialty areas](image)

In general units, patient populations are diverse and are often admitted with “all-organ” causes. In contrast, specialty settings commonly focus on single organs (e.g. kidney, heart), groups of diseases (e.g. cancer, CVD), or particular HCP skills or expertise (e.g. critical care). In response to the complex pathophysiology of many chronic diseases, specialty practices have proliferated (Rothman & Wagner, 2003).

Each of these areas (i.e. general and specialist) has a role in both general illness management and in HF-EOL planning and care. While many patients receive care from generalists throughout their illness, in most instances where patients have complex medical conditions, specialists are also included. Gott, Seymour, Ingleton, Gardiner, and Bellamy (2011) explained how this decision is often made: “the specialist role...focuses on management of
‘complex’ cases and providing support for generalist colleagues through partnership working” (p. 233). Generalists also deliver the majority of patient care in hospitals (Tu, Gong, Austin, Jaakimanian, & Tu, 2004) and throughout an entire illness trajectory, including HF-EOL planning and care. In partnership, specialist teams are consulted in situations where there is clinical complexity and greater expertise on a particular clinical issue is required, which is often the case in the HF patient population. I return to this point at the end of this chapter where I discuss heterogeneity and complexity in HF.

2.3.1.1. The cardiac specialty. The cardiac specialty is well established and a multitude of cardiac-focused services exist, especially in highly populated centers. In British Columbia, cardiac-specific services include both inpatient and outpatient resources. For example, cardiac medical units and cardiac intensive care units exist at several of the tertiary and quaternary hospitals. Outpatient services are also available and include programs such as cardiac rehabilitation, arrhythmia clinics, heart function clinics, and heart transplant clinics (Cardiac Services BC, 2011; Provincial Health Services Authority, 2018). These cardiac specialty settings also host a range of HCPs with specialty and sub-specialty training (e.g. HF and transplant physicians and nurses, cardiac pharmacists, cardiac dieticians, cardiac critical care physicians and nurses, cardiovascular surgeons, interventional physicians, etc.). Access agreements are in place throughout the province to promote access to these specialists.

While specialist cardiac services may be available, access and involvement of cardiac specialist clinicians is not automatic for all patients with cardiac disease. For example, having a
medical history that includes a serious cardiac illness does not secure acceptance of patients into specialty cardiac care units. In practice, admissions to specialty cardiac areas are typically for patients who present with primary cardiac issues such as new or decompensated HF requiring complex care (e.g. HF exacerbation requiring specific up-titration of cardiac medications). Individuals who may have complex cardiac disease histories including HF, who require hospitalization for non-cardiac causes (e.g. infection, sepsis, delirium), are more often admitted to general practice areas/units (e.g. acute medicine units). Admission processes vary with institutional procedures, physician preferences, and bed capacity management functions (Chang & Shapiro, 2016; Safavi, Dharmarajan, Kim, Strait, Li et al., 2013). Other factors may also influence admission processes and decisions; for example, Komajda et al. (2007) found that octogenarians, who make up a considerable proportion of patients with HF, are more likely to be admitted to medical units and less likely to be referred to cardiac specialty units. While this age-related trend may align with patients’ care preferences, this trend may also be illuminating possible implicit age-related drivers—that is, where medical decisions may be based on HCPs’

16 Of note, in my review of the literature, I found only limited published information about exactly how patients are admitted into specialty units. The admission trends described here reflect my understanding of what I have witnessed over the course of my own years of clinical practice.
assumptions and beliefs about patients’ care needs based on their age, rather than on the patient’s clinical indications or preferences.

**2.3.1.2. The critical care specialty.** Critical care areas specialize in the provision of intensive, often invasive, treatment-focused care (Andresen, Guic, Orellana, Diaz, & Castro, 2015; Huynh et al., 2013). The medical treatment and goals in critical care are commonly life-sustaining and saving and use invasive biomedical technologies. Chang and Shapiro (2016), for example, looked retrospectively at critical care admission data from 156,824 patient admissions in 94 different hospitals in Washington and Maryland, USA. Four admission diagnoses were examined: diabetic ketoacidosis, pulmonary embolism, upper gastrointestinal bleeding, and HF. Uses of invasive diagnostic and interventions were examined in relation to hospital-level ICU utilization (i.e. high ICU utilization hospitals compared to low ICU utilization hospitals). Chang and Shapiro found institutions using ICUs more frequently were also more likely to perform invasive procedures and use central venous catheters. Subsequently, costs in higher ICU utilization hospitals were also greater. Interestingly, despite the critical care procedures deployed, mortality rates were not improved in the higher ICU utilization group. Huynh et al. recommended critical care be considered a “therapeutic trial” with a plan to transition to from treatment-focus to support-focus when return to an acceptable health state is not expected (though in practice, this does not always happen).

Overall, patients with HF and their families experience high critical care admission rates; for example, van Diepen et al. (2014) found that approximately one-quarter of patients
hospitalized with acute decompensated HF are admitted to critical care. Safavi et al. (2013) reported that “one in five patients hospitalized with HF in the US are admitted to [critical care]” (p. 923). At EOL, Howlett (2011) noted that patients with HF are twice as likely to be admitted to critical care compared to patients with cancer. Critical care admissions may occur in part because the HF illness trajectory is typically characterized by periods of stability interrupted by episodes of acute exacerbation (Kheirbek et al. 2013). In some instances, these exacerbation episodes are treated with therapies where critical care expertise are needed (e.g. intravenous inotropes and vasopressors, mechanical ventilation, temporary dialysis systems, cardiac pacing, heart assist devices)(Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). Patients’ needs for specialized monitoring equipment including cardiac telemetry or continuous blood pressure, may also contribute to critical care admissions.

Much like the admission processes described above about patients’ acceptance into cardiac specialty units, having critical illness does not automatically mean patients are admitted to critical care. For example, Chang and Shapiro (2016) described critical care utilization for several patient groups including those with HF: “systemic institutional factors” such as bed capacity, nurse-to-patient ratios, hospital protocols, and physician practice preferences influence critical care admission and utilization (p. 1497). Similarly, Safavi et al. (2013) reported: “the decision to admit patients to [critical care] may be a result of multiple factors, including the patients’ clinical status, practitioner discretion, institutional policies and procedures, and hospital capacity” (p. 923).
Both the systemic institutional factors (including practitioner discretion, institutional policies, etc.), and the patient-related related factors described above (e.g. age-related drivers), point at decision-making within structural aspects in the hospital and critical care contexts. For example, HCPs may view older patients as less likely to achieve the “cure” goal that is sought in the critical care and cardiac specialty settings. In scenarios where schemas include assumptions about a patients’ deserving or appropriateness for critical care and thus admission is denied, under-treatment might occur. Likewise, the intensity of care within specialty settings such as critical care, which are designed with treatment and cure-focused aims, may exceed what HCPs think ought to be achieved for people with chronic illnesses, including HF. This notion illuminates a possible schema—that is, a HCP’s belief—about the value or appropriateness of a “cure” goal for a particular patient; this notion also illuminates how schemas interface with resources such as the specialty areas to structure the care. In this example, the structured practice might result in admission to a general medical setting and exclusion from a specialty or critical care setting.

2.3.1.2.1. The experiences of dying in critical care. The nature of critical care as intense, intervention-focused settings can have detrimental effects for the patients and families who experience this type of care in late illness and at EOL. Dying in critical care areas is thought to be a difficult experience for patients (i.e. patients with HF and non-HF alike), families, HCPs, and the health care system more broadly. For example, Safavi et al. (2013) described decisions to triage admissions to critical care as having “high cost” for patients with HF, their families, and
the health care system. This “high cost” stretched beyond finances; for patients, Safavi et al. explicated several risks inherently associated with critical care admission including medication errors, delirium, hospital-acquired infections, and posttraumatic stress disorder. Sleep deprivation, painful procedures, fear, and disrupted light-dark cycles associated with critical care can also considerable sources of stress for patients (Andresen et al., 2015).

In critical care, some patients with HF may face a death experience that they may not want, or may not have chosen, if given the opportunity to state their individual preferences in advance. In Goldstein and Lynn’s (2006) view, these preferences need to be considered well before an acute event that requires hospitalization. Indeed, Goldstein and Lynn claim that the existing lack of comprehensive advance care planning in the HF patient group “ensures that patients routinely receive life-sustaining treatments such as intensive care and mechanical ventilation, even if they would have preferred otherwise” (p. 12).

Family members and caregivers are also thought to experience difficulty when patients die in critical care and may endure additional stress and worsened emotional consequences from experiences in critical care. Anxiety, depression, and posttraumatic stress disorder have been recognized in family survivors (Andresen et al. 2015; Gries et al, 2010). Wright et al. (2008) reported, “caregivers of patients who received any aggressive care [at the EOL] were at higher risk for developing a major depressive disorder, experiencing regret, and feeling unprepared for the patient’s death… they also had worse QOL outcomes” (p. 1668). In general, critical care admission experiences, particularly for patients who are dying and at the HF-EOL,
can be associated with negative outcomes for both patients and families (Andresen et al.; Coombs 2010; Gries et al.; Wright et al.).

2.3.1.2.2. *Impacts on HCPs who support patients at EOL and their families in critical care settings*. Health care professionals can also be affected when HCPs perceive the treatments and interventions given to patients with HF at EOL in critical care as inappropriate or unwanted. For example, Baggs et al. (2007) have found that HCPs have described uses of biomedical technologies in critical care as excessive at the EOL. For some HCPs, critical care areas are also seen to be inadequately equipped to support patients and their families due to inadequate focus on symptom management and fewer opportunities to involve families and ensure open visiting and access (Baggs et al.). Burnout, sadness, frustration, anger, withdrawal from patient/family care, work place attrition, and moral distress have all been identified as consequences of HCPs’ perceptions of poor quality EOL care (Hamric & Blackhall, 2007; Huynh et al, 2013; Lamiani, Setti, Barlascini, Vegni, & Argentero, 2017).
To further illustrate, Huynh et al. (2013) examined notion of “futile”\textsuperscript{17} treatments in critical care and looked at HCPs’ beliefs about the “futility” of the care they were providing. The researchers surveyed 36 critical care clinicians in 5 critical care units about the care of n=1193 patients. Clinicians were asked to assess instances of futile care. Clinicians were asked to make determinations of futility based several factors: burden of treatment outweighing benefit, treatment unable to achieve patients’ goals, treatments used when death seen to be imminent, or treatment used when survival outside of critical care was unlikely. From Huynh et al.’s findings, clinicians reported that 8.6% of patients “probably” received futile treatment and 11% “did” receive futile treatment, suggesting that HCPs working in critical care perceive nearly 20% of all care to have some degree of futility. Huynh et al. also calculated mortality outcomes for patients seen to be receiving futile care: “as expected, the hospital and 6-month mortality rates were significantly higher for patients perceived as receiving “futile” and “probably futile”\textsuperscript{18} treatment compared with patients perceived as receiving no futile treatment (p<.001)” (p. 1892).

\textsuperscript{17} “Futility” is a value-laden word used in health care culture as an attempt to describe interventions or treatments that fail to meet a particular goal. In practice however, this word is commonly used without explication or clarification of what the goal actually is (e.g. “quality of life” or “length of life”?) and whose goals should be considered in evaluating a particular goal (e.g. a health care team or patients/families?). In recognition of this problematic underpinning, Truong and White (2013) suggested the term “potentially inappropriate” as an alternative.

\textsuperscript{18} Quotation marks added.
These findings point to the intensity of treatments and interventions used in critical care. The findings also point to a lack of clarity about patients’ goals and what they wanted in their care.

In summary, hospital settings generally, and critical care environments specifically, do not necessarily meet the needs of patients at the EOL. “Studies of the care dying people receive in acute hospitals provide evidence that hospital nurses experience difficulties meeting their needs and those of their families” (Hopkinson, Hallett, & Luker, 2003, p. 526). Commonplace attributes such as restricted visiting hours, excessive noise, space restrictions, heavy nursing workloads, limited nurse-patient interactions, and inflexible schedules often mismatch care with patients’ and family members’ needs during the EOL and may erode the quality of death (Andresen et al., 2015). Difficulties meeting patients and their families’ needs in hospitals is in part related to the focus of these settings; that is, acute and treatable illnesses (Thorne, Roberts, & Sawatzky, 2016). Indeed, many patients facing EOL, including those with HF, express a preference to die in non-hospital settings. This preference to die in non-hospital settings is one example of what is currently known about how to support patients and their family members plan, prepare for, and experience EOL.

2.3.2. The care needs for patients with life-limiting illnesses and their families. The needs of dying patients EOL and their family members are well described in the literature (Coombs, 2010; Curtis & Engelberg, 2006; Hamric & Blackhall, 2007; Heyland et al., 2000; Heyland et al., 2006; Howlett, 2011; Stajduhar, 2011; Steinhauser et al., 2000). In general, excellent quality EOL care is care that aligns with a patient’s own preferences and involves early
incorporation of palliative care principles, including quality of life (QOL) emphases (as defined by the patient), symptom management, relief of suffering, an individualized whole-person approach throughout the illness trajectory, and family support. In HF specifically, symptoms can be severe. Many patients endure anxiety, breathlessness, pruritus, and delirium (Goldfinger & Adler, 2010; Howlett, 2011; Jaarsma et al., 2009; Setoguchi et al., 2010). Other symptoms for patients with late-stage HF include profound activity intolerance; loss of independence and social isolation; fatigue and malaise; and fluid retention (Godfrey, Harrison, Medves, & Tranmer, 2006; Goebel et al., 2009; Goldfinger & Adler, 2010; Jaarsma et al., 2009; Low, Pattenden, Candy, Beattie, & Jones, 2011; O'Leary, Murphy, O'Loughlin, Tiernan, & McDonald, 2009; Setoguchi et al., 2010; Shah et al., 2013; Zambroski, Combs, Cronin, & Pfeffer, 2009).

Beyond symptom control, care needs at EOL also include retaining some control; participating in opportunities to strengthen or resolve familial relationships; ongoing and honest communication with HCPs; engaging in planning and goal-setting; attending to psychosocial and spiritual needs; and preparing for death (Detering, Hancock, Reade, & Silverster, 2010; Heart Failure Society of America, 2010; Heyland et al. 2013; McKelvie et al., 2011; Sinuff et al. 2015; Steinhauer et al., 2000; Zambroski, 2004). The *palliative care model* is a conceptual framework that outlines several core principles to support patients and their families prepare for EOL and address the complex array of needs associated with dying, death, and bereavement. While the palliative care model and related principles aligns with what patients and family members need at EOL, for patients with HF, access to this care model is limited.
2.3.2.1. The traditional palliative care model. Traditionally, the term “palliative care” has been used to describe a holistic care model based on a set of principles that have been evolving since the late 1960s (“palliative care” often also refers to specialist clinicians, which I will explain below). Palliative care principles were originally intended to meet the needs of patients/families with life-limiting malignancies (Clark, 2008; Kelley & Morrison, 2015). Palliative care principles include: a whole-person approach to care that includes psychological, spiritual, and logistical support; interdisciplinary involvement, planning and preparations for EOL, supportive decision-making and goal setting, and coordination of complex care; and attention to ameliorating suffering and treating the range of symptoms associated with the end-stages of disease progression (Carstairs, 2010; Goldfinger & Adler, 2010; Kavalieratos, Mitchell, Carey et al., 2014; Kelley & Morrison, 2015; Low et al., 2011; McKelvie et al., 2011; Mino & Lert, 2005; Meyers & Goodlin, 2016; World Health Organization, 2017). Increasingly, these palliative care principles are seen as appropriate for many more people with life-limiting illnesses regardless of the disease etiology or illness course (Kelley & Morrison). Integration of palliative care principles has shown to improve symptoms, QOL, and satisfaction across a range of populations with life-limiting illnesses including cancer, lung disease, multiple comorbidities, and frailty (Kelley & Morrison; Kristjanson, 2005).
As is reflected in Figure 2-2 below, the traditional model of palliative care largely reflects what was previously thought to be an expected illness trajectory for patients with cancer (Clark, 2008; Kelley & Morrison, 2015) (see Figure 2-2).

![Palliative Care Model Diagram]

*Figure 2-2: The traditional palliative care model.*


The illness course illustrated in the palliative care model in Figure 2-2 represents patients who retain a fairly high level of functioning from the point of diagnosis. During this period of high functioning, goals of care are “treatment” and “aggressive medical care” is provided. The patient’s illness course is then abruptly interrupted by a marked deterioration point (indicated on Figure 2-2 by the shift from light gray to dark gray), followed by a period of rapid decline until death. During the period of rapid decline, care goals shift from “treatment” to “hospice care” (i.e.
Patients with HF do not easily fit within the traditional palliative care model because the illness often lacks the distinguishable deterioration point. Lunney, Lynn, and Hogan (2002) and Lunney et al. (2003) proposed four models of dying trajectories: sudden death, terminal illness, frailty, and organ failure. The trajectory of organ failure (includes HF) is pictured below (see Figure 2-3):
Figure 2-3: Illness trajectories

The illness trajectories of cancer, organ failure (including heart), and frailty and dementia. From “Living Well at the End of Life Adapting Health Care to Serious Chronic Illness in Old Age” by J. Lynn and D. Adamson (2003). Copyright 2003 by RAND. Reprinted with permission.
As is illustrated Figure 2-3 above, from the time of diagnosis, patients with HF have diminished functional capacity. Episodes of acute exacerbation occur repeatedly throughout the illness course. Following each acute event, a patient with organ failure may regain some recovery; however, they return to a new, diminished baseline with less functional capacity. Death from HF is not necessarily predictable and is often perceived to be sudden. Patients do not necessarily experience a marked moment of decline that signifies the beginning of the EOL period. In Gott, Seymour, Ingleton et al.’s (2011) view, palliative care was previously synonymous with the term “terminal care”\(^\text{19}\) for patients with cancer but has come to be seen as an approach that is relevant for any patient where death from illness is anticipated; that is, the palliative care model has evolved to better support non-cancer illness trajectories (i.e. the terminal illness model). Stajduhar (2011) named this evolution and expanded application of palliative principles the palliative approach to care.

**2.3.2.2. The palliative approach to care.** The palliative approach differs from the palliative care model and may better match patients’ and family members’ needs in organ failure

\(^{\text{19}}\) There are many different terms that are used to described EOL care and experiences—Collectively, I came to call these terms “EOL-related words and phrases.” The understandings and meanings of these words differs, depending on the individual. Indeed, this is a major theme of findings in this dissertation, which I explore in Chapter Six.
(e.g. HF) illness trajectories. Chronic illness self-management, integration of palliative care principles, effective and ongoing communication about illness issues and EOL planning, and specialist palliative care services when appropriate, underpin quality care through an entire life-limiting illness trajectory, including the final EOL stage. Collectively, these elements have been described within a framework called the palliative approach to care (Canadian Nurses Association, Canadian Hospice Palliative Care Association & Canadian Hospice Palliative Care Nurses, 2015; Kristjanson, 2005; Reimer-Kirkham et al., 2015; Sawatzky et al., 2016, Stajduhar, 2011).

The palliative approach expands the application of palliative knowledge to a wider range of patients, to be delivered by all HCPs regardless of practice area or specialty expertise, and irrespective of patients’ diagnosis and stage of disease progression:

A palliative approach does not closely link the provision of care with prognosis, but focuses on conversations with patients/families about their needs and wishes; comfort measures; support for psychosocial, spiritual, and cultural issues; information requirements; and provisions for death and for care after death (Stajduhar, 2011, p. 10). As illustrated below (see Figure 2-4), the diagnosis of any life-limiting illness begins with treatment-focused (i.e. “disease modifying or potentially curative” focus) care (Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011). The palliative approach however differs from the
traditional palliative care model because it simultaneously involves “symptom management, palliative” through the early “curative” phases of the illness trajectory.

As the illness progresses, the emphasis on treatment-focused care wanes, and supportive/palliative care increases. The palliative approach also emphasizes “family bereavement” care after death (Goodlin, 2009; Lunney et al., 2003; Lynn & Adamson, 2003; Murray et al., 2005).

Communication is one of the pillars of the palliative approach to care. Stajduhar (2011) articulated this point by describing the palliative approach as a relational, communication-based health care strategy appropriate for all people with any life-limiting illness through the entire

Figure 2-4: The palliative approach to care, new model

disease trajectory. Pesut et al. (2014) built on Stajduhar’s work to describe the palliative approach similarly, focusing on conversations: “the term palliative approach refer[s] to a philosophy of care that includes conversations about goals of care and the supportive principles of palliative care in an upstream approach in any care setting where people with life-limiting conditions are cared for” (p. 47). Indeed, in Bernacki et al.’s (2015) view, the provision of EOL care that is consistent with individuals’ values, preferences and care goals is a “critical component of high-quality care” (p. 1)—and communication is a foundational aspect of how these values, preferences and care goals come to be known. As I introduced in Chapter One and noted in an earlier section of this chapter, this upstream communication (i.e. “EOL planning”) is under-utilized in the HF patient/family population and is likely related to the frequency of hospitalization in HF and associated poor-quality EOL experiences.

Three core characteristics distinguish the concept of the palliative approach to care from the traditional palliative care concept. First, there is upstream integration and intentional focus on understanding and addressing the needs of patients with life-limiting illnesses. Secondly, there is a broader application of palliative care principles to all individuals with life-limiting illness, regardless of diagnosis. And thirdly, there is engagement and inclusion of all HCPs in all areas where patients and their families access care, and inclusion of palliative care specialists, when appropriate (Reimer-Kirkham et al., 2015; Sawatzky et al., 2016). The successful integration of the palliative approach seeks to achieve three key goals: first, it may improve EOL planning and care experiences overall. Secondly, it may begin to address the widespread issue
of limited access to palliative care specialty services and thus bring into focus issues and care needs related to advanced illness and death (e.g. symptoms, grief, bereavement). And lastly, and perhaps most importantly, because it is communication-focused, integration of the palliative approach may ensure that the EOL care provided aligns with patients’ preferences. The Honorable Sharon Carstairs (2018) summarized this shift in understanding about what palliative care means in a short video: “People tend to think that palliative care is about dying. I think it’s about living. And I think it’s about living well until the very end” (Pallium Foundation of Canada, 2018).

Clinical leaders and cardiac expert consensus statements from nursing and medicine support broad applications of palliative care knowledge and ACP and EOL communication via the integration of a palliative approach for patients with HF (and their family members) from all HCPs regardless of clinical specialty (Canadian Council of Cardiovascular Nurses, 2015; Canadian Hospice Palliative Care Association, 2015; Canadian Nurses Association, 2015; Canadian Nurses Association, Canadian Hospice Palliative Care Association & Canadian Hospice Palliative Care Nurses, 2015; Jaarsma et al., 2009; McKelvie et al., 2011). The benefits of improved communication via early integration of the palliative approach, consideration and incorporation of palliative care principles, and the involvement of specialist interdisciplinary palliative care clinicians (when needed), are well established. Importantly, upstream communication and planning activities emphasize identification of patients’/families’ individual preferences, wishes, and goals and thus promote the delivery of EOL care that is aligned with
patients’ actual wishes. For example, HF-EOL-focused care can include conversations about ongoing care such as reevaluating pharmacological management and redefining the patients’ goals of care, planning for future acute exacerbations (e.g. identifying substitute decision-makers), discussing disease expectations and prognosis, and consultation with palliative specialist clinicians (Ezekowitz, O’Meara, McDonald, Abrams, Chan et al., 2017; Jaarsma, Beattie, Ryder, Frans, McDonagh et al., 2009; Kavalieratos, Gelfman, Tycon, Riegel, Bekelman et al. 2017; Ryder, Beattie, O’Hanlon, McDonald, 2011).

Incorporation of palliative care principles and involvement of palliative care specialists are also beneficial and may lead to improved QOL and mood for patients, fewer uses of unwanted aggressive treatment-focused medical interventions prior to death (e.g. better documentation of resuscitation preferences), and lengthened survival (Kavalieratos, Mitchell, Carey et al., 2014; Temel et al., 2010; Wong et al., 2016). Families’ experiences are also improved. Indeed, early integration of palliative care principles and specialists are associated with improved depression scores and QOL for family caregivers (El-Jawahri et al., 2017; Dionne-Odom et al. 2015; Fuerst, 2016).

2.3.2.3. Distinguishing the palliative approach from palliative care specialist programs and clinicians. In addition to the two models described above (i.e. the palliative care model and the palliative approach), palliative care is also a term that is used to describe a specialty program (similar to the cardiac and critical care specialties described above). Palliative care programs are commonly made up of specialist palliative care clinicians and practice
settings (e.g. specialty palliative care units, specialty palliative care outpatient services) (Nordgren & Olsson, 2004; Kavalieratos, Mitchell, Carey, Dev, Biddle et al., 2014; Quill & Abernethy, 2013). Palliative care services may also include government and social programs such as palliative care tax benefits, caregiver benefits, and/or access to home care supports.

Specialty palliative care programs and clinicians were established in the late 1960s primarily to address the care needs for patients with life-limiting malignancies; palliative care programs continue to remain tightly aligned with oncology (Clark, 2008; Quill & Abernethy; Twycross, 2002). In the last ten years, palliative care specialist programs have grown by more than 150 percent (Kelley & Morrison, 2015). In the United States for example, ninety percent of large hospitals (more than 300 beds) and around two-third of smaller hospitals (more than 50 beds) have some type of palliative care specialty service (Kelley & Morrison; National Palliative Care Registry, 2015). In Canada, “except for Yukon and the Northwest Territories, all jurisdictions have beds or units in hospitals dedicated to providing palliative care services. In some areas, the bulk of palliative care services are located in hospitals” (Canadian Institute for Health Information, 2018, p. 18)

Palliative services are commonly delivered by interdisciplinary outreach consult teams; occasionally, care is provided in specialist palliative care inpatient units. Most patients with HF do not die in these specialty palliative care settings (e.g. palliative care units, hospice). Compared to patients with cancer, patients with HF have less access to palliative specialty settings such as hospice (20% vs. 51%). Overall, Howlett et al. (2010) noted that patients with
cancer constitute more than 90 percent of the patients who receive EOL planning and care but malignancies only account for approximately one-quarter of the total deaths in Canada\textsuperscript{20} (p. 138). In contrast, CVDs contribute to one-third of the overall mortality, yet equivalent delivery of both important preparations for EOL care, and the delivery of palliative-oriented EOL care, are remarkably lacking (Hauptman et al., 2008; Howlett, 2011; Setoguchi et al., 2010). As Storch, Starzomski, and Rodney (2013) have explained:

Despite numerous calls for greater access to palliative care across Canada, many Canadians do not have access to such care as they enter their final months and days... at this time for instance, only a small majority are admitted to hospice, while thousands die waiting to get into hospice or other programs of palliative care (p. 349).

As I described above, greater integration of a palliative approach has been suggested as one strategy to both improve HF-EOL planning and care experiences overall, and to address the widespread issue of limited access to palliative care specialty services and programs. The palliative approach promotes the integration of the principles of palliative care to a wider patient

\textsuperscript{20}I am not suggesting that the total existing palliative-oriented EOL care services are sufficient to meet the needs of all patients and families facing death. Indeed, reports suggest that many people lack coordinated, quality EOL care and have limited access to palliative specialty services (Howlett et al., 2010; Kelley & Morrison, 2015).
population and regardless of disease etiology. The palliative approach can also be applied in all care settings including acute care in hospitals, and by all HCPs including non-palliative specialist clinicians. For the HF patient population, integration of the palliative approach guides HCPs (non-palliative specialists and palliative specialists alike) to attend to the diversity of individual patient/family needs, address issues of EOL planning and care early and repeatedly throughout disease trajectory, and co-create differentiated and tailored programs of care through the course of the chronic illness, including EOL and death. Indeed, the palliative approach may be a goal toward which HCPs in hospital settings can work.

The palliative approach to care also aligns well with the chronic illness management theory and principles. Chronic disease/illness management is a term that has been used to describe helpful approaches for people with chronic illnesses, including HF. I will therefore move next to this broader topic of chronic illnesses and I will situate HF in relation to the notion of chronic illness management. In the section forthcoming, I emphasize how self-management aligns with chronic illness management and in the HF patient population, also uniquely aligns within EOL planning and care.

2.4. Chronic Illness Management: Exploring the Unique Care Needs for Patients with Chronic Illnesses such as HF

Chronic illnesses are defined as conditions that exceed three-months duration and do not self-limit (Institute of Medicine, 2001). Chronic illnesses including HF impact a substantial number of people in Canada. Diseases such as cancer, diabetes, and respiratory and CVD are
widely prevalent. Given the demographics of aging presented at the beginning of this chapter, along with other collateral socio-political-environmental changes such as poverty and pollutants, the prevalence of many chronic diseases is expected to grow (Penning, 2002; Rothman & Wagner, 2003; Thorne, 2008a; Thorne, Roberts, & Sawatzky, 2016; Thorpe & Philyaw, 2012; Wagner et al., 2001). In British Columbia specifically, the prevalence of all chronic conditions is forecasted to increase by 58 percent over the next 25 years (British Columbia Ministry of Health, 2013). Many chronic pathologies are life-limiting conditions that will culminate in dying and death (Canadian Institute for Health Information, 2018; Goodlin et al., 2004; Hauptman & Havranek, 2005; Statistics Canada, 2012). While uncertainty permeates most aspects of chronic illness experiences generally, in the setting of many CVDs including HF, there are also particular and significant uncertainties concerning the length of life expectancy, QOL, and the trajectory of death.

Chronic disease processes are characterized by attributes that differ from acute, episodic illnesses (Institute of Medicine, 2001; Thorne, Roberts, & Sawatzky, 2016; Wagner, Austin, & Michael Von Korff, 1996). Acute illnesses usually manifest suddenly from distinguishable origins and health care is treatment-focused and aimed at restoration. Chronic disease processes however, are less linear and often appear gradually; progress and evolve; and are generally brought on by multivariate etiological causes (Holman & Lorig, 2004; Penning, 2002; Wagner et al., 1996). As noted in a section above, individuals and their families who coexist with chronic illnesses endure difficult and multifaceted challenges and must cope with
uncertainty amidst a myriad of health and social issues. Such issues may include accessing and navigating health care services; adapting to extensive interpersonal changes in areas such as work and finances, family, and social roles; preventing further disease complications and curtailing illness progression; living with a diverse range of unpleasant physical symptoms (e.g. chronic pain, debilitating fatigue, restricted mobility, dyspnea, and so forth); and managing a multitude of psychological and/or emotional impacts (McKelvie et al., 2013; Wagner et al., 1996; Wager & Groves, 2002). Moreover, the challenges and issues with chronic diseases change and evolve as the disease course unfolds; new issues continually arise with different stages of disease progression (Holman & Lorig, 2004).

2.4.1. Models of care for people with chronic illnesses. Since the 1990s, Wagner and colleagues have written extensively on the particular health care needs of people with chronic illnesses. Wagner et al. (2001) used a helpful metaphor to describe the scope of health care needs, likening the complexity of coordinating and managing chronic illness(es) to piloting a small aircraft. The pilot of the plane is the individual living with a chronic illness. Health care professionals are meant to provide support to the pilot; keeping the aircraft in-flight and assisting the journey by ensuring the pilot has strong flying skills, a safe plane, a mutually understood flight plan, and access to a control tower for regular communications and updates.

Wagner et al.’s (2001) piloting metaphor illuminates three essential components of an effective chronic illness care model: communication and continuity; knowledge and decision-making capacity; and self-management (Rothman & Wagner, 2003; Wagner et al., 1996;
Wagner et al., 2001). Communication is typically regarded as the foundation of chronic illness care because patients and their families are instrumental observers of their continually unfolding physical and emotional status. Using communication, information and knowledge about the disease and its impacts, should transfer reciprocally between the patient/family and HCPs. Just as pilots must learn about their aircraft and how to fly, individuals and families experiencing chronic illnesses require varying amounts of information about their unique physiological responses to the disease process (Holman & Lorig, 2004; Lorig et al., 1999). Wagner et al. (2001) called self-management the third essential component of chronic illness care, noting that self-management is built on communication, knowledge, and shared decision-making. In HF in particular, self-management is an essential component of care because many acute exacerbation events that may require hospitalization and be associated with morbidity and mortality can be avoided by HF-specific self-management strategies.

To achieve these three chronic illness care goals—that is, communication and continuity, knowledge and decision-making capacity, and self-management—Wagner et al. (2001) argued that a person living with chronic illness(es) must be strategically supported by
HCPs\textsuperscript{21}. For instance, patients and families living with a chronic illness (or illnesses) need to be assisted by HCPs to gain the skills and confidence to self-manage their illness; have access to appropriate treatments and services to prevent disease complications; participate in the development of individualized and evolving health care plans; and receive regular and long-term follow-up with their HCPs (Wagner et al., 2001, p. 66).

Wagner et al.’s (2001) metaphor for coordinating and managing chronic illness issues can be simplified by a chronic illness health care model that is underpinned by two foundational principles: HCP-patient/family relationships must nurture illness knowledge development and foster self-management skills; and health care systems and services ought to reflect, nourish, and facilitate such HCP-patient/family interactions. Goodlin et al. (2004) summarized HF management as “chronic illness care interspersed with hospitalization and aggressive rescue efforts” (p. 201).

\textsuperscript{21}Thorne, Roberts, and Sawatzky (2016) have articulated critiques about this approach, highlighting the potentially problematic responsibilities placed on patients, with increasingly problematic implications where supports are inadequately available and/or there is failure to address other socioeconomic issues that contribute to chronic illness: “Nurses also began to recognize there were inherent challenges associated with the limited vision of [chronic illness management models] in that it devolved increasing levels of responsibility down to the level of patients and families, often without the necessary community-based infrastructure supports in place” (p. 94).
2.4.2. Self-management: A key chronic illness management strategy for patients with HF. One of main focuses in HF management and therapies is to minimize acute exacerbations and prevent rehospitalizations (Bergethon et al., 2015). This focus is central because mortality outcomes are worse for individuals who experience episodes of decompensated HF. Acute HF exacerbations also commonly result in Emergency Department (ED) and hospital-use (Godfrey et al., 2006; Hasegawa, Tsugawa, Camargo, & Brown; 2014; Wan, Terry, Cobb, McKee, Tregerman, et al. 2017). Godfrey attributed such exacerbations directly to breakdowns in the self-management processes. Building self-management skills is particularly important for people with HF because lifestyle modification and careful self-monitoring are cornerstones of effective disease management and are used to prevent episodes of acute, decompensated HF.

Self-management is well articulated in HF care and is defined as “the individual’s ability to manage symptoms, treatment, physical and psychological consequences, and the lifestyle changes inherent in living with a chronic condition” (Mikkonen & Hynynen, 2012, p. 397). Cardiac expert guidelines include specific self-care activities and recommendations (Howlett et al., 2016) and emphasize three elements of HF self-care which are: maintenance, monitoring, and management. Beattie (2019) summarized the role of self-management in HF in relation to the broader context of cardiology care:
Heart failure care is embedded within a relatively rigid biomedical model as enshrined in national and international heart failure societal guidelines. The widely advocated care structure is founded on a clinician-led multidisciplinary team approach, bolstered by patient education to promote self-management, but commonly there is a lack of coordination and poor communication between healthcare professionals, patients, and their families. Yet, much of the everyday care of those with heart failure depends on the support of family members, often their spouses, or other close relatives, or indeed people from their wider social circle. These individuals offer an array of assistance in providing general care, promoting heart failure-related dietary and medication adherence, and straightforward practical support in facilitating clinic attendances (p. 1)

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22 The biomedical model is constructed on several assumptions: symptoms and illness relate to a pathological process (e.g. disease); health is the absence of disease; patients are passive recipients of treatment; and compliance with prescriptive regimens is integral (Bolaria, 2002; Borrett, 2013; Fuller, 2017; Noguchi, 2012; Wade & Halligan, 2004; Wagner, Austin, Davis, Hindmarsh, & et al, 2001).

Acute care services reflect the biomedical model because they aim to address acute illnesses, usually in the format of diagnosing, prescribing treatment, and seeking illness resolution (Booth, Fallon & Hollis, 2016; Reuben & Tinette, 2014; Rothman & Wagner, 2003; Steinman & Auerbach, 2014). Likewise, the related clinical competencies expected from HCPs working in acute care hospital settings reflect this biomedical focus, which I show in Chapter Five where I present findings about how particular patient information and tasks are prioritized.
To assist with self-care with HF, in British Columbia a large library of patient/family teaching materials is freely available online with information about key topics within the elements of maintenance, monitoring, and management including daily weights, sodium restriction, early warning signs, medications, and many others (BC Heart Failure Network, 2019).

Hospitalizations can result from breaks in self-management; and as I have indicated earlier, hospitalizations are associated with death. This relationship underscores how illness education and self-management fits in with EOL planning and care. This relatedness between self-management, hospitalizations, and mortality aligns within what Howlett et al. (2010) have described as the first stage of HF support: create opportunities for patients and their families to participate in goals-of-care conversations, discuss illness expectations, and learn how to self-manage. Indeed, the *particular* skills that HCPs need to support patients with self-management are complex. The content I have presented in this section provides a foundation through which to consider the findings I present in Chapter Five. In Chapter Five, I present and discuss study data that illuminates the difficulties that some HCPs in acute care settings have in simply *seeing* HF—that is, in actually identifying HF from the many concurrent illnesses and admission causes that patients present to hospitals with. As I will also show from my study findings, study participants explicated other aspects of “HF-EOL planning” as difficult, including ascertaining the “timing” of when to start thinking about EOL issues. Such difficulties relate in part to *heterogeneity* in the HF patient population, which I will explore next.
2.5. Heterogeneity in Heart Failure: Comorbidities and Frailty, and Illness Trajectory

The HF patient population is heterogeneous. Heterogeneity relates in part to the common presence of concurrent and often multiple chronic illnesses. Other age-related complications including frailty are also common. Coupled with a diverse etiological picture and a substantial range of increasingly effective therapies (e.g. pharmaceuticals, biomedical technologies), the HF patient population is increasingly heterogenous. While the content in this section is technical and largely medically-focused, I provide this detailed overview in order to illuminate the depth and degree of clinical knowledge and expertise that HCPs use to support this patient population. Heterogeneity is also important because it adds to the uncertainty in the illness trajectory and the optimal “timing” of EOL planning and care.

There are different types of HF, variable etiologic causes, grades of associated symptoms and disease progression, and divergent degrees of comorbidity burdens. To capture the range of HF symptoms, the New York Heart Association (NYHA) classification 4-point scale is used to convey symptom severity based on patients’ reported limitations (Dolgin & New York Heart Association. Criteria Committee, 1994) (see Table 2-1).

*Table 2-1: The New York Heart Association (NYHA) Functional Classifications*

<table>
<thead>
<tr>
<th>Class</th>
<th>Degree of symptoms with physical activity and at rest</th>
</tr>
</thead>
<tbody>
<tr>
<td>I – mild</td>
<td>Asymptomatic with ordinal physical activity, no limitations on physical activity, and comfortable at rest</td>
</tr>
<tr>
<td>II – mild</td>
<td>Symptoms with ordinary activity, slight limitations on physical activity, and comfortable at rest</td>
</tr>
</tbody>
</table>
Disease progression can be estimated using the American Heart Association (AHA) staging system. Stage “A” describes people who are at high risk for HF but do not have cardiac abnormalities (Jessup & Brozena, 2003). Stage “D” represents advanced and end-stage HF and is signified by the occurrence of refractory symptoms despite maximal therapies. Approximately ten percent of people living with HF are classified as advanced (stage D) (American Heart Association, 2018). Hospitalizations for HF often result when patients experience NYHA III and IV.

### Table 2-2: Heart Failure Staging

<table>
<thead>
<tr>
<th>Class</th>
<th>Objective Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>No objective evidence of cardiovascular disease. No symptoms and no limitations in ordinary physical activity</td>
</tr>
<tr>
<td>C</td>
<td>Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.</td>
</tr>
<tr>
<td>D</td>
<td>Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms while at rest.</td>
</tr>
</tbody>
</table>

Note: Reprinted from the AHA and American College of Cardiology’s A-D staging system (American Heart Association, 2018)
2.5.1. Etiology and pathophysiology. Heterogeneity in the HF patient population in part stems from the different etiological origins and concurrent pathophysiological conditions, which are often other chronic illnesses. Heart failure manifests from diverse etiologic causes including HTN, valvular heart disease (e.g. aortic stenosis, mitral regurgitation), ischemic heart disease (IHD), and cardiomyopathies (Ho et al., 2013; Jessup & Brozena, 2003; Johnson, 2014; McMurray et al., 2012). These conditions contribute to hemodynamic abnormalities that stimulate systemic activation of compensatory neurohormonal responses (e.g. sympathetic nervous system, renin-angiotension-aldosterone (RAA) pathway) (Gibson & Nordby, 2014; Gibson & Raphael, 2014; Johnson; Sayer & Bhat, 2014). While initially helpful for improving stroke volume and cardiac output (CO), prolonged neurohormonal activity becomes maladaptive and contributes to a negative process called ventricular remodeling (Udelson & Konstam, 2011). Cardiac cellular changes associated with remodeling result in further deterioration of myocardial function and ventricular dilation, which bring about worsened hemodynamic irregularities (e.g. elevated end-diastolic pressure, tachycardia) (Jessup & Brozena, 2003; McMurray et al., 2012).

Currently, two categories are used to describe HF: HF with reduced ejection failure (HF-REF) and HF with preserved ejection fraction (HF-PEF)(Arnold et al., 2006; Campbell & McMurray, 2014; McMurray et al., 2012; Meta-analysis Global Group in Chronic Heart Failure, 2012). Ejection fraction (EF) impairments seen in HF-REF reflect systolic dysfunction associated with inadequate contractile capacity. In contrast, people with HF-PEF often have
adequate systolic function (commonly EF ≥50%) with diastole impairment due to hypertrophic myocardial changes and/or impaired relaxation.

Conditions that contribute to HF-PEF differ from HF-REF. Female sex\textsuperscript{23}, HTN, and atrial fibrillation more commonly precipitate HF-PEF (Campbell & McMurray, 2014; Duca et al., 2018; McMurray et al., 2012; Meta-analysis Global Group in Chronic Heart Failure, 2012; Scantlebury & Bourlaug, 2011). In contrast, ischemic heart disease underlies approximately two-thirds of HF-REFs. Viral, chemical (e.g. alcohol, chemotherapy), and idiopathic causes make up other common etiological origins of HF-REF (McMurray et al., 2012). Though similar one-year mortality outcomes have been described in HF-REF and HF-PEF (Arnold et al., 2007; Jessup & Brozena, 2003), more recent literature has reported worsened mortality outcomes for patients with HF-REF compared to HF-PEF (Meta-analysis Global Group in Chronic Heart Failure, 2012).

Cardiac output (CO) is decreased in both HF-REF and HF-PEF. Inadequate CO triggers the prolonged activation of compensatory neurohormonal responses and remodeling ensues. Tachycardia, sodium and water reabsorption, and vasoconstriction lead to persistently elevated

\textsuperscript{23} The concentric thickening and stiffening of the left ventricular that occurs in HF-PEF is thought to be a sex-related maladaptive response to aging and HTN in females (Scantlebury & Bourlaug, 2011)
filling pressures. Congestive HF symptoms (e.g. pulmonary edema, peripheral edema) and the effects of increased intracardiac pressures (e.g. arrhythmias) result (Sayer & Bhat, 2014). Other common HF symptoms, including diminished activity tolerance and exhaustion also result from continually poor CO. The presence of comorbidities and concurrent frailty also contributes significantly to heterogeneity.

2.5.2. Comorbidities and frailty. Heart failure is commonly complicated by the presence of multiple comorbidities (Butrous & Hummel, 2016; Goodlin et al., 2004; Howlett et al., 2010; Kheirbek et al., 2013; Komajda et al., 2009; Rozzini, Sabatini, Frisoni, Trabucchi, 2003). Up to 80 percent of people with newly diagnosed HF have previous HTN, 40 percent have previous diabetes, and nearly half have previous IHD (British Columbia Ministry of Health, 2015). “Patients with HF-PEF have a higher burden of non-cardiovascular comorbid diagnoses when compared with those having HF-REF” (Butrous & Hummel, 2016, p. 1141).

Stroke/transient ischemic attack, impaired renal function, and chronic obstructive pulmonary disease are more seen more frequently in octogenarians with HF (Komajda et al., 2009). “One obvious explanation of why patients with end-stage HF have different [illness trajectories] could be their comorbidities” (Kheirbek et al., 2013, p. 479).

McMurray et al. (2012) described four reasons that comorbidities are important in patients with HF: recommended treatments may be contraindicated in the presence of other-organ illness (e.g. renal dysfunction); therapies used to treat other conditions may worsen HF (e.g. chemotherapy); treatments in HF may counteract treatments used for other illness (e.g.}
beta-blockers and asthma); and, most comorbidities are indicators of poorer prognosis (e.g. diabetes). Chronic illness and comorbidities have substantial impacts on QOL for patients and their families and involve emotional commitments, altered daily activities and routine, sleep disruptions, financial costs, and changes in social life (Golics, Basra, Salek, & Finlay, 2013). In addition to comorbidities, frailty in HF is also common and may also be a risk factor for developing HF (Afilalo et al., 2014).

Frailty is defined as an age-related, multi-system syndrome characterized by increased risk of adverse events (e.g. deterioration, death) when exposed to stressors (e.g. hospitalization, illness) compared to people the same age (Fried et al., 2001; Gibson & Crowe, 2018; Morley et al., 2013; Rockwood, 2016; Rockwood et al., 1999; Rockwood, Fox, Stolee, Robertson, & Beattie, 1994). Frailty may contribute to the physical heterogeneity seen in older adults and can reflect biological rather than chronological age (Afilalo, 2009). Because the

24 The concept of frailty currently has evolved with considerable definitional debate. A colleague and I published an article explaining this debate in greater detail (see Gibson & Crowe, 2017). There are two “camps” of thinking and two predominant models: The Frailty Phenotype (FP) and the Frailty Index (FI). “Though both of these models recognize aging and disease as contributing factors, and both highlight diminished physical capacity as a major attribute of frailty, the models diverge on how other factors such as comorbid conditions, disabilities, and psychosocial aspects should be considered” (Gibson & Crowe, p. 29). In light of there being different conceptualizations and definitions (and multiple models and screening tools), the “measure” or thresholds of frailty vary. In both models, however, where frailty has been identified, the risk of an adverse event in response to a stressor, should be considered.
prevalence of HF increases in older adults, frailty can become a significant component of HF and affects morbidity and mortality (Afilalo, 2016). Afilalo (2011) explained that CVD and aging share causal biologic pathways that accelerate frailty development. Pathological up-regulation of neurohormonal compensatory systems seen in HF contributes to frailty via a complex pathway that includes aging-related insulin resistance, antigen exposure, and chronic inflammation. Maladaptive redistribution of amino acids related to chronic inflammation and insulin resistance leads to sarcopenia, thought to be a significant component of frailty. Continued symptoms and chronic maladaptive responses to physical and physiological states in illnesses such as HF also present risks for both disability and frailty, particularly if symptoms are poorly managed over a long period (Booth, Fallon, & Hollis, 2016).

Increased circulating inflammatory markers (e.g. neutrophils, C-reactive protein) and thrombic factors are also present in both frailty and CVD. Problematically, inflammation triggers redistribution of amino acids and results in muscle mass loss. Insulin resistance similarly causes loss of muscle mass via diminished availability of amino acids needed for muscle function and repair. In combination, inflammation and insulin-resistance contribute to sarcopenia and muscle loss, which further alters metabolic ability and reduces intrinsic self-repair functions thus reducing resistance to stressors (Afilalo, 2011; Afilalo et al., 2014; Afilalo, 2016).

People with frailty have a 30 percent higher risk of developing HF compared to those without frailty. As Afilalo (2014) explained, this vulnerability relates to the pathological and detrimental impact of frailty on muscle mass and function at the myocardial level. Consequently,
the risk of developing HF is also increased for people with frailty and myocardial ischemia, infarct, or abnormally elevated intracardiac pressures because they have diminished myocardial muscle resilience and lowered ability to repair the muscle when injured.

**2.5.2.1. Frailty and mortality.** Overall, the risk of a negative outcome for patients with frailty and HF can be severe and include worsened clinical symptoms during acute exacerbations and mortality (Afilalo et al., 2014; Goldfarb, Sheppard & Afilalo, 2015). Depending on how frailty is measured, 25 – 50% of people with HF have concurrent frailty (Afilalo, 2011; Uchmanowicz, Łoboz-Rudnicka, Szeląg, Jankowska-Polańska, Łoboz-Grudzień, 2014). People with frailty and HF experience more hospitalizations; endure worse QOL and higher incidence of depressive symptoms; and face worsened mortality outcomes at 1-year (Afilalo et al., 2014; Goldfarb, Sheppard & Afilalo; Lisiak, Uchmanowicz, & Wontor, 2016; Lupón et al., 2008; Volpato, Margherita, Gianluca, & Fotini, 2008).

Cacciatore et al. (2005) compared 12-month mortality in n=120 adults with HF and n=1139 adults without HF. Survival curves illustrated *increasing* mortality with worsening frailty. The authors measured frailty with the Frailty Staging System, which is an index of functional impairment severity that examines seven domains including disability, cognition, visual and hearing abilities, urinary function, and social support). Cacciatore et al. concluded that frailty was a predictor of mortality in patients with HF compared to those without. Lupón et al. (2008) reported similar findings in their study of n=622 patients with HF. Mortality at one-year was 3.5 times higher in patients with HF and frailty compared to those without.
Frailty is increasingly recognized as a risk factor for worsened outcomes. Recurrent hospitalizations, symptom burden classification, and the patient’s current illness stage are also determinants of poor mortality outcomes (Butrous & Hummel, 2016; Gibson & Crowe, 2018). Goldfarb, Sheppard, and Afilalo (2015) highlighted both emotional and physical impacts of frailty: “frailty is highly prevalent in older adults with HF and has consistently been shown, from stage A to stage D, to deleteriously affect survival, hospitalizations, and quality of life” (p. 92).

As I discuss in Chapters Five and Six, these important risk profiles (i.e. illness stage, frailty) are poorly understood and not commonly integrated into decision-making or patient assessments in current clinical practices. Thus, information about mortality risks associated with patients’ frailty, hospitalization history, disease progression (e.g. AHA stage) are rarely foregrounded in clinical interactions.

**2.5.2.2. NYHA classification and mortality.** The degree of symptoms as determined by the NYHA classification has also been shown to be predictive of mortality in patients with HF-REF (Ahmed, Aronow, & Fleg, 2006; Bouvy, Heerdink, Leufkens, & Hoes, 2003; Muntwyler, Abetel, Gruner, & Follath, 2002; Scrutinio et al., 1994). For patients with HF-PEF, higher NYHA classifications (e.g. III, IV) are similarly associated with higher mortality rates and re-hospitalization events (Ahmed, Aronow, & Fleg). As outlined in the European Society of Cardiology (ESC) guidelines, NYHA class is highly correlated with survival and hospitalization:

- Patients in NYHA class I have no symptoms attributable to heart disease; those in NYHA class II, III, or IV are sometimes said to have mild, moderate or severe symptoms
respectively. It is important to note, however, that symptom severity correlates poorly with ventricular function, and that although there is a clear relationship between severity of symptoms and survival, patients with mild symptoms may still have a relative high absolute risk of hospitalization and death (McMurray et al., 2012, p. 1793).

Serious adverse outcomes including hospitalization and mortality for patients with HF relate to a range of variables including HF type, illness stage and symptom classification, and concurrent frailty and comorbidities. Such variables illuminate the heterogeneity of the HF patient population and also highlight the need for a consistent approach to HF care that includes considerations for advanced illness and EOL planning and care.

2.5.3. Therapeutic options: Treatment-focused care for patients with HF. The Canadian Cardiovascular Society (CCS), the AHA, and the ESC regularly publish HF consensus guidelines, which are interdisciplinary decision-support tools primarily for physicians (Arnold et al., 2006; Arnold et al., 2007; Howlett et al., 2016; McKelvie et al., 2013; McMurray et al., 2012; Moe et al., 2015). Consensus guidelines promote standardization and maximal utilization of a range of diagnostic criteria (e.g. cardiac imaging, biomarkers) and medical management options including pharmaceuticals, biomedical technologies, and physical rehabilitation and self-management programs. As outlined throughout these expert documents, the goals that guide therapies in HF include minimizing risk factors; impeding disease progression; alleviating HF symptoms; and reducing morbidity, hospitalizations, and mortality
(Jessup & Brozenna, 2003; McMurray et al., 2012). Adherence to guideline recommendations is a common quality indicator for assessment of HF care.

The multitude of treatment options for patients with HF underpins the heterogeneity of this patient population and adds to the uncertainty that characterizes the disease course. While aimed at managing symptoms, biomedical technologies can also prolong life. Howlett et al. (2010) argued that the nature of cardiac medical technologies “may create confusion in the minds of both the patient and HCPs as to the actual goals of therapy—that the goal may be primarily to prolong life rather than primarily to alleviate symptoms” (p. 136). The range of options also underpins the difficulty HCPs describe about knowing when to shift from treatment-focused to support-focused care, and was evident in my research fieldwork. The following section therefore briefly reviews commonly used pharmacology and biomedical technologies for patients with HF.

2.5.3.1. Pharmacological therapy in HF. Pharmacological therapy is an essential component of HF care. Beta-blockers, angiotensin converting enzyme (ACE) inhibitors, aldosterone receptor agonists, and diuretics are mainstays and are used to manage sympathetic nervous system responses and the RAA axis, which was introduced in a section above. Intended therapeutic responses include reductions in heart rate and myocardial oxygen demands; decreased afterload and lowered systemic blood pressure via counteraction of RAA-mediated vasoconstriction; and reduced preload and circulating fluid volume via control of sodium and water reabsorption (Gibson & Raphael, 2014; Gibson & Nordby, 2014). Such
actions help prevent ventricular remodeling while simultaneously mitigating symptoms of congestion (e.g. edema) and sympathetic activity (e.g. tachycardia); pharmacologic therapies slow ventricular remodeling (McMurray et al., 2012). Occurrences of refractory HF are commonly treated with intravenous inotropic agents and vasopressors. These medications are used to increase CO via augmentation of myocardial contractility and vasoconstriction. Biomedical technologies and cardiac surgical procedures including mechanical circulatory support devices may also be considered in refractory HF and in the advanced illness stages (e.g. stage D) (Jessup & Brozena, 2003).

2.5.3.2. Biomedical technologies and interventions in HF. Biomedical technologies are used in HF to improve symptoms, decrease incidences of acute exacerbations, and reduce the risk of sudden death (Arnold et al., 2006; McKelvie et al., 2011; McKelvie et al., 2013; McMurray et al., 2012). Jessup and Brozena (2003) estimated the rate of sudden death in people with HF to be six to nine times higher than the general population. About half of deaths from HF occur unexpectedly, thought to be largely due to ventricular arrhythmias. Thus, prevention of sudden death via treatment of ventricular arrhythmias is a main goal of therapy (McMurray et al., 2012, p. 1813).

Implantable cardiac defibrillators (ICDs) are used for patients with HF to prevent sudden death associated with life-threatening ventricular arrhythmias (McKelvie et al., 2013). Cardiac resynchronization therapy (CRT) is a different type of implantable pacemaker that is surgically inserted to optimize CO and slow disease progression by improving cardiac electrical
synchronization (Jessup & Brozena, 2003; McMurray et al., 2012). Current guidelines recommend CRT be considered for patients with NYHA III or ambulatory IV who are on maximal pharmacological therapy and who have conduction abnormalities that indicate ventricular conduction asynchrony (McKelvie et al., 2013). Additional treatment options include electrophysiology procedures and ablations, electrical cardioversion, coronary revascularization\textsuperscript{25}, valve procedures (e.g. aortic value replacement, mitral value repairs) and cardiac transplantation.

For individuals with extremely poor ventricular function and cardiogenic shock, mechanical circulatory devices, including ventricular assist devices (VADs), may be implanted to augment ventricular function and CO (Arnold et al., 2006; McKelvie et al., 2013; McMurray et al., 2012). Temporary circulatory support devices such as the intra-aortic balloon pump, percutaneously inserted axial-flow pumps (e.g. Impella) (Abiomed Inc., 2017), or extracorporeal membrane oxygenation provide invasive short-term (days to weeks) cardiac support (Abiomed Inc., 2017; Makdisi & Wang, 2015; Thiele, Zeymer, & Werdan, 2013). Circulatory support

\textsuperscript{25} Revascularization through cardiac surgery (e.g. bypass grafting) or cardiac catheterization (e.g. percutaneous coronary intervention) can improve ischemia and cardiac performance and also reduce sudden death (Jessup & Brozena, 2003).
devices are most often used in conjunction with other fully supportive options including mechanical ventilation.

The outcomes and usefulness of many invasive medical interventions are often uncertain in patients with complex (and often concomitant) chronic illnesses and outcomes are particularly unknown when used during the end-stages of disease progression (McMurray et al., 2012, p. 1835). It is important to note that when employed at the EOL, many medical interventions can inadvertently prolong suffering and dying and contribute to considerable physical and psychological discomfort for patients (Baggs et al., 2007; Wright et al., 2008). Such consequences may misalign with the patient/family needs during the final stages of illness. The use of biotechnologies also underpins existing unpredictability and uncertainty in the HF illness trajectory and concomitant experiences of patients and their families and at EOL.

None of the current HF therapies, including heart transplant, are curative; however, existing therapy options confer survival successes that underpin uncertainty and confound prognosis estimates. The unpredictable illness trajectory is commonly related to the existing challenges identifying the “ideal time” for introducing patients and their families to EOL planning and care discussions (including ACP, goals-of-care conversations, wishes for EOL). Strachan et al. (2009) explained the difficulty distinguishing patients’ location on the illness trajectory: "patients with HF tend to have a fluctuating trajectory of illness that has promoted a focus on acute care and optimization of treatment up to the time of death; this focus creates challenges for EOL planning and care” (p. 635). Such unpredictability and variability in the disease
trajectory has also fostered a tendency for HCPs to avoid discussing EOL issues (Strachan et al.). Ryder et al. (2011) similarly explained that HCPs struggle with timing the transition from “disease-modifying therapy” to “predominant symptom relief” (p. 318).

2.6. Chapter Summary

In this second chapter, I presented a synopsis of HF and EOL-related literature that informed my research study. I focused on four topics in this discussion: HF-related hospitalization and mortality; dying in hospitals, the care needs for patients and their families at EOL, and the concepts of palliative care as underpinning excellent quality EOL care; chronic illness management and the role of self-management in HF; and heterogeneity in the HF patient population. Building from the introductory information about HF that I provided in Chapter One, I opened this second chapter with a more focused discussion about the relationship between acute HF exacerbation hospitalizations and mortality. I highlighted HF hospitalizations as significant events and explained how authors have recommended that HCPs should recognize hospitalizations as important events related to EOL planning and care. This important linkage underscores why I focused on hospitals in the design of the study sample and settings, which I review in Chapter Four.

I followed this discussion about HF-related hospitalizations and mortality with a review of the literature that has described the experiences of dying in Canada in general. I focused on and explained acute care practice settings in hospitals. I then explored what is known about how to care for patients facing death with a discussion about the palliative care model. I
explained how the traditional palliative care model has been evolving into the palliative approach to care. I then shifted into a broader discussion about chronic illness management and explained how self-management in particular relates to HF. Because of the linkage between self-management, hospitalization, and mortality, I explained why I situated self-management within EOL planning and care.

I closed Chapter Two by examining the complex issue of heterogeneity in the HF patient population. I explained this heterogeneity in relation to variability in HF etiology, symptom burden and disease progression, and in relation to the common presence of concurrent comorbidities and frailty. I also explored heterogeneity in relation to therapeutic options, which contribute to issues of uncertainty in the illness trajectory and also highlight the technical and clinical complexities in caring for this patient population. Heterogeneity can create difficulty identifying the “right” time to discuss EOL planning and care issues with patients and their families. Heterogeneity also adds complexities to clinicians’ practices because patients do not necessarily fit within a standard (or single) care approach thus creating greater knowledge demands for the HCPs involved with this patient group.

In light of the empirical findings explicated in Chapters One and Two, I argue that existing practices in acute care fall short in fully meeting the complex HF-EOL planning and care needs of patients and their family members. As such, this is a critical gap in our existing health care services and warrants further inquiries aimed at improving HF-EOL planning and care. Thus, in what follows I present the research study that I carried out for the purpose of greater
understandings about HF-EOL planning and care and with the goal of improving care. I commence in Chapter Three which follows, where I present and explore my theoretical framework and explain how I sought to understand EOL planning and care practices in hospitals using a theory that allowed me to examine structuring in health care. This theoretical grounding also supports my subsequent data analyses of how and why it has been difficult to improve HF-EOL planning and care despite many expert endorsements to do so.
Chapter 3
A Theory of Structure and Critical Theory Perspectives: Philosophical and Methodological Implications of the Theoretical Framework

Having reviewed empirical literature supporting my research focus in the previous chapter, I will now turn to explicate the theoretical groundwork that informed the methodological approach and interpretive work I carried out. In particular, I use this third chapter to more thoroughly explain two theories: Sewell’s (1992) Theory of Structure; and approaches to critical theory. As stated in Chapter One, the purpose of this research was to examine hospital contexts and acute care settings where patients with HF access EOL planning and care in order to better understand how these practice contexts shape (or structure) existing care. I intentionally used Sewell’s (1992) Theory of Structure to define “structure” because Sewell provided theoretically and empirically grounded explanations for what structures are; how structures influence social behavior and people’s practices and how people (i.e. agents) influence behavior; how structures relate to power in social interactions; and how structures can be altered to bring

26 Sewell (1992) defined agency simply as “the efficacy of human action” (p. 2). Though productiveness of action is emphasized in Sewell’s definition, his theoretical work actually points to agency as both action and inaction. Thus, I am regard agency as both action and inaction.
about *social transformation* and change. In what follows, I explain why and how Sewell’s conceptual work is distinct and how it was particularly useful in my research.

While issues of social power are evident throughout Sewell’s (1992) work, he does not explicitly align his work in relation to a particular theorist\(^{27}\). Sewell’s presentation of power within structures as ubiquitous, inequitable, and both oppressive and productive, aligns with Kincheloe and McLaren’s (2005) reconceptualized critical theory. Thus, both Sewell’s theory of structure and Kincheloe and McLaren’s critical theory formed the theoretical framework for my study. Both components of my theoretical framework were integrated into all aspects of this dissertation from development of the study proposal, to methodological considerations, to data collection methods and analysis, to the interpretation of the data and presentation of my findings.

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\(^{27}\) Sewell (1992) discusses issues of power throughout this paper. However, he does not explicitly align his work with a particular theorist. In his efforts to situate his theorizing in relation to Giddens (1984), he distances his work from Lévi-Strauss with a criticism that Lévi-Strauss had a “sublime indifference to questions of power” (p. 9): “I agree with Giddens that any notion of structure that ignores asymmetries of power is radically incomplete” (Sewell, p. 9). In other words, although Sewell does not explicitly align with a particular theorist regarding power, he does indicate the need to consider power.
3.1. Overview of Chapter Three

As I introduced in Chapter One, hospital contexts and acute care settings are made up of *structures* that can be said to influence HCPs' agency and shape the EOL planning and care experiences for patients and their families. Imbued by both transformative and oppressive power, some structures are dominant such that many agents may have difficulty altering them whereas other structures are more flexible and susceptible to agents' influences. This third chapter builds on the introductory discussion of Sewell's (1992) theory of structure from Chapter One.

I begin by discussing Sewell's theoretical contributions in relation to Anthony Giddens, who had previously written about social structures. I justify my use of Sewell's work in the theoretical framework by explaining two key strengths that Sewell established: a presentation of humans as capable of enacting some degree of self-determination and agency within a complex interplay of axes of power; and, a normative (i.e. ethical) praxis-orientation with the possibility for ethnically-oriented social transformations.

Following my discussion about structure theory, I explain Kincheloe and McLaren's (2005) “reconceptualized” critical theory and explicate why integration of critical theoretical perspectives was necessary within the overall conceptual geography of this dissertation. I differentiate Kincheloe and McLaren’s work from other critical theories via a short historical explanation of how critical theories have evolved. Specifically, I highlight how the contributions from other critically-oriented scholars expanded the lens of critical theories to encompass many
different social factors that relate to sources of social power. I also explain how critical theory aligns with Sewell’s theory of structure.

I close this third chapter with a discussion about the philosophical implications of working within a critical paradigm. Here, I examine ontological, epistemological, and methodological assumptions and review any incongruence or tensions within the framework. This sets the theoretical stage for my subsequent explication of my methodology and methods in Chapter Four.

3.2. Structure: Implicit Reproduction of Social Conditions

What are structures? According to Sewell (1992), *structure* explains an important characteristic of social relations: “the tendency of patterns of [social] relations to be reproduced, even when actors engaging in the relations are unaware of the patterns or do not desire their reproduction” (p. 3). Anthony Giddens (1984) described structures as the “principles” that guide social behavior. The difference between these two statements about what structures are is important. In Sewell’s view, Giddens described structures as virtual; Sewell disputed this assertion. Sewell’s conceptualization of structures as both virtual and actual was important because it provided theoretical space to better account for how actual resources (e.g. written laws, policies) have shaped historical social experiences. The distinction between what exists virtually and what exists actually, also undergirds the philosophical, theoretical, and methodological congruence for which I aimed throughout this dissertation, which I explain further below.
Patterns of social relations are reproduced by people, acting with some degree of agency. Giddens (1984) used the word “duality” to explain this recursive reproduction of social relations. Duality describes the reciprocal influence between structures and people’s practices; and, people’s practices and the formation and reproduction of structures. Duality is an essential assertion because the role of agents in both creation and change of structural conditions is foregrounded. For the purpose of my research, I created a simple illustration of my understanding of duality (see Figure 3-1):

![Diagram of duality]

*Figure 3-1: Dual, recursive relationship*

Figure 3-1 illustrates my simplified interpretation and illustration of duality elucidating the repeating, reciprocal, and recursive influence between structures and people’s practice. Agency (as reflected by people’s practices) is underpinned by some degree of control. In my study, I examined the influence of structures in clinical practice contexts for the purpose of explicating implicit thinking, beliefs, and practices, which creates opportunities for agents to alter
these structural influences. Ultimately, opportunities to alter structured practices have the potential to improve the EOL planning and care experiences for patients with HF and their family members. Thus, within the theoretical framework for my study I needed to foreground agency and awareness of the possibility for people to change the structural influences.

While Sewell (1992) accepted the notion of duality from Giddens, Sewell delineated several “cardinal weaknesses” that he viewed as problematic in Giddens’ previous conceptualizations of structure. Two of these weaknesses in Giddens’ work were important in justifying why I used Sewell’s definition of structure specifically for this study. The first weakness was an overly rigid, deterministic\textsuperscript{28} presentation and a failure to account for the influence and effects of agency (i.e. human action and inaction). The second weakness was a limited capacity to explain change and social transformations.

\textsuperscript{28} Sewell (1992) did not define this use of “deterministic.” As I learned from Layder (1985), determinism can be situated within a dichotomy with voluntarism (i.e. freely-willed). I use the expression “anti-determinist” to point to a modified position for structures and agents, which aligns more easily with the overall theoretical framework as it allows for consideration of structures and agents as situated within context.

Anti-determinist positioning also implies mutability (i.e. ability to change). As I carried out this study for the purpose of changes that improve EOL planning and care for patients with HF and their families, a conceptualization of structure as having a degree of mutability was necessary to undergird the idea that these structures are transformable.
3.2.1. Strengths in Sewell’s theory. The constituents of structure that Sewell (1992) proposed, built from Giddens’ (1984) work. As I introduced in Chapter One and have pointed to above, according to Sewell (1992), structures are composed of schemas and resources and they exist both virtually and actually (they are objectively observable). In contrast, Giddens (1984) said structures are composed of “rules and resources” (p. 377). Rules, according to Giddens, are the virtual procedures that guide the enactment of social life. However, Sewell argued that the term “rules” describes social features that exist both virtually and actually (e.g. laws, contracts, and policies exist as empirically observable objects not merely as virtual constructs). To address this definitional issue, Sewell proposed the word schemas to denote and isolate the virtual entities of structures (e.g. thought processes that exist but are not objectively observable).

Giddens (1984) described resources as mechanisms for social power. Sewell (1992) explicated resources further, differentiating resources as both human (e.g. physical strength, knowledge) and nonhuman (e.g. money, weapons, food). In Sewell’s view, resources are instruments used to enhance or maintain power in social relations and thus relate to the efficacy of humans’ action, meaning their enactment of agency. Because Giddens defined structures narrowly as the principles that are virtual (i.e. existing, but not empirically observable), resources that are actual are secondary or excluded. In contrast, Sewell placed resources within structures and allowed resources to exist as both virtual (e.g. resilience, coping) and actual
instruments. That is, Sewell argued that resources embody and incorporate schemas and recursively reinforce and shape the schemas they instantiate.

Sewell’s (1992) argument that resources fit within structures (i.e. are not secondary to) can be understood by returning to an example I presented in Chapter One. I described hospitals as a compilation of observable, appreciable, actual resources and I contended that hospitals have considerable influence on the experiences of a person who requires hospital services, and on the HCPs delivering care within them. That is, I argued that hospitals function with social structures because actual resources embody various virtual schemas. In the absence of such schemas, the hospital would merely be a building filled with medical equipment. Importantly, it is the interface among agents, schemas, and resources that become integral in the formation of structures. The positioning of both schemas and resources within structure was important in my research study because it clarified and strengthened schema/resource interfacing in the creation of structures. As schemas belong to agents, this positioning also foregrounded the role of agency in structures.

3.2.1.1. Foregrounding agency: Duality in structures. Agency is an important premise in the theoretical framework of this research. Agency supports the notion that HCPs who are embedded within clinical practice contexts where patients with HF and their family members access EOL planning and care are able to alter the structural conditions—that is, change conditions through the efficacy of their human actions. Sewell’s (1992) proposition that structures are simultaneously composed of both schemas and resources was important
because it guided clearer attention to the influence of agency into structure theory. Duality is hinged on the precept that human agents are not passive recipients but instead, participate intelligently in the enactment and modification of their practices—that is to say, humans enact agency. Such conceptualization recognizes the contributions of human agents and recognizes that humans are continually interfacing with structures. The notion of duality then, foregrounds this interface between human agents and structures and supports structures as evolving processes rather than static constructs.

Overall, Sewell (1992) resolved what he described as the first cardinal weakness of Giddens’ work (i.e. the positioning of structures as causal determinants and the failure to fully account for the influence and effects of agency) by redefining the constituents of structure as an assembly of both virtual and actual social entities. An implication of Sewell’s revisions to the constituents of structure—that is, the delineation of structures as schemas and resources (instead of rules and resources)—is that agency becomes established as an inextricable component of structure. Agency becomes inseparable from structure because schemas belong to human agents. By retaining Giddens’ notion of duality, Sewell (1992) argued that structures, as constantly interfacing interrelationships of schemas and resources, will both shape and be shaped by, the activities of social agents. Thus, Sewell foregrounded agency and constructed an anti-determinist conceptualization of structure.

Importantly, Sewell accentuated that knowledge about schemas underpins agency because understanding schemas may enable social actors to alter their operationalization. The
idea that knowledge may potentiate agency underscores the justification that I presented in Chapter One for why I carried out this research. That is, knowing something about structuring of health care services for HF-EOL patients and their family members makes visible the implicit and taken-for-granted in their health care experiences. Explication of such structuring may bring about greater understanding of the schemas being enacted, which can underpin opportunities for change. Clear foregrounding of agency, and the ability to act (and not act) differently, was necessary within the theoretical framework I chose because the aim of this study was to change and improve existing EOL planning and acute care practices for patients with HF and their families.

3.2.1.2. Social transformation and structural change. Within the theoretical framework I deployed, it was important to also have the possibility for social transformation and change because it made room for the idea that HCPs can alter the structural conditions and bring about social transformation and change. Indeed, Sewell (1992) argued that previous conceptualizations of structure had been described as immutable and rigid. Sewell also argued that such immutability and rigidity implies directionality and causation (e.g. if structures dictate human behavior, this reflects a determinist thinking about human will). Consequently, Sewell asserted that evolutions in social patterns could not be explained by previous structure theory and contended that this limitation was antithetical to observations that had been collated about society and social behavior:
... Social historians have shown that in a great variety of times and places, structures are in fact dual: how historical agents’ thoughts, motives, and intentions are constituted by the cultures and social institutions into which they are born, how these cultures and institutions are reproduced by the structurally shaped and constrained actions of those agents, but also how, in certain circumstances, the agents can (or are forced to) improvise or innovate in structurally shaped ways that significantly reconfigure the very structures that constituted them (p. 5).

In summary, Sewell (1992) resolved the issue of a prior overly-determinist view of structure through careful delineation of the constituents of structures; that is, the explanation of structures as a compilation of simultaneously operating schemas and resources. This contribution was significant because Sewell was able to foreground the instrumental influence of agents and build social change and transformations into structure theory. Specially, Sewell conceptualized human agency as the ability to transpose schemas in varied contexts with a range of resources. The emphasis on agency provided a framework for understanding social transformations and change without disregarding the patterning influence of structures on shaping social life.

Though Sewell did not explicitly identify critical theories as an undergirding of the Theory of Structure, Sewell’s attention to power, and emphasis on the transformative possibilities in structures, are consistent with critical theoretical perspectives. Sewell’s definition of agency as the efficacy (i.e. the ability to produce) of human action also implies the existence of social
power that equip agents differently, depending on the circumstances of the social context in which they are situated. I will therefore discuss an approach to critical theory and explain how I drew from it within the theoretical framework as a way to consider and examine power.

3.3. Critical Theory

Critical theories can be understood as the family of theoretical perspectives that are concerned with uncovering the often taken-for-granted, implicit and explicit, structures of power and domination in society (Crotty, 1998; Kincheloe & McLaren, 2011; Morrow & Brown, 1994). As I have explained, the aim of this study was to explicate taken-for-granted aspects of acute care contexts and explain their influences as structured clinical practices and impacts on HF-EOL planning and care. I took direction from Kincheloe and McLaren, who explained, “in a research context [critical theory] does not determine how we see the world but helps us devise questions and strategies for exploring it” (p. 288). Critical theory challenged me to examine taken-for-granted hierarchies and produce explicit descriptions and interpretations about the phenomena of HF-EOL planning and care in the clinical practice settings I studied. Critical theory also guided me to pay particular attention to what reinforced existing situations by considering issues of power.

Critical theories are used to interpret power structures and inform the construction of social critiques. Social critiques are intended to open up new ways of understanding and advance transformative reform in the pursuit of more equitable and just societal configurations (Crotty, 1998; Kincheloe & McLaren, 2011; Morrow & Brown, 1994). There are different critical
theories and theorists and the theoretical work has evolved considerably since first proposed by scholars at the Frankfurt School in the 1930s. As Mill, Allen, and Morrow (2001) noted, “the term critical theory is applied to a number of approaches that share a radical historical theory of knowledge and a conflict theory of society in which the domination of the social subject is a central theme” (p. 111).

3.3.1. Critical theory: Historical shifts. Early origins of critical theories are generally aligned with the work of Karl Marx (Crotty, 1998; Kincheloe & McLaren, 2011). Marx’s social critique focused predominantly—and as we understand now, narrowly—on capitalism and social class structures in society. Modern day critical theories are evolving and have undergone considerable development in response to scholarly contributions from several disciplines. For instance, Kincheloe and McLaren (2011) explained the significance of observations made by Horkheimer, Adorno, and Marcuse about American culture:

Offended by the taken-for-granted empirical practices of American social science researchers, Horkheimer, Adorno, and Marcuse were challenged to respond to the social science establishment’s belief that their research could describe and accurately measure any dimension of human behavior...piqued by the contradictions between progressive American rhetoric of egalitarianism and the reality of racial and class discrimination (p. 286).

Critical thinking evolved in two key ways as a result of such critiques by social science scholars such as Horkheimer, Adorno, and Marcuse. First, taken-for-granted assumptions about the
philosophical underpinnings of social science scholarship were challenged—specifically, the epistemological issue of objectivist knowledge claims. This challenge resulted in a marked shift in epistemological considerations where critical inquiries tend now to contextualize knowledge claims within a complex socio-political-historical picture, rather than claim objective observations (i.e. “truths”) about reality. Indeed, I have integrated that shift and reported my findings as situated within a sociopolitical-historical context. This context includes recognizing my interpretive lens being a HCP with clinical practice experiences in cardiac care and elsewhere, and being a researcher with graduate-level academic education and experiences entering clinical practice areas. Methodologically, critical theory underpinned my decision to account for my own interpretive lens and context and use a reflexive journal as one of the data collection methods.

The second shift that occurred as a result of critique was an expanded consideration of social features beyond socioeconomic class. Drawing attention to the interface of a multitude of other significant social features—including race, ethnicity, religion, education, age, sex, sexuality, and socioeconomic class—current critical thinking has broadened substantially. Social analyses are now challenged by this approach to examine the interface, interrelationships, and implications of many different power-laden social structures. Rodney (1997) acknowledged the pivotal contributions of feminist theory scholars. Noting that while dynamic and evolving, Rodney explained that feminist theory “offers significant direction for praxis because it is committed to non-oppressive, democratic, and pluralistic values” (p. 33). In addition to
emphasizing praxis and foregrounding gender in structures of social relations, feminist theory scholars also challenged previously unquestioned epistemological assumptions (Gilligan, 1982).

Kincheloe and McLaren’s (2011) Reconceptualized critical theory is an approach to critical theory that has developed as a synthesis of these various theoretical contributions. This expanded critical lens challenged me to also consider issues of power in relation to multiple social features including, for example, education, cultural positions (e.g. the role of a particular HCP), and disciplinary roles/authorities. Different power privileges between (and within) disciplines, for example, was one of the power mechanisms that I describe in relation to findings about communicating about issues of HF-EOL planning and care with patients and their family members. As I will present in Chapters Five, Six, and Seven, disciplinary hierarchies were an important source of power and participants indicated how they sought to comply with often tacit understandings of which discipline was “allowed” to do which work with respect to EOL planning and care activities such as talking about illness issues.

Overall, critical theory arguments pushed me to emphasize my attentiveness to power relationships in the clinical practice settings where this study was carried out. In the next section, I examine the philosophical implications of working within a critical paradigm and more closely explicate ontological, epistemological, and methodological commitments within this theoretical framework.
3.4. Philosophical Congruence: Considerations Across the Theoretical Framework

Guba and Lincoln (2005) and Lincoln, Lynham, and Guba (2011) have elucidated the general characteristics of “scientific paradigms” of inquiry. These authors indicate that evolutions have occurred in understandings about ontological, epistemological, and methodological issues within scientific paradigms and that debates exist. As my positioning on ontological, epistemological, and methodological issues influenced decisions in how I carried out my study, I will situate my thinking in relation to these evolutions and debates. As Kincheloe and McLaren (2005) have emphasized: “critical researchers enter into an investigation with their assumptions on the table, so no one is confused concerning the epistemological and political baggage they bring with them” (p. 301) and thus I proceed with an effort to position my thinking in relation to the critical paradigm and explore incongruences or tensions across the theoretical framework I have described.

3.4.1. Ontological commitments: Modified realism. Ontology is the branch of philosophy that examines the nature of reality or “what exists” (Crotty, 1998; Lincoln, Lynham, & Guba, 2011). Realism is “an ontological notion that realities exist outside the mind” (Crotty, p. 10), which is a position that is associated with both positivist and postpositivist paradigms, including critical theories (Hegelund, 2005). In Paradigmatic controversies, contradictions, and emerging confluences for example, Guba and Lincoln (2005) described the ontological
foundation of the critical paradigm as “historical realism”\textsuperscript{29}. In an updated version of that 2005 work \textit{Paradigmatic controversies, contradictions, and emerging confluences, revisited}, Lincoln, Lynham, and Guba (2011) avoided the title “historical realism” and instead the authors described the nature of reality as within the critical paradigm as contextualized, which I refer to as \textit{modified realism}\textsuperscript{30}.

Within the critical paradigm, knowledge and realities are based within a modified conception of realism because realities are regarded as historically and socially contextualized and are shaped by various circumstances such as political and economic status, disciplinary role, ethnicity, gender, and sexuality (Lincoln, Lynham, & Guba, 2011). Moreover, because realities exist as contextualized, complete understandings may not be fully possible (Mill, Allen, 2001).

\textsuperscript{29} Historical realism is an ontological position about the nature of reality as historically situated and contingent. For example, Guba and Lincoln (2005) defined historical realism as: “virtual reality shaped by social, political, cultural, economic, ethnic, and gender values; crystallized over time” (p. 193), which points to the inextricable relatedness between reality and the social context.

\textsuperscript{30} There are differences in how authors have attempted to name the ontology of the critical paradigm (e.g. historical realism). In Mill, Allen, and Morrow’s (2001) writing, the name “critical ontology” has been used: “the ontology of critical theory assumes a mediating position between the extremes of subjectivism and objectivism and acknowledges the reflexive and subjective aspects of science...Ontologically, critical realism asserts that although reality claims about its capture are always situated, contingent, and potentially fallible; an absolute representation of objective reality cannot be achieved” (p. 113). To avoid confusion between the diverse references that I have cited throughout this chapter, I use the term “modified realism.”
Guba and Lincoln (2005) have explained the nature of contextualized realities. The authors also expounded on why complete understandings may not be possible:

Rather than locating foundational truth and knowledge in some external reality “out there”, [positivist-leaning] critical theorists tend to locate the foundations of truth in specific historical, economic, racial, and social infrastructures of oppression, injustice, and marginalization. Knowers are not portrayed as separate from some objective reality, but may be cast as unaware actors in such historical realities (“false consciousness”31) or as aware of historical forms of oppression, but unable or unwilling, because of conflicts, to act on those historical forms to alter specific conditions in this historical movement (“divided consciousness”) (p. 204).

31 In an updated version of Guba and Lincoln’s (2005) chapter, Lincoln, Lynham, and Guba (2011) more explicitly foregrounded the influence of social power in understandings of reality. The advancement of a “false consciousness”, meaning individuals’ unawareness of realities, has been moderated. These earlier writings about the false consciousness pointed to emancipation as an optimal outcome (Kincheloe and McLaren, 2011). In contrast, in the 2011 writings, power is emphasized in relation contexts and understandings are sought for the pragmatic purpose of social change.

I am convinced of the more current thinking about power as having substantial influence on our conceptions of reality and of knowing reality for the purpose of social change. Throughout this dissertation, I have refrained from proposing that the knowledge generated from my own study of HF-EOL planning and care would have an emancipatory effect and instead have positioned my findings in relation to social transformation.
As Guba and Lincoln (2005) further argue, from the position of modified realism, complete understandings of reality may not be possible and thus postpositivist inquirers work from a foundationalist\(^{32}\) position to form approximate understandings about reality (Guba & Lincoln, 2005). Within the critical paradigm, inquirers also seek approximate understandings about reality for the more specific purpose of stimulating and catalyzing social change. Power in relation to circumstances of privilege and oppression are foundational aspects of understandings about reality. Thus, issues of social power imbalance also undergird critical inquirers’ central purpose of seeking social change.

Power is apparent across the theoretical framework I have laid out in this chapter. For example, Sewell (1992) asserted that agents’ knowledge about structural functions and influences underpins empowerment—that is, that knowledge about structuring and social configurations may catalyze structural transformation. Sewell’s *Theory of structure* implies that a reality exists and thus necessitates a meta-theoretical perspective that advances a realist (modified) position. A critical paradigm advances a modified realist conception about reality

\(^{32}\) I derive my understanding of the term “foundational” from Guba and Lincoln (2005). Guba and Lincoln called the foundationalist/anti-foundationalist a “criterial question” (p. 203). That is, a question of whether or not discernable criteria exist which can be used to assess a phenomenon within a reality (described similarly by Lincoln, Lynham, and Guba, 2011, p. 118).
(Thomas, 1993) and thus aligns easily with the ontological foundation of Sewell’s *Theory of Structure*\(^\text{33}\).

Overall, I am convinced by the ontological position of critical theory and see the knowledge produced in my research as having a situated ontological status, developed with the pragmatic intention to contribute to improving a problematic situation in HF-EOL planning and care in the acute care context. That is, my pursuit of knowledge in my research was done with the purpose of improving HF-EOL planning and care experiences in acute care settings rather than simply creating an account of an approximate understanding of reality.

### 3.4.2. Epistemological assumptions: Knowledge as situated and constructed.

Crotty (1998) defined epistemology as the exploration of what constitutes knowledge and as the

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\(^{33}\) As Sewell’s *Theory of Structure* draws from Giddens’ (1984) theoretical work around structure and structuration, I also considered the ontological foundations laid out by Giddens and examined them for congruence. Giddens’ emphasized an idea of “time-space” as an epistemological and ontological position from which to understand human knowledge and social reality. Epistemologically, Giddens said that knowledge is embedded within collective social understandings and is recursively reproduced. This notion of reproduction was an epistemological claim that reflects a constructionist underpinning (as defined by Crotty (1998)).

Ontologically, time-space describes the formation of social reality; Giddens (1984) said: “An ontology of time-space as constitutive of social practices is basic to the conception of structuration, which beings from temporality and thus, in one sense, ‘history’” (p. 3). Here Giddens is acknowledging reality as inextricably related to “time” or history; this acknowledgement reflects the modified realist conception of reality. Thus, I think the ontological and epistemological undergirding of Giddens’ work as a foundation of Sewell’s work, is similarly congruent within the overall philosophical underpinnings of this dissertation.
study of how we come to know. Guba and Lincoln (2005) called the epistemology of a critical paradigm “transactional/subjectivist; value-mediated findings” (p. 195); these authors explained that critical inquirers are primarily concerned with socially constructed, subjective and intersubjective knowledge (p. 203). Crotty (1998) suggested the term “constructionism” to describe the epistemology in a critical paradigm. Constructionism\textsuperscript{34} “is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, p. 42).

In exploring the epistemological issue of how we come to know, Lincoln, Lynham, and Guba (2011) described the nature of the relationship between the researchers, and “that being researched” (p. 103):

\textsuperscript{34} Guba and Lincoln (2005) and Lincoln, Lynham, and Guba (2011) do not differentiate the definitional differences between “constructionism” and “constructivism.” In several instances, the authors conflate the two terms. Therefore, I am using Crotty’s (1998) definitions in this dissertation as he clearly distinguishes the terms.
Research is driven by the study of social structures, freedom and oppression, and power and control. Researchers believe that the knowledge that is produced can change existing oppressive structures and remove oppression through empowerment (p. 103).

On the bases of the theorists I have drawn on, explication and awareness about the influence of structure underpins agents’ abilities to carry out change by enacting schema/resource relationships differently. Thus, knowledge that builds HCPs’ awareness of how clinical practice contexts shape current care experiences, such as what is produced in this dissertation, may improve HF-EOL planning and care.

In summary, on the basis of what I understand about the epistemological commitments of working within a critical paradigm, through this study I came to regard the knowledge I created in this study as situated, as constructed, and accessible via interaction between and among agents. Such commitments had implications for myself as a researcher in that it was important that I attempt to identify the assumptions I entered the research with. It was also important for me to recognize and account for my own role in the interpretation and construction of the study findings.

Lincoln, Lynham, and Guba (2011) did not define their use of the term “structures” in this reference.
Working within the critical paradigm also required that the research methods I used included interactive and dialogic exchange. In Chapter Four, I explain how I enacted these epistemological commitments using strategies such as reflexive journaling to account for my own role and to create an “audit trail” for my interpretive logic. In the next chapter, I also explain how participant observations and semi-structured interviews were valuable interactive, dialogic data collection methods needed because they offered me access HCPs’ knowledge that was inaccessible with observation alone.

3.4.3. Methodology. Crotty (1998) defined methodology as “the strategy, plan of action, process of design lying behind the choice and use of particular methods and linking the choice and use of methods to the desired outcomes” (p. 3). Guba and Lincoln (2005), Lincoln, Lynam, and Guba (2011), and Mill, Allen, and Morrow (2001) all explained the methodology within a critical paradigm similarly. Named as “dialogic/dialectical36”, and emphasizing dialogue and relational reasoning as core strategies for investigating phenomena within a critical paradigm,

36 In common uses, the term “dialogic” relates to dialogue and exchange. In contrast, the word “dialectic” holds more substantive meaning within Philosophy. According to The Cambridge Dictionary of Philosophy, the term dialectic has origins from the Green dialegein meaning “to argue” or to “converse” and has been developed from Aristotle’s early works (2019). Cambridge defines dialectic as “an argumentative exchange involving contradiction or a technique or method connected with such exchanges” (2019). In this dissertation, I use the term “dialogic” to refer to communication and exchange and in recognition that the notion of dialectic has broader uses and philosophical underpinnings.
inquirers researching within a critical paradigm rely on direct interactions within the research
environment. Interactions include methods that emphasize dialogical strategies such as
interviews and observations.

In the next chapter, I explain how I achieved and maintained congruence across
philosophical and theoretical framework as I carried out my research. I emphasize how I used
dialogic methods including observation and interaction, and interviews as key data collection
strategies. I also explain how these methods were crucial for hearing directly from participants
who are regularly embedded within these contexts I was studying. This includes explaining my
own developing learning about the structural interrelationships within the acute care clinical
practice contexts where patients and their family members access EOL care, and about my
developing understanding of the clinical practice implications of these contexts.

3.5. Chapter Summary

In this third chapter, I described the theoretical framework underpinning this dissertation.
I explicated two theories foundational to my research: Sewell's (1992) Theory of structure and
Kincheloe and McLaren’s (2011) Reconceptualized critical theory and explored the
philosophical congruence between each. I argued that Sewell’s theoretical contributions
provided a robust explanation for what structures are, how structures influence social behavior
and people's practices, how structures relate to power in social interactions, and how structures
can be altered to bring about social transformation. I also discussed Sewell’s work in relation to
critical theory and explained the implications and assumptions inherent to working within a
critical paradigm. In the latter part of this chapter, I examined philosophical congruence across the theoretical framework by discussing issues of ontology, epistemology, and methodology. Specific implications for my research within a critical paradigm were explored throughout.
Chapter 4

Study Methodology, Methods, Data Analysis, and Quality

In Chapter Three, I explained the foundational theoretical framing for this study and explicated the philosophical implications of researching within a critical paradigm. In this fourth chapter, I build from that theoretical framing and explain how I actually carried out my research study—that is, what I actually did. To set the stage for how and why I chose to use a qualitative ethnographic approach to learn about the structural relationships in the contexts of specific acute care settings, I return to a point I raised in the previous chapter about Sewell’s (1992) explication of structures and schemas in relation to “cultures.”

In Sewell’s (1992) view, there are inextricable relationships among agents and schemas, structures, and cultures. Sewell claimed that several “cardinal weaknesses” existed in previous iterations of the concept of structure (and in particular, Giddens’ (1984) work); one of these weaknesses (which I did not touch on in the previous chapter) was the presence of discrepant and mutually incompatible uses of the term structure in relation to the notion of culture. Common anthropological and sociological uses of the term structure had been contradictory—anthropologists regarded “culture” as a precedent to structure, whereas sociologists employed the term “culture” as the effect of structure. Sewell attempted to resolve this definitional discrepancy by discarding both the sociological and anthropological uses of structure and restating the relationship between culture and schemas. That is, Sewell argued that schemas
are *constituents* of structures, and structures are *constituents* of cultures; which means schemas can be conceptualized as the *basis of cultures*.

To support the claim that schemas are constituents of cultures, Sewell (1992) proposed a straightforward definition of “culture”: “after all, the usual social scientific term for ‘what people know’ is ‘culture’” (p. 7)\(^3\). When Sewell argued that schemas form the basis and foundation of culture, he dissolved the definitional discrepancy by arguing that neither culture nor structure can be antecedents to the other. By emphasizing a *reciprocal* influence between schemas (i.e. culture) and structures, Sewell asserted that each presupposes the other. Sewell’s explication of schemas as the basis of “cultures”, points to inquiries about structures—including my research—as a form of *cultural study*. Thus, in this fourth chapter, I describe inquiry about structures in relation to ethnographic methodology, which has been traditionally used by anthropologists to study cultures.

\(^3\) Of note, Emirbayer and Mische (1998) defined “cultural context” similarly to Sewell (1992): “the cultural context encompasses those symbolic patterns, structures, and formations (e.g. cultural discourses, narratives, and idioms) that constrain and enable action by structuring their actors’ normative commitments and their understandings of their world and their possibilities within it” (p. 970).
4.1. Overview of Chapter Four

This fourth chapter opens with a short history of qualitative research and general overview of ethnography. I align my research study within a particular methodological style called critical ethnography and I refer back to the philosophical discussion from Chapter Three to review the implications of working within a critical paradigm. Study site selection, sample, and experiences entering the field are also described. I discuss how I used theoretical sampling and explain my decisions about both site selection and recruitment.

Following the discussion about study sample design decisions and recruitment, I explain how I collected study data and why I used particular data collection methods in relation to my epistemological commitments. I justify my use of interactive and dialogic data collection methods including participant observations and semi-structured interviews. I also explain why I used reflexive journaling. I then explore the analytical process and I explain my complementary use of Thorne’s (2008b) Interpretive Description to guide both the data collection and analytical process within a critical ethnographic approach. I close this chapter with discussion about how I considered research ethics and quality.

4.2. Background to Methodology: Qualitative Research

In examining acute care contexts and cultures, my goal was to better understand schemas and resources and interpret interrelationships and structured practices within HCPs’ experiences and thinking about EOL planning and care for patients with HF in hospitals. Sewell’s (1992) linkage of schemas (and structures) with culture is consonant with a style of
qualitative research called *ethnography*, which has traditionally been used to study cultures. However, to address issues of power, and to ensure congruence between the theoretical framing and the praxis-mandate inherent within my disciplinary (i.e. nursing) focus, I was also informed by the postmodern genre of ethnography called *critical ethnography*.

**4.2.1. Ethnography: Origins and historical shifts.** Scholarly discussions about the evolutions and history of ethnography contain several terms: ethnology, ethnomethodology, and ethnographic methodology. Explication of these terms here distinguishes the methodological approach I used in my study from these other related approaches. *Ethnology* originated in the early 1800s and stemmed from anthropology, which was heavily influenced by positivism and the biological paradigm at the time (Gobo, 2008, p. 8). Anthropological ethnologists studied social life and cultures through the examination of material artifacts only; direct observations were not used—that is, there were few, if any, interactions with participants. *Ethnomethodology* is the scientific study of the means and manners used by social beings to conduct their daily lives via a postvisistic analysis of the day-to-day measures of methods that social people use to carry out ordinary social actions (Coulon, 1995). *Ethnographic methodology* originated between the late nineteenth and early twentieth centuries and is distinct from ethnology and ethnomethodology because it emphasizes direct participant observations and fieldwork. The
research approach utilized and described in this dissertation fits within ethnographic methodology\(^{38}\).

In general, ethnography is a style of qualitative methodology used to create knowledge about social contexts and cultures (Hammersley, 1992; Thomas, 1993). Thomas explained, “at its most general, conventional ethnography refers to the tradition of cultural description and analysis that displays meanings by interpreting meanings” (p. 4). Geertz (1973) asserted that understanding ethnography is a matter of understanding what it is to do ethnography. That is, Geertz said that ethnography is an intellectual effort toward the production of a “thick description” (p. 6). Overall, ethnographies are broadly characterized by four defining features: reliance on participant observations; understanding observations in relation to the whole; attention and sensitivity to context; and the production of sociocultural descriptions (Stewart, 1998). While participant observation was historically the common and primary source of data (Gobo, 2008; Hegelund, 2005; Stewart), Gobo argued that since the 1980s, data collection

\(^{38}\) Ethnography has origins with both anthropology and sociology and their uptake in each discipline has been distinct. Gobo (2008) has explicated the historical distinction between sociology and anthropology. According to Gobo, sociologists study the industrialist “Western” societies. In contrast, anthropologists study “exotic” societies (p. 9). As I was studying in a Western societal context and have some familiarities with the clinical practice contexts where this research was conducted, the methodological approach I deployed has sociological roots.
Methods in ethnographies have expanded to include participant interviews and analyses of various socially meaningful documents (both texts and visual) (Gobo, p. 53). Ethnographic researchers collate observations and other data, and endeavor to interpret such observations in relation to the whole cultural picture. The emphasis on understanding the linkages between data and the whole illustrates sensitivities to context.

Ultimately, ethnographers have traditionally aimed to generate detailed depictions and analyses of social relations within entire cultures (Stewart, 1998, p. 7); however, my study was not designed as a full ethnography. To denote this distinction, I refer to the study design as having used an ethnographic approach. Studying entire cultures (a full ethnography) is questionable on points of both practicality and achievability (Stewart, 1998). However, I did use ethnography as a guide because this work was a type of cultural study. At the outset of this chapter, I emphasized Sewell’s (1992) assertion that culture is simply what people know and therefore, I contend that Sewell regarded culture as a compilation of social schemas. Thus,

39 Stewart (1998) used the term “holism” to describe the emphasis on understanding data in relation to the whole. Traditional ethnographies were aimed at creating comprehensive reports about entire cultures. However, Stewart noted that comprehensiveness is generally limited both practically (e.g. space limitations in publications) and in achievability (that is, can a comprehensive report about a “culture” ever really be obtained?). Thus, the trend in ethnographies is now a more circumscribed view. To capture this distinction, I used the phrase “ethnographic” instead of “ethnography” throughout this dissertation.
examining the schemas (and related structures) within the health care contexts where patients with HF access EOL care is akin to cultural inquiry and aligned well within the ethnographic tradition. In accordance with Sewell’s emphasizes on power within social structures, I specifically used a *critical* ethnographic approach.

**4.2.2. Critical ethnography: Power within social structures and epistemological considerations.** Critical ethnography fits within the umbrella of “nonpositivist” postmodern ethnographies. Thomas (1993) described critical ethnography as an approach to inquiry that examines relationships among social features such as knowledge, culture, society, and political action while attending to influences of social power and authority, researcher roles (p. vii). Critical ethnographers “describe, analyze, and open to scrutiny otherwise hidden agendas, power centers, and assumptions that inhibit, repress, and constrain” (Thomas, p. 3). In general, the purpose of critical ethnographic research is to produce knowledge that fosters social transformation and change, which is consistent with the aims of my dissertation research.

Working within a critical paradigm has specific philosophy of science parameters including a: *modified realist ontology, a constructionist epistemology, and a dialogical/dialectical methodology* (Guba & Lincoln, 2005; Lincoln, Lynham, & Guba, 2011). Hegelund (2005) has proposed “interpretation” as an alternate epistemological position for critical ethnography. Kincheloe and McLaren (2011) similarly argued that critical hermeneutics—the idea that all research, and perception, is interpretation—undergirds critical inquiry epistemology. Interpretation as critical hermeneutics does not countermand my earlier references to
constructionism in a critical paradigm; interpretation is a component of constructionism because social agents interpret their social reality (within modified realism). Indeed, there is consonance between critical ethnography and the theoretical framework elaborated on in Chapter Three. Sewell’s (1992) conceptualization of structure includes an explicit transformative element. This transformative potential illuminates a praxis-orientation that is similarly reflected in Kincheloe and McLaren’s (2011) Reconceptualized critical theory. Both Sewell as well as Kincheloe and McLaren explicated the influence of power in maintaining social relations. Likewise, these authors also illuminated the essential need to understand the implications of power relationships in order to bring about social change.

4.3. Study Sites: Identifying the Relevant Clinical Contexts for Data Collection

The literature presented in Chapter Two informed how I identified and conceptualized the relevant clinical contexts (i.e. the acute care clinical practice settings where patients with HF access EOL planning and care) for my study. As was empirically supported by the literature, in hospitals, patients with HF experience EOL planning and care in both general and specialty acute care settings including general medicine acute care units, cardiac specialty units, and critical care areas (see Figure 2-1). Thus, I chose particular clinical settings because they were appropriate for collecting the data necessary to answer my research questions.
I selected two study sites within one regional health authority\textsuperscript{40} in my province. While I have worked professionally within other health authorities in my province, I had not worked within the health authority selected, nor had I worked at either of the study sites. This was an advantage because I entered as an unknown researcher, not a known clinician. I had to use navigation tools that community members use (e.g. wayfinding maps, public directories) and I had to learn about the services offered, the ways services were organized, and how the system was designed.

4.3.1. Explanation of my two study sites: Site A and Site B. I originally had planned to use a large tertiary hospital and a near-by smaller community hospital. However, when I met with my first site contact at the quaternary hospital (site “B”), they\textsuperscript{41} recommended a different smaller hospital because it served a larger portion of patients with HF within the region. I submitted an addendum to my approved ethics application and connected with another contact at the second site (site “A”).

\textsuperscript{40} The term “health authority” refers to the way health care services are owned, operated, and organized within the province where I carried out this research. Health authorities are generally organized by geographic regions, which are called “regional health authorities.” However, some province-wide health services are also organized within separate health authorities (British Columbia, 2019).

\textsuperscript{41} Gender-neutral pronouns (i.e. “they”) are use throughout this dissertation as one strategy to protect identities of study participants and contacts.
Site A was the identifier I gave to a smaller 300-bed, university-affiliated, community-based hospital (community population under 150,000 people). At the time when I collected data, several inpatient and outpatient services were offered at Site A including a cardiac specialty unit (with both critical care and telemetry beds), acute medicine units, a palliative specialty care unit, and interdisciplinary outpatient clinics for patients with HF. Though Site A was smaller than Site B, both were centrally-located hospitals designed to provide a multitude of health services. Site A was also geographically located in a smaller community; however, this community was adjacent to several large urban centers (for example, a nearby city had a population of more than 500,000 people, which belonged to a larger metropolitan with a population of over 2 million people) and was accessible by car and also by public transit. Several large quaternary and tertiary sites were also in the vicinity (within 100 km) of this smaller hospital.

Site B was the identifier assigned to a larger 400-bed, university-affiliated, urban quaternary hospital. Site B had an extensive range of inpatient and outpatient services and received referrals from smaller sites within the health authority (including Site A) for advanced procedures and specialized surgeries. Outpatient services were also well established and included interdisciplinary outpatient clinics for patients with HF. There were extensive critical care services and diagnostics (e.g. cardiac catheterization, cardiac surgical units, and step-down/high acuity units), various cardiac interventions and surgical procedures (e.g. value replacements, acute HF interventions). Of note, Site A had service agreements with site B and
patients were routinely transferred from the smaller Site A to the larger Site B for acuity challenges and/or to access interventions, procedures, specialists, and so forth.

Across the health authority and in place at both Sites A and B, there were several advanced practice nurses and practice leaders who provided different specialty support and leadership (e.g. cardiac care, critical care, palliative care, advance care planning). Professional teaching was active at both sites though Site B hosted comparatively more students and researchers. Both Site A and Site B had access to specialist cardiologists for all inpatient medical and specialty units; both sites also had access to specialist palliative care specialist consultants for all inpatient units. Both sites also had large medical programs (i.e. inpatient units that provided acute general medicine services), which I initially found difficult to navigate due to their range and size and thus will explain further.

4.3.2. Organization and layout of the acute general medical units. At both study sites, the acute medical programs were large and inpatient areas were divided across multiple units, which also spanned multiple levels in the hospital. At Site B, there were four inpatient areas that site contacts and participants identified as general medical units. Participants told me that clinical and operational leaders made efforts to organize these units by particular patient populations or technical needs, though study participants also explained that at times, patients were admitted based on bed availability and thus crossed multiple areas. For example, at Site B patients who had experienced strokes (cerebral vascular accident) were cohorted onto one specific medical unit, whereas patients with tracheostomies were grouped onto another unit.
Both sites A and B also had acute medical units where older adults (ages 75 or greater) were preferentially admitted (e.g. elder care units). Overall, there was a lot of overlap between the focus on these units, including the way staff worked among them.

The size of the general medical programs added complexities for me as an outsider because they were difficult to understand and navigate. As I gained familiarity with the site leaders and clinicians, I came to appreciate how the units worked together while also having additional focus on particular patient populations. Clinicians moved throughout these areas; for example, nurses who worked in casual positions frequently worked in multiple units. Likewise, physicians saw patients who were admitted into these different units. The HF patient population was not specifically cohorted on any one medical unit. Between these two sites, I was able to recruit a sample of clinicians who had a great deal of cross-specialty experiences and expertise. I think this was related in part to the study sites being hospitals where a range of services were readily available which created opportunities for participants to work in many settings and with many different patient populations.

4.3.3. Advantages to using multiple study sites. Confidentiality and protection of both participants and the study sites was strengthened by the use of two study sites. As noted by Varcoe (1997), using two study sites offers additional privacy protection for study participants: “In order to protect the identity of the participants, units in two separate hospitals were used. One hospital served as the ‘primary site’; the other served as a secondary site for collateral data and to protect the privacy of participants” (p. 63). Rodney (1997) similarly noted
the advantage of using two study sites to protect site and participant confidentiality. Likewise, I
was better able to protect the confidentiality of study participants with the use of two study sites.
The site identifiers “A” and “B” were arbitrary and non-revelatory which meant “A” or “B” was not
associated with any particular site feature.

4.4. Sample: Inviting Study Participants

Overall, my aim was to recruit HCPs from clinical areas at both sites A and B who held
knowledge about interrelationships of structures within the acute care contexts where patients
and their family members accessed HF-EOL planning and care. As Robley (1995) has
explained, “the persons selected as research participants are usually those who serve the
purpose of the research” (p. 46). Morse (1994b) outlined the aim of sample selection similarly
noting that the goal of sampling in qualitative research is to include participants who know the
topic and can represent the experiences being studied. As Robley (1995) has cautioned,
researchers need to consider additional ethical commitments for sample selections in qualitative
research: “an ethical basis for selection would also involve attention to the inclusion of those
whose voices need to be heard: women, minorities... and those with less personal or
professional status” (p. 46). Indeed, Robley’s recommendation aligns within the critical paradigm
that I explicated in the previous chapter—that is, to recognize the situated and contextualized
nature of knowledge and understanding and thus seek to include a multitude of perspectives to
achieve the most complete knowledge account. Therefore, HCPs with a variety of acute care
clinical practice experiences, from diverse disciplinary backgrounds, and with varying degree of
institutional authority (e.g. leadership), who had clinical experience working with patients with HF and EOL planning and care, were invited to participate as study participants\(^\text{42}\).

The recruitment strategy I used can be described as theoretical because I invited and included participants who held the necessary knowledge needed to answer the research questions. Sampling strategies in qualitative research range and different strategies have been proposed to strengthen study samples. For ethnographic research studies like the one I am describing in this dissertation, Thorne (2008b) explained theoretical sample designs and proposed auditability and sampling logic:

There is no fundamentally right way to sample, but rather an essential requirement that we conduct our study on the basis of some transparent sampling logic and report on our findings in keeping with what we understand our sample to represent (p. 89).

Within this idea of sampling logic in mind, I sought out participants with practice experiences and understandings of the clinical practice contexts where patients with HF experience EOL planning and care.

\(^{42}\) Thorne (2008b) noted that the term “informants” has been commonly used in ethnographic research (p. 93). However, Thorne drew an interesting critique of the term highlighting that “informants” has different meanings in the public context and can be negative (e.g. police informants). As a more neutral term, Thorne suggested that people who participate in the research study be called “study participants”, which I have adopted (p. 94).
4.4.1 Sample design: Estimating my sample size and fieldwork hours. Originally, I estimated my fieldwork hours and sample size based on what I expected would be needed to collect sufficient data to answer the research questions. Thorne (2008b) emphasized that a sample size should be consistent with the research questions:

There is no firm and fast rule regarding what constitutes the right sample size...it is incumbent upon the researcher to generate a coherent and defensible claim about the proposed number of cases, subjects, or instances that would have to be included in the study in order for its results to be worthwhile (p. 96).

I anticipated 15 to 35 study participants and approximately 200 to 300 hours of fieldwork would be necessary to gather sufficient data to support my analysis. This estimate was based on the complexity of the research questions and the depth of observation and interviewing I thought would be needed to interpret the contextual conditions. In coming to further justify my sample size and fieldwork hour estimates, I also reviewed three doctoral dissertations with research questions and methodologies that were reasonably similar to this one. These three dissertations similarly used qualitative approaches to examine research questions related to different social contexts in health care settings. For example, to examine how the culture of an organizational context affects nurses’ experiences, Rodney (1997) carried out 218 hours of fieldwork (180 hours at site one; 38 hours at site two) and completed interviews with 14 study participants. Varcoe (1997) examined how the social context (and the power relations within that context) of health care influences nurses’ care. To answer three specific research questions
related to social context and structuring of health care, Varcoe completed approximately 200
hours of fieldwork over a two-year period and carried out 41 interviews with a total of 35 study
participants. More recently, Chan (2014) studied how the cultures of acute medical wards shape
health care practices concerning patients who are dying. Chan\textsuperscript{43} carried out 600 hours of
fieldwork over approximately twelve months of study. In addition to the fieldwork, Chan
completed semi-structured interviews with 35 study participants. In summary, these three
researchers were able to answer their research questions by interviewing 14 to 35 study
participants and conducting 200 to 600 hours of fieldwork. While these numbers provided some
direction for how many participant interviews and fieldwork hours I expected, the estimates were
a guide only.

\textsuperscript{43} Of note, Chan (2014) specifically stated that participant observation was the primary data
collection method, which likely accounts for why the fieldwork hours are so much greater
compared to the other two studies.
4.4.2. Entering the field: First experiences recruiting study participants. I used a study poster (see Appendix A) and study introduction letter (see Appendix B) to enter the field. I first sent posters and letters to “1”, who was a key person at Site B (see Figure 4-1).

![Figure 4-1: Study participant, recruitment flow chart](image)

Person 1 is well known provincially throughout the cardiac specialty and had previously been in an advanced clinical and leadership role at a hospital where I had been acquainted with them. I met with Person 1 and reviewed the study background, purpose, aim, and sample recruitment plans. Person 1 offered several ideas for how to meet and connect with other key managers and practice leaders. Person 1 then arranged a multiple-stakeholder meeting and forwarded the study information letters to other managers and leaders at sites A and B. Following my meeting
with Person 1, I connected with Person 2 at Site A. As Site A is considerably smaller, the logistics for meeting the clinical leaders were more straightforward. Person 2 outlined a list of clinical contacts and recommended different recruitment strategies. Person 2 suggested I first connect with a participant, who identified additional key contacts and further distributed the study information to HCPs at Site A.

The meeting arranged by Person 1 at Site B was held as organized; Person 3, a participant, and several other clinical leaders were in attendance. I introduced the study more formally with a presentation outlining key components of the research including the background, purpose, study questions, sample and recruitment plan, and data collection methods. I felt particularly nervous during these initial group meetings because I perceived these first meetings to be of significant importance for establishing whether or not leaders at the study sites would permit my entrance to their clinical areas. In keeping with my commitment to reflexivity, I documented feelings like this throughout the research process in my research journal. Despite personal feelings of uncertainty and worry before first field experiences and recruitment, study site contacts and study participants were warm and inviting. As I discuss in my findings, this warm reception seemed to stem from HCPs’ eagerness and willingness to talk about the difficulty discussing dying and death. However, in the findings chapters that follow, I will show how I learned that while talking about the difficulty of death comes easily, actually talking directly to patients and families about death can be difficult.
As I will also show in subsequent chapters, and particularly in Chapter Six, the importance of the words I was using (i.e. my language) became apparent early on during these experiencing gaining access to study sites. The shortened title of the study was the “HF-EOL Study” (see Appendix A). During these first field experiences and introductory study meetings, my use of the word “EOL” resonated as relatable for some, while estranging others (i.e. EOL was seen to not be their work). As introduced in Chapter One, I foregrounded the phrase “end-of-life” in the study title with the underlying premise that upstream EOL planning activities influence the care experiences at EOL. I found myself feeling surprised by participants who did not associate their clinical practices with patients and families with HF in acute care as related to EOL. I documented these surprised feelings in my reflexive journal, which became relevant in the analytical process—my surprise was an early cue to observe HCPs’ language and narratives around EOL. This later became an important study finding, which I discuss in depth in Chapter Six.

Participants joined the study in different ways. Study participants commonly recommended other study participants and explained their importance in understanding more about this topic. For example, one participant described their experiences learning EOL communication skills from another participant and identified this other participant as someone who had contributed substantially to the development of clinical practice resources including pre-printed order sets, documentation, and practice standards. In another instance, a participant stressed the importance of another participant’s input, and advised me to contact them. I was
open to suggestions like these and made ongoing decisions about the study sites and sample of study participants as my data collection and analysis progressed. These sample and recruitment decisions reflected Thorne’s (2008b) recommendation to adapt the sampling strategy with ongoing data collection and analysis work. I documented these choices in my journal to ensure transparent sampling logic.

### 4.4.3. Reaching the final sample of twenty-two interdisciplinary study participants:

**Characteristics and recruitment insights.** Twenty-two interdisciplinary HCPs joined this study as participants. Study participants had a range of clinical experiences, knowledge, and skills (see Figure 4-2). Indeed, I underestimated the amount of experience and exposure that clinicians would have to the various areas where patients with HF access care. As illustrated in Figure 4-2, some study participants identified clinical expertise in multiple practice areas. For example, one participant had clinical experience and expertise in critical care (including medical intensive care environments, cardiac specialty critical care settings, and cardiac intervention procedure settings), the acute palliative specialty unit, and general cardiac ward settings. Physicians had a similar range of clinical experiences; through various training opportunities (e.g. Fellowships), physicians developed diverse clinical practices and related expertise that included clinical leadership responsibilities (e.g. administration responsibilities), outpatient
cardiology clinics, critical care and cardiology inpatient attending physician roles, and inpatient consultant roles.

![Study sample diagram](image)

**Figure 4-2: Study sample (N=22), with clinical expertise**

White ovals represent Registered Nurses; gray ovals represent Physicians; green ovals represent Advance Practice Nurses and/or clinical leaders; and, orange ovals represent Social Workers.

The final study sample included multiple disciplines: direct care registered nurses, n=13 (59%); physicians, n=4 (18%) (cardiology with critical care, n=3; palliative specialist, n=1); social
workers, n=2 (9%); and nurses in advanced practice and/or clinical leadership roles, n=3 (14%)
(see Table 4-1).

Table 4-1: Study sample characteristics

<table>
<thead>
<tr>
<th>Profession/discipline</th>
<th>Number of participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registered Nurses working in direct care</td>
<td>13 (59%)</td>
</tr>
<tr>
<td>Physicians</td>
<td>4 (18%)</td>
</tr>
<tr>
<td>Registered Social Workers</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Registered Nurses working in advanced practice</td>
<td>3 (14%)</td>
</tr>
</tbody>
</table>

I expected to group study participants by their area of clinical expertise (e.g. cardiac clinicians, general practice) however this expectation was not met. Many participants had multiple expertise in multiple areas and could not be clustered into a single practice area or even a single specialty. Figure 4-2 highlights the breadth of clinical perspectives, experiences, and diversity of clinical knowledge of the participants, which is reflected in the data I collected. The original estimate of 15 – 35 study participants was underpinned by the assumption that the clinical practice perspectives of the HCPs would be more confined within one practice area. However, in recognition of the unexpected clinical range captured in this study sample, and the resulting data collected, I stopped recruiting after 22 participants had joined.
The disciplinary compilation and proportion of HCPs of the final study sample (N=22) resembled estimates I had planned in the preparation and proposal phase (see Figure 4-3). In Canada, Registered Nurses make up 62% of HCPs overall. As nurses also provide the greatest amount of direct patient care, engage continuously with patients and families during hospital admissions, re-state and clarify communication encounters between patients and other HCPs, and carry out patient care directives from multiple physicians and allied HCPs, I expected that nurses would need to make-up the largest proportion of disciplines represented in the study sample.

![Figure 4-3: Proportions of HCPs in Canada](image-url)
The allied\textsuperscript{44} HCPs category included dieticians, physiotherapists, respiratory therapists, and social workers (hospital administrators are not represented in this data) (Canadian Institute for Health Information 2014; Canadian Institute for Health Information, 2017).

The final sample (\(N=22\)) was close to predicted estimates and proportionately similar (see Figure 4-4). Combined, nurses working in both direct care and in advance practice positions made up 73\% of my actual sample of study participants.

\textbf{Figure 4-4: Final study sample, professional disciplines}

\textsuperscript{44} The phrase “allied HCPs” refers to the health care professionals who are not nurses and not physicians (e.g. pharmacists, dietitians, physiotherapists, respiratory therapists, psychologists, spiritual support practitioners, and social workers).
While notably smaller in numbers, physicians, administrators, and allied HCPs are also integral to HF-EOL planning and care. Physicians in particular often hold considerable decision-making power and influence in acute care settings. Estimating from the proportions of specialty and general practice physicians captured in Figure 4-3, I expected to include 1 to 4 general practice and 1 to 3 specialty physicians. In total, I recruited n=4 (18%) physicians. The proportion of allied HCPs was similarly estimated and 1 and 3 participants were expected. I recruited n=2 (9%) allied HCPs. Of note, I was unable to recruit a general practice physician (e.g. non-specialist), which is a limitation I highlight in Chapter Nine.

4.5. Ethical Research: Protections for Study Participants

Ethical research involves a rigorous review and approval process (Fisher, Russel, Browne & Burkholder, 2018). Joint ethics approval was granted from the University of British Columbia and the health authority where the data collection was carried out. The ethics approval process involved review of the research purpose and problem, questions and aim, proposed study sample and methods, recruitment approach, and potential risk to study participants. The approval process also included review of all of my study advertising (see Appendix A); information for HCPs (see Appendix B); patient/family information sheet (see Appendix C); and participant consent forms (see Appendix D).

There are three foundational principles outlined in the TCP2 that must guide ethical research: respect for persons; concern for welfare; and justice. These three principles undergird requirements for ethical research including informed consent, confidentiality, and access, which I maintained throughout my study.

4.5.1. The principle of respect for persons. The principle of respect for persons promotes study participants’ welfare and integrity above any other research priority and foregrounds study participants’ autonomy; that is, participants’ rights and abilities to contemplate and consider their decision and choose their action(s) (Government of Canada Panel on Research Ethics, 2018). As a researcher, I applied this principle by seeking participants’ free, informed, and ongoing consent and created various study materials to support this goal (see Appendices A – D).

I promoted free and voluntary participation in several ways. For example, I included direct statements in my study materials, which indicated participants were free to withdraw from

Emanuel, Wendler, and Grady (2018) elaborated on these three foundational principles and propose eight principles and benchmarks for ethical clinical research: collaborative partnerships, social value, scientific validity, fair participant selection, favorable risk-benefit ratio, independent review, informed consent, and respect for persons (p. 9). Though I have limited my discussed in this section to three foundational principles, I addressed all eight throughout my research study and discuss how I have done so in other sections of this dissertation. For example, in section 4.8 of this chapter I expound on issues quality in qualitative research, which addresses the principle of scientific validity.
the study at any time and no penalties would be incurred. I also provided both print and electronic versions of all my study materials including copies of the consent forms with site contacts (e.g. unit managers, nurse leaders, nurse educators). Contacts at Site A and Site B distributed my study information and invitations on my behalf. However, in order to ensure participants’ confidentiality and remove any influence or conflicts of interest that might have applied for my site contacts (e.g. those acting in a supervisory role), I also invited participants to connect with me directly through their preferred manner (e.g. email, phone). At the same time, distributing study invitations and materials through the site contacts also created distance between myself and potential participants so that I too could avoid exerting undue influence.

I also used several strategies to promote informed consent. For example, I created different types of study information materials (e.g. plain language, detailed consent forms) and widely circulated these study information materials at study sites and to site contacts. Participants who contacted me and expressed interest in joining the study were given twenty-four hours (or longer, when possible) in order to maximize opportunities to review the study consent form in advance of any observation or interview experiences. Informed consent was also promoted in how I provided information about the study including my study purpose and the possible risks and benefits of participating.

Application of the principle of respect for persons also meant and I sought to address informed consent as a continually negotiated and ongoing process (Government of Canada Panel on Research Ethics, 2018; Rodney, 1997). For example, I reintroduced myself and re-
invited participation at each encounter which was important because I came in and out of study sites and clinical areas repeatedly over the course of several months and commonly encountered participants who had consented at an earlier time. I also was explicit in making ongoing efforts to reestablish and clarify my purpose in any of subsequent meetings by making statements such as: “I’m here as a researcher today. Are you still comfortable with our conversation possibly being included in the study?” I also created several printed resources including study information posters and detailed consent forms for anyone to review. I left study information materials on the units so that the information was continually and freely available.

4.5.2. The principle of concern for welfare. The principle of concern for welfare means researchers must consider and identify any risks that participants might face when they join as study participants (e.g. physical, social, mental, economic); steps to mitigate any unnecessary risks must also be taken (Government of Canada Panel on Research Ethics, 2018). I upheld the principle of concern for welfare by providing clear information about my study and outlining potential risks and benefits in the study materials (see Appendix D). I also considered particular risks and ethical issues that can apply in qualitative research. For example, as Fisher et al. (2018) have indicated, “for observational research, the main ethical requirement is to protect the confidentiality of the research data that is collected” (p. 478). Confidentiality was an important principle that I maintained throughout my research study and throughout this dissertation which is why participants’ and study sites’ identities are masked.
Qualitative researchers face particular ethical issues which stem from the manner through which researchers interact with participants and also in the way the researchers interpret and create knowledge about the phenomena under study (Fowler, 1988; Munhall, 1988). Robley (1995) reminds us: “how the researcher behaves, how the respondent is invited, and how the respondent is viewed as an active participant in the research process creates new and more difficult ethical responsibilities for the researcher” (p. 45). In qualitative research generally, and in my research study specifically, I was cognizant of the care owed to study participants in how informed consent was obtained, as well as how study participants navigated different social positions including those between the participants and myself as the researcher (Fowler; Robley). Thus, for any other people in the clinical areas (including patients/families) I had separate study information materials including a pamphlet explaining my purpose as a researcher. I collected no information or study data about any HCP or patient/family encounter without prior consent.\footnote{I obtained written consent on my REB-approved study consent form from participants who joined formally (e.g. with an individual interview or as an observation buddy). I sought verbal consent from anyone who was in the study settings and who may have interacted with me as a researcher. This approach to consent is reflected in guidelines about consent in qualitative fieldwork (University of Toronto Social Sciences and Humanities Research Ethics Board, 2009).}
4.5.3. The principle of justice. The third foundational principle for ethical research is justice. Applying the principle of justice means researchers must consider fairness in opportunities to participate in research. The Government of Canada Panel on Research Ethics (2018) has explained:

Justice refers to the obligation to treat people fairly and equitably. Fairness entails treating all people with equal respect and concern. Equity requires distributing the benefits and burdens of research participation in such a way that no segment of the population is unduly burdened by the harms of research or denied the benefits of the knowledge generated from it (section “justice”, para 1).

In order to address and uphold issues of fairness and the principle of justice, I outlined specific inclusion and exclusion criteria prior to recruiting for my study. I also produced different study information materials that were written with simple language with the goal of accessible information.

4.6. Methods: Collecting Data from Dialogic Interactions and Reflexivity

Methods are the techniques or procedures used by researchers to gather data related to research questions (Crotty, 1998). Different methods provide access to alternate types of data thus the use of several methods can enrich the caliber of a qualitative study. Thorne (2008b) advises against relying solely on one method as each method has characteristic strengths and weaknesses (p. 86). As described in the previous chapter, structures are simultaneously comprised of both schemas and resources (Sewell, 1992). As schemas belong to agents, the
path towards understanding context is through interaction with agents. That is, interactive exchanges and dialogic methods were crucial in order for me to capture the data I needed to address the study focus. I also sought to observe participants to access information not said and also to directly interact with resources that worked within the structural relationships of the practice contexts. I used four data collection methods: 1. participant observations in fieldwork; 2. in-depth semi-structured interviews; 3. reflexive journaling; and 4. document and text-based content analysis. The use of multiple methods helped me access a variety of data and strengthen interpretations.

4.6.1. Data collection with participant observations and fieldwork. Dialogic methods were necessary to directly connect with HCPs who understood and worked within the clinical practice contexts where patients with HF access EOL planning and care. Participant observation is an example of a dialogic (i.e. conversational, interactive) method and is a primary method used in ethnographic research, including my study. Observation begins by accessing the field and via fieldwork (de Laine, 2000; Mulhall, 2003; Stewart, 1998; Thorne, 2008b). Thorne explained that observations are intended to access people’s thinking by trying to understand the patterns in their behavior. Such patterns are usually underpinned by tacit
understandings about the meanings of behavior. Observational data is valuable because it can attune a researcher to context and also reveal incongruences and inconsistencies between what is said (e.g. said within an interview or written within a text document) and what is done (e.g. observed through fieldwork) (Hammersley, 1992; Mulhall). Participant observation involves establishing direct relationships. Fieldwork takes place in participants’ settings, and is carried out with the purpose of observing behavior and aiming to understand the meanings of actions (Gobo, 2008; Stewart, 1998). Morse (1994a) explicated several techniques that researchers should use when doing fieldwork including, for instance, a “spirit of inquisitiveness”, asking

47 An example of the tacit understanding of human behavior can be demonstrated by considering very common social gestures such waving or smiling. The physical observation is simply a raised hand or contracted facial muscles. The task of a qualitative researcher is to try and understand the shared meanings of these patterns of behavior. The researcher also tries to understand these gestures in relation to a context. For instance, raising a hand to engage a “wave” motion has different, tacitly understood, meanings from one context to another. Standing on curb in an urban center, sitting in a classroom, and walking towards a familiar individual, are different contexts and raising a hand has different meanings (e.g. summoning a taxi, asking a question, a non-verbal acknowledgement).

In clinical practice environments, there are many different behaviors that are underpinned by complex and mutually understood meanings, norms, rules, and so forth. For example, if a patient asks to be repositioned in the bed, there is a culturally embedded understanding about which HCP will assist the patient to reposition. A ringing phone or a call bell share similar characteristics. Many of these “rules” are taken-for-granted and widely understood within the cultural group; however, these rules are not necessarily discernable to an outsider without deliberate investigation.
questions (e.g. What? Where? Why? Tell me about...) and seeking answers, absorbing, and
drawing in information.

I completed approximately 250 total hours of fieldwork over an eight-month period in
2016. The length, timing, and frequency of observation sessions were negotiated with study
participants. Observation experiences were flexible and participants chose the length of time
and date. Early observation sessions were eight to ten-hours long. I spent longer durations in
first observational experiences because it helped to build trust and familiarity with the people in
the clinical areas. As I became more known in the clinical areas, observation experiences
averaged between four and six hours in order to ensure quality observations and avoid fatigue.
In all instances, I aligned observation periods with participants’ usual work schedules. I joined
for portions of day, evening, and night shifts on weekdays and weekends.

I started fieldwork trying to understand basic organizational features including parking,
wayfinding within the buildings, introducing myself at the nursing stations, and looking for
people’s offices and contact information. I used many of the same resources that the public
would be expected to use to carry out these similar activities (e.g. websites, maps, directories,
general hospital contact emails). Some of these activities were notably difficult. For example,
the common naming of inpatient units involves the floor and geographic orientation (e.g. “west”) or a nickname (e.g. “alpha”). These titles become meaningful to the HCPs working with them but as an outsider, they were disorientating and confusing. Program sizes were also
disorienting, particularly at the large Site B. The acute medical inpatient areas were distributed
between two floors and multiple units. I had to take notes about which medical unit the study participants would be reporting to and I spent a considerable amount of time remembering how managers and clinical practice leaders (e.g. clinical educators) divided their responsibilities across the related areas, many of whom overlapped different units.

At the beginning of my fieldwork, my observation experiences were aimed generally and broadly at understanding the environments of my study settings and coming to better know the context. I was seeking to observe how HF patient care was organized and carried out, how HCPs identified and prioritized their work, what the clinical days looked like and how they were organized, and how and where patient care and communication was delivered and by whom. For example, in this early stage, I created several sketches of the unit layouts including the location of what were identified as important areas such as the medication carts, patient charts, and computers (see Figure 5-1).

As my fieldwork progressed and my understanding of the acute settings developed, and as my iterative data collection and analytical process unfolded (described in more detail in Section 4.7 below), my observations became more specific and focused towards more in-depth explorations of my early interpretations and findings. For example, I became increasingly focused on non-verbal and implicit communications (e.g. sighs, laughs, facial expressions, words that were used with implied meanings). I also used observation experiences to clarify what participants said or described in the semi-structured interviews. For instance, a participant referred to a provincial ACP tool called *My Voice*, which I asked to see and for the participant to
explain. Most documents included in my data were identified by participants during observations
and fieldwork.

**4.6.1.1. Evolutions in understanding of what it meant to “do” fieldwork.** My
understanding of “doing field work” evolved during this study. Initially, I understood fieldwork in a
limited sense as direct participant observation/interaction experiences. However, my
understanding what fieldwork actually was evolved as I came to also recognize the significance
of other critical encounters that were outside of direct observations. For example, while I have
an established clinical practice in one of the health authorities in my province, I was not well
known at either of the clinical sites where this research was carried out. I recruited many
participants through electronic invitations, which resulted in further email exchanges with
consent forms and subsequent telephone follow-up conversations. In many instances, pre-
meeting telephone conversations were in-depth as study participants were often eager to hear a
full overview of the study. “Have you talked to ---? You should connect with ---!” was an example
of a comment/question that study participants commonly asked me before meeting and
occasionally resulted in detailed conversations. I reflected about these types of encounters in
my reflexive journal (e.g. feelings of worry when participants advised me to talk to someone
else), which became relevant to my findings later on.

Questions from participants about my clinical and academic background were also
common. In one case a study participant had heard me lecture at an educational event and was
interested in future teaching events with which I was involved. In another situation a study
participant shared their own experiences with graduate school and thesis work and expressed recognition for the considerable undertaking of the study and interest in the results after its completion. In my early recruiting experiences, I joined nurse educators and nurse managers at their morning rounds. These were shorter fieldwork sessions that were essential for the clinicians to learn who I was and what my purpose was. As the study progressed, I recognized these types of observation/interaction encounters as crucial elements that built and undergirded trust in my relationships. This trust then allowed me to spend consecutive hours in observational and/or interview interactions. de Laine (2000) emphasized the interactivity and engagement in observation. “The term ‘fieldwork’ stresses the continuous presence of the researcher in the field, as opposed to the ‘grab-it-and-run’ methodologies like the survey, in-depth interview or analysis of documents and recordings” (Gobo, 2008, p. 11). I kept detailed written records of my observations during fieldwork as fieldnotes (Kirk & Miller, 1986; Morse, 1994a).

4.6.1.2. The value of observations and fieldwork: Accessing implicit and non-verbal data. Observations were important because they created opportunities for me examine non-verbal aspects of communication exchanges. For example, early on during field work, I heard and saw what I perceived to be emotion in a conversation about resuscitation. Specifically, I observed a non-verbal demonstration of emotion that was attached to a statement about a patient’s resuscitation direction:

Fieldnote (FN) (p. 40-44): [participant] scrunched [their] nose when [they] said "oh he's full code"
Intuitively, I sensed this observation to be important and I recorded it in my fieldnote journal. This example, and other encounters that felt intuitively significant, were early sparks of what later became major areas of study findings. The experience of collecting observational data also helped me establish trust with study participants. Over time, conversations with study participants became increasingly comfortable and candid and important information was shared during “down time” (e.g. sitting at the nursing station on night shift). Physicians and nurses also started to recognize me and would often stop to check-in and see how things were going; in these encounters, it was common for someone to offer another participant’s contact info (and often provide an explanation of why they would be a great participant). Together, I believe this sense of trust undergirded my ability to access what was not said, and see and hear participant’s candid recollections of their experiences with EOL planning and care.

4.6.1.3. How I used fieldnotes. I used fieldnotes to document observations, feelings, analytic insights, and ideas. Kirk and Miller (1986) recommended that fieldnotes be categorized into three groupings: literal statements made by participants, observers’ descriptions about the context of the social interactions, and early impressions and interpretations of the meanings of social interactions. Kirk and Miller recommended that basic requirements of fieldnotes are legibility and chronological ordering. These authors also noted that quality of note taking is improved with deliberate and consistent editorial style. For instance, capital letters and periods for complete sentences; quotation marks to note statements, and open punctuation to record incomplete thoughts.
Kirk and Miller’s (1986) fieldnotes grouping called “early impressions” illustrates the close simultaneity of data collection and data analysis in qualitative inquiry (Baggs et al., 2007; Thorne, 2008b). Data collection and analysis occurs somewhat concurrently because early impressions and preliminary analysis often inform ongoing data collection and construction (Thorne). Thorne illuminated the need for systematic documentation as an integral component of effective, simultaneous data collection and analysis:

An important element in managing...data is carefully documenting what has been gathered and thought about, and finding ways to track the evolution of each within [the] process over time. Some researchers refer to an ‘audit’ trail as a feature of [the] eventual research report that will be requisite to the credibility of [the] findings (p. 138).

I used a software called NVivo© to facilitate careful documentation and organization of observation data notes and analytical decisions. I transcribed written notes and created digital memos for NVivo©. Drawings, sketches, and conceptual maps were also digitally converted. Electronic copies increased my ability to quickly recall data as the program supported multiple-page viewing (e.g. multiple pages of my research notes could be viewed at once). Using NVivo©, fieldnotes were also clustered using multiple tags (the program calls these cases and nodes) including study participant (e.g. AC012), site (e.g. A), idea (e.g. ask about...), etc. This feature allowed me to rapidly recall notes involving participants or study sites that were not necessarily written in consecutive pages.
Hammersley (1992) challenged the idea of “naturalistic” research settings and asserted that all data is produced in a setting that the researcher has, at least in part, created—thus emphasizing the complexity of the interrelationships between researchers and study participants. While traditional ethnographies commonly used participant observation as the main source of data, modernized ethnographic methods also emphasize dialogic interactions. Hammersley’s explication of the complexity of interrelationships undergirds the rationale for engaging in research with both observation and dialogic interactions (not simply observation in isolation)(Kincheloe & McLaren, 2005; Kincheloe & McLaren, 2011; Thomas, 1993; Thorne, 2008b). This interrelationship was why I also chose to carry out data collection with in-depth and semi-structured interviews.

4.6.2. Data collection with in-depth, semi-structured interviews. I used in-depth interviews as another dialogical method to collect study data. As Thorne (2008b) explained, knowledge gleaned from participant interviewing is primarily subjective⁴⁸. Interviewing is used to access the personal accounts of social experiences from a single participant. Thorne also

⁴⁸ Thorne (2008b) explained the rationale for seeking “subjective” data: “there is still good reason for capitalizing on individual interviews as a useful core for the development of knowledge in relation to many of the clinical issues we encounter... We might get a feel for issues quite quickly, but we as clinicians know that we might well have tapped into those one or two who represent others” (p. 79).
asserted that interviewing participants about the meanings of behaviors is a foundational ethnographic method because such experiences may represent others who share similar social locations (p. 79). Use of interviews aligned theoretically with the overall methodological approach (that is, moving beyond researcher-as-authorial-observer towards an interactive, integrated exchange between researcher and participants). An N of 18 study participants contributed a semi-structured interview (the remaining 4 participants joined as observation buddies only).

Participant interviews were loosely organized with an interview guide (see Appendix E). I began interviews with a brief preamble that summarized content from study advertising (e.g. study poster, information letter). For example:

This research study designed was to investigate and understand how clinical practice environments influence the end-of-life care for patients and families who have heart failure. These clinical practice areas primarily include general medical units and may also include cardiac specialty areas, and critical care settings. I am interested in your perspectives because you interact firsthand with the features that make up these complex clinical practice environments and you have experiences with people who are facing the end of life and who die from heart failure

Following a short introductory statement, I opened interviews by asking broad trigger questions or open statements (e.g. Describe your current clinical practice position. How did you come to work in this role and in this area? Describe a situation where you were involved with a patient
and family who had heart failure and was at the end-of-life). Trigger questions were intended to facilitate dialogue and help the interviewees discuss and describe their experiences. Probing questions such as tell me more about... or I’m wondering if you could explain what you mean by... were also used to further explore content shared by participants.

4.6.3. Data collection and reflexive journaling. A reflexive journal was the third data collection method used. Anderson (2008) described reflexivity as the process by which a researcher strives to become aware of what is underlying and shaping analytical decisions and research outcomes. Reflexivity in postmodern research such as critical ethnographic inquiries is based on the notion that knowledge produced is interpreted and constructed—that is, “knowledge is not separate from the knower” (Anderson, p. 185). Reflexivity attempts to account for the researcher’s influence in the creation of knowledge and builds auditability, transparency, and accountability into the research process. Kincheloe and McLaren (2011) stressed the important of “self-conscious” criticism and explained that researchers engage in reflexivity to “become aware of their ideological imperatives and epistemological presuppositions that [are informing] their research as well as their own subjective, intersubjective, and normative reference claims” (p. 301).

Reimer-Kirkham and Anderson (2010) similarly emphasized the need for researchers to strive to understand their position within research through reflexivity, particularly in managing the conflict that nurse-researchers can face between their role as both advocates and analysts:
It is a fine balance between maintaining the analytic stance of a researcher, with a certain detachment, and slippage into advocacy, as we enter into a research participant's personal and social space. Yet, enter this space we must, if we are to do rigorous inquiry and apply good science—herein lies the challenge. Our sense of obligation to those who have allowed us to enter into their lives can be a strong force in tipping the balance toward advocacy; it is for this reason that critical reflexivity is crucial as we engage in such encounters (p. 199).

Anderson (1991) and Thorne (2008b) further expounded the issues and challenges with being a nurse-researcher. Thorne explained, “the task of the participant observer is to rigorously and systematically ensure that the lens through which you are looking is open, transparent, and clear, and the quality of your research project will depend entirely on how convincingly you can accomplish that” (Thorne, p. 81). Such transparency and openness are necessary to avoid what Reimer-Kirkham and Anderson (2010) described as “oppression everywhere in our data” (p. 203)—that is, the risk of reinstating or reinforcing oppressive relationships through the validation of research texts. Rodney (2015, personal correspondence) also maintained that openness helps the researcher move beyond a researcher seeing “what they want to see” and remaining receptive to alternative perspectives.

4.6.3.1. How I used journaling as a reflexive tool. Reflexivity is commonly carried out with journaling. I documented my reflexive insights and emotional experiences (Kleinman & Copp, 1993) in my own reflexive journal. I also documented analytical decisions with a self-
conscious examination and subjective comments about how I interpreted particular events (e.g. my judgments, assumptions, expectations, disappointments, surprises, concerns). The journal also provided a space for my ongoing reflections about my place within the constructionist experience (e.g. my selection of language, things that work well/not well, decisions about recruitment/exclusion, and so on)—that is, acknowledging my own role in the data collection and interpretations.

My journal entries were hand written and completed following all fieldwork and interview experiences as close as possible to the moment (for example, before leaving the field site or immediately following an interview). Entries were also included whenever I made study decisions including recruitment or questions for study participants. I aimed to build openness and transparency and produce knowledge that reflected interpretations outside of my own existing experiences and beliefs by committing to the reflexive process throughout this study. I also aimed to produce a written document that contextualized the analytical decisions and interpretations generated from this study for readers and knowledge users in the future. My analytical record facilitated my ability to discuss analytical decisions and examine my interpretations in conjunction with my supervisory committee.

4.6.4. Data collection from documents and other text-based content. Some clinically meaningful/significant texts and documents were also included as study data. Thorne (2008b) stated “documents, including such things as policy documents, records of important meetings... or public media, may tell us a lot... if thoughtfully analyzed” (p. 82). Thorne also explained that
there two key advantages to including document/text content within a study. First, that most documents are created prior to the researcher entering the field and therefore, the researcher will usually have minimal influence on their construction. Secondly, documents/texts commonly contain a range of subjective and objective information that, when considered in relation to origins of the document, and in relation to the context for which the document was intended, may offer a unique angle of data. Thorne concluded, [based on such strengths], that documents as “either primary or collateral sources” may be worthy of consideration (p. 83). Some documents were used as data sources and informed my overall analysis. In particular, these documents were helpful in better understanding the standardized and supportive clinical practice infrastructure. For example, participants identified and described resources such as multidisciplinary practice standards and professional guidelines, pre-printed physician’s orders, and institutional statements.

As I will explore in Chapter Six, participants described code status and related clinical documentation as clinically important documents, which were used to support my analysis in findings how what “code status” was intended to mean versus what it actually meant. Decisions about how and which documents to include were based on observations (fieldwork) and participant interviews. Pre-printed orders (e.g. resuscitation directions), patient education materials (e.g. BC Heart Failure Network patient teaching materials), and educational resources for HCPs were also identified as clinically meaningful (e.g. handouts and posters from education events).
While some of the printed materials and practice resources that participants identified were publicly available documents (e.g. British Columbia Ministry of Health (2013), ACP tool, My Voice) others were specific to the site and/or the institution where I collected data (e.g. Physician’s orders where resuscitation directions were described). In order to uphold the confidentiality of both the participants and the study sites where I collected my data, I refer to the institutional-specific documents generally and using their informal names only (e.g. the “code status” orders I describe in Chapter 6).

4.6.5. The nature of data gathered through dialogic methods. Dialogic, interactive, and observational methods allowed me to gather data in a way that permitted exploration of both agent and context (both explicit and implicit dimensions). These data collection methods were philosophically consistent within the constructionist epistemological position explained in Chapter Three. Both the explicit and implicit dimensions of context became simultaneously accessible through the use of observation and fieldwork. During observations, participants frequently showed me actual (i.e. empirically observable) resources within the clinical environments that informed their experiences and understandings of EOL planning and care; pre-printed order sets about resuscitation directives were one example of an explicit contextual element that was explained to be important to both the provision of, and formation of thoughts about, HF-EOL planning and care. Observation also allowed me to examine agents’ actions and conversations and explore what was not said within these contexts. For instance, implicit and
assumed meanings of particular words and phrases within these practice contexts became an important theme in the overall findings of this study.

In keeping with both the philosophical and theoretical commitments expounded previously, in the next three chapters (Chapter Five, Six, and Seven) I also support my findings and interpretations with the inclusion of study participants' voices, along with my own observations and reflective fieldnotes. This technique aligns well with the epistemological position with which knowledge within a critical paradigm is constructed. That is, “that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42).

Epistemologically, the nature of knowledge-as-contextually-situated also accounts for why I devote portions of the next three chapters to findings about the acute care environment. For example, in Chapter Five, I present findings about the diverse patient populations that characterize acute medical areas. Later, I use this description to situate related subsequent findings and interpretations.

4.7. Data Analysis: How I Constructed Interpretations

In keeping with the philosophical commitments across the theoretical framework that informed my approach throughout this study, from an epistemological perspective, I recognized knowledge as situated and constructed in relation to a particular social context. That is, I
operated from the position that knowledge is imbedded, interpreted, and transmitted via social
teractions (Crotty, 1998). Thorne (2008b) cautioned however:

By using [construction], we are also setting up something of a dilemma for the
researcher, since the point of empirical research is not simply giving license to picking
and choosing among available information to bolster a particular bias or preconceived
opinion (p. 124).

Heeding Thorne’s warning, I endeavored to bolster accountability in my analytical decisions and
presentation of findings with use of Thorne’s (2008b) *Interpretive Description* as an analytic
guide. I also endeavored to be explicit about how I moved through the interrelated phases of
qualitative data analysis and came to understand meaning from the data collected. Tools
including a research journal and note keeping, and frequent exchanges with my dissertation
supervisor, were critical towards my broad commitments and overall goal of authentic,
auditable, and responsible knowledge production.

According to Thorne (2008b), the goal of data analysis in qualitative research is to make
pieces of data meaningful and coherent in relation a whole data set, with the purpose of
answering research question(s). This goal is achieved inductively, through a process of iterative
reasoning, involving continual engagement with pieces of data in relation to the whole, until the
meanings produced are beyond the obvious. Overall, Thorne’s articulation of the goal in
qualitative research is congruent with Geertz’s (1973) assertion that ethnographic research is
the intellectual effort toward the production of a “thick description” (p. 6). Thorne emphasizes
three interrelated phases in the process of qualitative data analysis: the initial phase, the use of generic codes, and the final understanding.

4.7.1. The initial phase of data analysis. In the first “initial phase” of analysis, the researcher begins to note their first impressions (Thorne, 2008b). That is, the researcher notes their preliminary reactions and early impressions. In my experience, some of these preliminary reactions were felt emotionally and formed first impressions that later became much more significant. For example, I encountered confusion and experienced personal uneasiness in my first attempts to communicate study information to others for the purpose of gaining access to study sites and recruiting. In this early fieldnote, I reflected on how others were understanding the words I was using:

Fieldnote (FN) (p. 24): * Early, thinking about I mean when I say "EOL" and is that what it means to others? Because I'm noting differences in how people understand what I'm saying.

[Questions] I’m wondering: 1. What do you think of when you hear the term "EOL"? 2. What does late-advanced illness mean to you? 3. When does that start? How do [patients]/families themselves know when [EOL] begins?

I flagged this example because I experienced the encounter emotionally with feelings of worry and anxiety. In contrast, other experiences evoked personal feelings of excitement, inspiration, gratitude, and intrigue. I used a rudimentary word tag (“my experience/feelings”) that purposefully lacked any particular meaning. Instead, this tag was simply used to collect pieces
of data that evoked personal emotion using an electronic flag called a node\(^{49}\). Nodes, used as flags, allowed me to collocate these encounters so that I could examine them in relation to each other. These flags also helped me simply organize groups of data, such as these emotional experiences, for quicker retrieval.

I also used flags during the transcription of the audio recordings of participant interviews and during digital conversation of fieldnotes (e.g. scanning and importing sketches into NVivo©). I reviewed audio recordings and transcripts of participant interviews in a multi-step process, which resulted in me investing considerable amounts of time spent with interview data. At first, I had intended to contract the audio transcription. However, I ended up transcribing the interviews myself because I found that the process of transcribing greatly enhanced my familiarity of the discussion content through prolonged periods spent both listening to the audio and reviewing the transcripts for accuracy. Each recording was slowed during transcription to match my typing

\(^{49}\) As I explained in an earlier section in this chapter, I used software called NVivo© (version 11.4.1, for iOS) as an organizational tool to manage the large amount of data I collected. The “node” function supported early “flagging” of content (e.g. entire notes, or partial sections of any imported document (including images, sketches, etc.), can be tagged with the “node” function). I named node and I used the software as a way to view whole documents and sections of documents with all other similarly flagged nodes. The way I used NVivo© aligns easily with Thorne’s (2008b) guide as she encouraged researchers to develop a “flagging” system (e.g. color markings or using particular symbols) to allow easy re-retrieval of content after the initial phase.
speed and then reviewed after transcription. On average, I spent approximately one-hour typing
and another hour checking accuracy for each 15 minutes of recorded audio. As interviews
varied in length, some transcriptions were completed within a week whereas others were more
complicated and took longer (more than one week). I used square brackets ([ ... ]) to add
observational data (e.g. facial expressions) or non-spoken content (e.g. sighs, laughs). In some
instances, I also used square brackets to clarify meanings.

Thorne (2008b) stated that flags may also be added for “particularly poignant” examples,
model cases, or content that “sticks out” (p. 148). While transcribing, I commonly used simple
word-tags to flag content that stood out. For example, I used a flag to highlight areas of audio
that seemed significant (perhaps from my own emotional reaction, or from what I heard or saw
as emotion from participants themselves). Importantly, Thorne (2008b) differentiated between
the action of “flagging” content, and “coding” content. Flagging provides a system for the
researcher to easily return to moments in the data. In contrast, coding involves using labels or
terms to try and make sense of the data. That is, how I named the nodes as I moved past the
initial phase of flagging data, was much more intentional and thoughtful and conveyed some
idea or meaning within the node’s name or phrase itself. According to Thorne, this next phase is
called “the use of generic codes.”

4.7.2. The use of generic codes. In Thorne’s (2008b) view, in the second analytic
phase, generic coding can be used to begin to form thoughts about themes, ideas, and
meanings (Thorne, Reimer-Kirkham, & O’Flynn-Magee, 2004). According to Thorne, coding
implies that the researcher has some sense about what the coded content means (and does not mean) and uses codes to distinguish (or note similarities) with other coded content. Thorne recognized the utility of coding as a strategy to manage inevitably large amounts of data. However, Thorne also cautioned that premature coding can be a serious threat to analysis and thus she explicitly instructed researchers to delay coding until ideas about the meanings of data become sturdy and concrete.

In my experience in this second phrase of analysis, I avoided premature transformation from “flags” (i.e. word-tags intended to aid organization rather than convey meaning) to “codes” (i.e. words assigned to reflect some thought about themes, ideas, or meanings) by engaging in reflective and recursive exercises where I considered pieces of data in relation to other pieces and in relation to my evolving understanding of the whole. For example, I frequently challenged myself to articulate my rationale for the coding labels I gave to the nodes. I undertook this challenge both verbally in discussion with my dissertation supervisor and in research journal entries. As my thoughts and ideas became clearer, I used coding labels to both organize study data and also to convey some meaning. For example, the word “heterogeneity” was initially a flagging label that helped me collate references to the heterogeneous characteristic of the HF patient population. Later, “heterogeneity-EOL” became a generic code that aided me to group study data that highlighted and explicated the particular complexities associated with heterogeneity and EOL planning and care—that is, the meaning of heterogeneity became more apparent in relation to the structured practices of EOL planning and care.
The act of recognizing my own emotional experiences, and the related work of exploring the circumstances surrounding my own emotions was useful and important in the overall analytical process. For example, following my experience of emotional worry after recognizing my words were not being understood, I invested in understanding my own use of words. I then began to more carefully listen to participants’ words, particularly when speaking with one another to convey clinical information about patients and their family members. This focus allowed me to catch a significant encounter that deeply shaped my analysis and became a major finding. Hearing and seeing the phrase “he’s palliative,” offered as an explanation to a colleague, was a memorable “Ah ha!” experience. I engaged participants in dialogic conversations, inviting their insights about what it means to be palliative and how they came to understand and use that phrase. I gathered this encounter, and many other similar examples of simple statements used to convey complex and highly nuanced information about patients and families, into a flag called “language.” Later, data grouped within this flagged content I initially called language, became a generic code called narratives which was substantially meaningful in relation to the whole data set, as I will present in Chapter Six.

4.7.3. The final understanding: Knowing the data. Thorne (2008b) argued that effective coding steers researchers towards gathering data that are similar and facilitates the researcher’s ability to contrast data with different characteristics. As my analytical work progressed, my code labels changed and evolved and provided substantial opportunity for me to contrast related data towards the overall goal of making meaning in the final phase of
analysis. Thorne called this final phase “knowing the data” and explained that the movement from *coding to understanding* involves continually shifting attention from individual data (and cases) to the whole data set.

The process of transforming my experiences and interpretations into major areas of findings followed after prolonged periods engaging in thought and as I sought to clearly write the findings in the chapters of this dissertation. For example, my interpretations about words and phrases followed from a process that included recursive consideration for how HCPs are actually using particular words in relation to what they actually meaning. This process fit with how Thorne’s (2008b) described the process of coming to understand meaning. Thorne described this process:

> A series of technical and/or intellectual operations that will allow you to know your data intimately, to consider similarities and differences with respect to a wide range of dimensions along the various cases you have included in your sample, and to follow a logical line of inquiry in relation to individual cases as they illuminate those aspects that might legitimately be considered patterns and themes within the data set overall (p. 150).

Strategies such as mind mapping and sketches were also useful during this final analytical stage. I followed Thorne’s (2008b) recommendation to refer back to theoretical assumptions about human social organization to facilitate analysis and interpretations. The process of referring back also involved engaging my dissertation supervisor and committee, which furthered additional analytical considerations including identification and description of a meta-
theme linking my first descriptions efforts together. Throughout the entire last phase of analysis, I transformed pieces of my data that I had grouped within evolving conceptual understandings using codes, into meaningful and coherent knowledge that encompasses the whole. The methods I used (e.g. journaling) created documentation records of my analytical decisions, which reflected my ongoing commitments to researching with quality.

4.8. Researching with Quality: Strategies I used to Ensure Integrity, Credibility, Logic, and Authority

Thorne (2008b) proposed four credibility criteria for qualitative research: epistemological integrity, representative credibility, analytic logic, and interpretive authority. According to Thorne, epistemological integrity describes the existence of a defensible line of reasoning that is applied through all stages of a research study. Thorne recommended building in a “reflexive accounting” strategy to demonstrate credibility throughout the entire research process (that is, from planning to completion). Credibility requires a researcher to examine all aspects of the research study for philosophical and theoretical congruence: “It is essential that qualitative researchers demonstrate an appreciation of the nature of their epistemological positions and create decisional strategies that respect those positions” (p. 224). As I detailed above, I recorded decisions about all aspects of this study (e.g. sample recruitment, analytical process) in a notebook.

Thorne’s (2008b) second criterion is representative credibility. Thorne explained that representative credibility refers to consistency between the theoretical claims, the manner in
which the research is carried out, and the construction and representation of findings. For instance, Thorne noted that prolonged periods of engagement with the phenomenon under study are likely to be afforded greater credibility than brief interactions. Thorne also stated that the use of multiple methods could bolster representative credibility. I used multiple data collection methods for this study to enhance my representative credibility. I also justified periods of engagement (e.g. fieldwork) and sample recruitment decisions by considering how other researchers answered similar research questions. Decisions I made to stop recruiting and field work were justified by carefully considering the specific characteristics of the study participants (e.g. rich clinical backgrounds) in relation to the breadth and range of data I collected towards answering the research questions.

*Analytic logic* is the third quality criterion that Thorne (2008b) emphasized. As Thorne has explained, analytic logic suggests that an outside observer could access the information through which the decision-making processes were carried out. For instance, Thorne described an “audit trail” as an “explicit reasoning pathway along which another researcher could presumably follow” (Thorne, 2008b, p. 225). I maximized auditability by transcribing audio to text and maintaining notes. Data collection and analytical commitments were also reviewed by a qualified supervisory committee as part of the doctoral dissertation process.

The fourth criterion that Thorne (2008b) described is *interpretive authority*. Interpretive authority is the trustworthiness of the interpretations produced through the research process. Interpretive authority is maintained through deliberate strategies to account for researcher
reactivity. For instance, Thorne noted the use of reflexive accounting. My use of reflexive journaling supported my efforts towards maintaining interpretive authority through this project.

Thorne (2008b) further noted that health care researchers ought to maintain additional criteria of moral defensibility (that is, the information we are gathering and taking is necessary and has purpose), disciplinary relevance\(^{50}\), pragmatic obligation (that is, sorting through the propensity for health researchers to investigate particular phenomenon, while attending to a moral, and disciplinary mandate that requires more generalizable, and usable knowledge), contextual awareness (and consideration for the meanings of research findings), and probable truth (p. 102). Nurses-as-researchers face particular disciplinary obligations. I had to consider issues such as navigating clinical research contexts as both a clinician and researcher, utilizing and accounting for previously known clinical knowledge in this research project; and foregrounding practical applications from the knowledge generated (producing knowledge aimed at improving health care rather than simply generating knowledge for the sake of knowing).

\(^{50}\) de Laine (2000) explained the postmodern influence on researchers and the movement towards engaging in relevant and meaningful research: “knowledge for its own sake was no longer acceptable among some segments of the academic audience, who argue for a critical perspective on social life” (p. 9).
4.9. Chapter Summary

In this fourth chapter, I explained the methodological approach I used to answer the research questions for this study. I opened with a short history of qualitative research and a general overview of ethnography. I then proceeded to align my research study within a particular methodological style called critical ethnography. I explored the implications of working within a critical paradigm and explained how I made decisions about the study sites and sample.

I then explained how I collected study data using four data collection methods: observations and fieldwork, semi-structured interviews, reflexive journaling, and document and text-based analysis. From here, I shifted focus to discuss my analytical process where I explicated my use of Thorne’s (2008b) Interpretive Description as a complementary approach to the critical ethnographic design. I closed Chapter Four with a discussion about issues of quality in qualitative research and explained the strategies I used to bolster integrity, auditability, and credibility of my findings.

In the next Chapter, I will explain what I actually found. As I outlined in Chapter One, in this study my findings related to three major areas: What HCPs saw and knew, What HCPs heard and understood, and How HCPs felt and acted. In the forthcoming Chapters Five, Six, and Seven, each of these major areas of findings are presented.
Chapter 5

What Health Care Professionals Saw and Knew: Acute Care Practice Knowledge, Disciplinary Scope, and Positioning EOL Planning and Care as the Work of Experts.

In Chapter Four I described how I came to understand and interpret meaning from study data through an analytical process—that is, how I learned about the explicit and implicit features within the contexts in acute care and related structural implications. I described the way I learned about structured clinical practices in these acute care settings using a qualitative research approach and dialogic data collection methods including observation with fieldnotes and semi-structured interviews. In this fifth chapter, and in Chapters Six and Seven which follow, I explain what I actually found; that is, I present findings from this study. Collectively, my study findings indicate that the context of acute care hospital settings where patients with HF access EOL planning and care, and the related structural implications of these contexts, are largely implicit and unquestioned (i.e. “taken for granted”). Indeed, I will show the structured clinical practices in acute care contexts, which may be purportedly understood by HCPs as explicit and known but are more complex than HCPs commonly appreciate. Altogether, I identified three major areas of my findings regarding HF and EOL planning and care, which I explore over the next three chapters. These thematic areas were: What HCPs saw and knew (Chapter Five), What HCPs said and heard (Chapter Six), and How HCPs felt and acted (Chapter Seven).
5.1. Overview of Chapter Five

In the analysis presented in this fifth chapter, I examine a major area of findings about *What HCPs said and heard*. This major area of my findings relates to two topics of discovery: 1) what I learned about issues of awareness of HF in acute settings; and, 2) what I learned about practice knowledge, skills, competencies and professional expectations. Thus, to begin I present study data that reveals the context of acute setting. I draw from this data to show how particular aspects of the acute care context and resources made it difficult for HCPs working in these acute care hospital contexts to both see and be aware of HF. These features within the context of acute care also made it difficult to foreground HF in relation to the wide range of other acute illnesses that were seen in acute care. I explore these issues under an umbrella of thinking about *awareness* and explain such as layers of invisibility of HF in acute care.

The second area of discovery within this chapter is about practice knowledge, skills, competencies and professional expectations. I share my learnings about how HCPs think about *knowledge, competencies, and skills* needed to do HF-EOL planning and care. I present data highlighting a common experience that I had—participants commonly self-assessed deficits in their own knowledge, competencies, and skills related to HF-EOL planning and care. I explain how these self-assessed deficits were not necessarily regarded as problematic by participants. Instead, requirements for HCPs’ knowledge, skills, and competencies in acute care were prioritized by what was thought to actually be needed for practice in acute care hospital settings. This prioritization represented a hierarchy of knowledge for acute care contexts, which reflected
a schema that I refer to as “need-to-know.” I discuss how this schema structured HF-EOL planning and care practices by positioning HF-EOL work as the work of clinical experts. These experts were seen as having particular knowledge and skill sets and permissions and/or authorities to do HF-EOL planning and care work.

5.2. Awareness of HF and EOL Planning and Care in Acute Care Contexts: Challenges and Complexities Seeing EOL Issues as Relevant in HF, and Seeing HF at all

In this first discussion, I focus on issues of HF awareness and I describe the context and resources of acute care with the goal of explicating how it can be hard to see HF in these practice areas. At times, access to general clinical practice tools was difficult and I heard and learned about limited resources which included, for example, equipment such as scales to weigh patients, and resources such as patient education materials including HF teaching tools. During an observation experience, I joined a nursing report and handover. One nurse asked

51 “Nursing report” and “nursing handover” are terms used to describe the event where nurses exchange patient information with one another. Report and handover occur many times throughout a day as they take place whenever a nurse enters or leaves their patient care assignment (e.g. coffee breaks, shift end, leaving the unit, etc.).
the other nurse to complete a daily weight for a patient with HF. Ultimately, the weight did not get completed because the sit-scale was missing and could not be located prior to the patient eating breakfast:

FN (p. 134-137) [observation with BM018]: 4 [patients]...1 [patient] with HF admission - had daily weights ordered and IV Lasix.

The [patient] was actively diuresing but unable to get [weight] even though RN knew order and physician had [prescribed] it. Bed scale broken (wouldn't turn on). And the hallway scale large [and] requires [patient to be able to] balanc[e].

The missing/broken equipment made it difficult to actually carry out the necessary and indicated care; and in fact, the weight was not completed in this encounter.

In my observations and findings, issues of inadequate access to key resources such as equipment were emphasized most strongly from participants recalling practice experiences on acute medical units. However, and as I will explicate below, across all of the practice settings where I was immersed (i.e. both general and specialty settings), staffing resource issues were

52 A daily weight is recommended for most patients with HF because it is an early indicator of fluid retention and a possible indicator of an exacerbation event (BC Heart Failure Network, 2019). A daily weight is generally regarded as one of the easiest ways to detect HF decompensation early. It is most accurate when measured with an emptied urinary bladder and before consuming food or beverages.

53 A “sit-scale” is a type of scale that a patient can sit down in while being weighed. This equipment is ideal for patients who cannot tolerate standing still on the small platform that traditional scales use (e.g. patients who are dizzy or who may not be able to balance on the weighing platform).
raised. At times, nurse-patient ratios and other staffing resources were seen to be manageable; and at other times, participants described feeling rushed for time, overwhelmed, and unable to complete everything they wanted to. Such variability related to the dynamic nature of acuity and workload and were usually expressed in terms of time—that is, not having enough time.

5.2.1. Acuity, workload, staff mix, and diverse patient populations: Resource-related complexities of seeing HF in acute practice settings. Participants commonly used descriptions such as “acuity”, “workload”, and “diverse patient populations” to characterize the acute inpatient settings where this study was carried out. Workload, for example, was a descriptor used to talk about the volume of tasks and duties. As I understood from participants, workloads were said to be excessive or overwhelming when tasks or duties were left unfinished. Participants commonly used the idea of time—that is, not enough time to complete the tasks or duties—to explain workload and discuss its implications. In the excerpt below, a participant who practiced as a cardiac specialty nurse in a clinical support role was describing how limited time and perceived volume of assigned tasks (“they’ve got us all doing so much”), was a barrier to HF-EOL planning and care conversations, particularly for nurses:

54 Workload refers to the amount of care and support patients require.
AC001: They’ve got us all doing so much all the time that everything is, needs to be... given [away] to [another] service.

Social work needs to be responsible for [engaging patients and their family members in conversations about EOL] because left to the general acute care population [and staff], things are so chaotic, things are being missed.

And nurses are not having time to have these conversations. Nor are they even getting to have any sort of therapeutic relationship with [patients and their family members] to be able to, be comfortable to initiate that conversation.

JG: So, time is also the barrier for the nurses?

AC001: Oh huge

Another participant who practiced as nurse in cardiac specialty settings, similarly described how time was a barrier for physicians, who were predominantly regarded as being responsible for HF-EOL-related conversations:

BC003: And, just by the nature of the physician’s time, they don’t have necessarily the time to have those conversations. Should they? Possibly, yes.

But, you know, I’m not so foolish to think they are going to have a **half-hour long** [emphasis in the original] conversation about, you know, what the end of life wishes are for every single patient.

In both excerpts above, participants were talking about direct care clinicians (nurses and physicians). However, I also heard about how high workloads and issues of limited time affected clinical leaders and mentors. For instance, the participant AC020 explained the impact of having only a part-time advanced practice nurse, who held responsibilities across multiple practice sites and areas:

AC020: [There is only one cardiac advanced practice nurse and they are part-time] and that’s for the whole region and all the cardiac work.

So, it’s kind of like, when are you going to [implement a standardized guideline and admission process for all patients with HF]?
I hate to say that but I mean it's prioritizing. And it's, you know... So that's kind of what's happening with HF in general.

In scenarios where time was rushed or there were feelings of being overwhelmed, participants talked about having to prioritize particular tasks; for example, assessments and vital signs55 (VS) and medication administration were emphasized. Resource needs and capacity to respond to patients’ clinical needs were described in relation to time; time to review the diagnosis; time to respond to the range of needs; and time needed for the HCP to learn about and remember the patient’s unique clinical picture. Tasks seen as non-essential were delegated, rescheduled, or deferred. For example, in two of the excerpts above, participants were describing how HF-EOL planning and care conversations become overlooked entirely in response to the prioritization of other clinical tasks and duties—that is, HF-EOL planning and care was frequently deferred in place of higher priority duties (e.g. vital signs and medications).

5.2.1.1. Challenges responding to the needs of diverse patient populations in general medical units. While participants described fluctuating workloads, acuity, and limits to time similarly in all the settings where I conducted my research observations, there were dissimilar resource features as well. In particular, an important and distinguishing resource issue

55 “Vital signs” is a term that refers to metrics such as blood pressure, heart rate, respiratory rate, blood oxygen saturation (and others).
between general and specialty practice settings, was the diverse and complex patient population that is cared for in general acute medical units, as contrasted with the more specialized population seen in cardiac specialty settings. Participants who spoke about practice experiences from acute medical units commonly stressed this point about diverse patient populations, whereas participants from specialty settings (e.g. acute cardiology) did not.

Generally, causes of admission to cardiac specialty settings were cardiac-in-origin. For example, cardiac specialty units predominantly see patients admitted for primary cardiac reasons such as chest pain with CAD or arrhythmias. In contrast, in acute medical units, patients were admitted with all-cause conditions, which varied widely from cardiovascular to endocrine to respiratory and so on. Indeed, a participant who had critical care and clinical leadership experience in general medicine, articulated the presence and challenges associated with navigating “diversity” in the medical unit patient population. This participant also emphasized the high workload demands (i.e. the “hard” work) in general acute practice:

BM007: ...I think medicine is very underrated, I think. They, [HCPs] say, “get two years of experience before you go to critical care.” And it’s like, no you need to have three or four years of medical experience! [laughing]

I would be safe to say that it’s probably one of the hardest places to work because of the complexity and because of the diversity. When I came up here from ER, I was greatly humbled.

I had to come off my little pedestal, and I was just like holy cow, I had no idea how hard they worked on a medical floor.

The diversity of patient populations on acute medical units from other participants who described how diversity was also related to the variety of patients and families with illnesses that
originated from a wide range of pathologies and from all body systems, including HF. Patients admitted to acute medical units also presented with both episodic and chronic recurrent all-organ illness events and could be at various points along any illness progression, from newly diagnosed to the final disease stages. I saw this diversity during my observation experiences; comorbidities and frailty commonly complicated presenting illnesses and patients had a multitude of care needs (e.g. from wounds to chest tubes to antibiotics to mobility rehabilitation and so on). For example, one of the nurses I was observing was caring for someone admitted with newly diagnosed HF who also had concurrent end-stage renal disease and diabetes. In another instance, a nurse was working with a patient who had long-standing HF, admitted with urinary infection and sepsis, which was further complicated by homelessness and recent intravenous drug use.

In practice, HF can also be overlooked. As a participant who practiced in a specialty HF-outreach role recounted in the interview fieldnote below, nurses and other HCPs in medical units can overlook HF because exacerbations manifest with generalized symptoms that may relate to other non-HF admitting diagnoses. For example, arrhythmias, dyspnea, and hypotension were common admitting diagnoses with multifactorial causes, which included HF. I documented a conversation that I had with a participant where I learned about complexities related to all-cause admissions:

FN (p. 18): ...started off discussing the referral process [to a HF-specific service].
[The referral process] is difficult because it relies on RNs and HCPs being aware of patient’s diagnosis (i.e. [the HF outreach service] follows any patient with a HF diagnosis in their history – all cause admission).

HCP turnover, especially on medical units; knowing how/when to refer [patients] is difficult

In the scenario described above, the participant was describing the challenges of HCPs being aware of a concurrent HF diagnosis; the participant was also describing the way HF can become masked by other illnesses which manifest similarly. After the observation hours I shared alongside participants, I came to appreciate the tremendous knowledge demands across all acute care units, but especially in acute medicine units where patient populations and reasons for admission were so diverse. This particular challenge was also described as difficult in relation to the general experience of HCPS who were working in the general medical units.

5.2.1.2. Staff experience in general medical units: Impacts of collective clinical experience in the context of many newly graduated nurses. In the acute medicine units particularly, participants also emphasized staff experience, which referred to the proportionately higher quantity of newly graduated nurses as well as high staff nurse turnover56. I also heard about challenges with staff experience from participants describing practice in specialty settings such as cardiac units but more so in general medical units. In the fieldnote above (FN (p. 18)),

56 “Turnover” is a phrase used to describe both staff attrition and the resulting hiring.
for instance, the participant related challenges of both recognizing HF, and knowing how and when to refer patients to HF-related services, to high staff turnover. The high staff turnover also referred to both nurses and physicians as the residents moved through different practice areas every few weeks. Other participants similarly described acute medical settings as having proportionately higher numbers of HCPs who were early in their careers (e.g. new graduates) and described the impacts of high attrition related to frequent staff turnover. In the excerpt below the participant described the complex challenge of supporting newly graduated nurses working in casual positions on medical units, where attrition was commonly perceived to be a challenge in their units:

BM007: think, just coming to work and working hard is how [newly graduated HCPs] learn best, right? I think we need to have a better health authority program. So, I think, most health authorities have a new grad program.

However, [newly graduated RNs are only offered] casual [episodic work]. And so every day is their Monday. And that to me is just poor. Like, they need to come [more consistently]. They need to really consolidate [their practice].

They need to take care of four patients for four days in a row. So that they know what they’re like and that they can actually see, “okay today Mrs. Smith looks awful but on my night shift she looks fantastic.”

Because of, you know, all of that stuff. Continuity, not just for patients, but also for familiarity. That’s hard, yea. And for patients is important.

JG: Do you get a sense that all new people are casual?

57 A “casual” position means there is no set schedule.
BM007: Right now, yea [laughing]

JG: And casual would be sporadic shifts? I imagine that would be a large barrier trying to get people up to speed quickly.

BM007: Large barrier...yep, yep. And I think in medicine [units], you’ll find that our...attrition? Is that the word for people who stay? People leave a lot.

JG: Yes.

BM007: We have a high turnover. I think that’s due to the heavy nature of the unit. Uh, we have some people come and do their orientation and then leave [laughing].

This is hard. Like you, you can’t come to work and just sit. It’s not like that anymore. Like night shifts, we used to be able to sit down and [document care in the patient chart] on nights. You don’t get that time anymore like, it’s always busy.

As I learned from the account above and my research fieldwork overall, the significance of being a newly graduated nurse, especially on a general medical unit, was multifaceted. New graduates faced the challenge of needing to acquire considerable theory and practice knowledge. Having high proportions of new graduate nurses also shaped the overall staff experience (i.e. collective clinical and practice experience was affected). Coupled with attrition, the collective experience, practice expertise, and clinical wisdom in settings with a high proportion of newly graduated nurses was described to me as challenging. Yet the complexity in these settings was significant.

Overall, what I learned about both collective staff experience and the diverse patient populations indicated that nurses and other HCPs needed to rapidly acquire knowledge and information in order to know how to provide patient care for any one individual patient, including patients with HF. Indeed, as I illuminated in Chapter Two where I discussed heterogeneity in HF, there is a large amount of theory, technical knowledge, and skill associated with HF patient
care and the focus of the interventions can shift throughout the illness trajectory. The task of acquiring all this theoretical and technical information was not straightforward. In fact, acquiring even general knowledge about patients was a complicated endeavor in all acute care settings where I observed and interviewed research participants. Such complications were related to resource issues such as the physical layout of the unit and competing multidisciplinary needs for patient information.

5.2.1.3. Participants’ experiences accessing patient information: Physical layout of acute environments, organization of work duties, and multidisciplinary demands for patient charts. In many instances, gaining access to patients’ information was difficult and complicated. Methods used to exchange patient information during report and handover and retain it were also unwieldy. Such difficulties related to several concomitant circumstances including the organization of the unit and the timing of nurses’ patient care duties, the physical layout of acute environments, and multidisciplinary demands for paper-based patient charts and computer access.

At the time that my research data were collected, patient health histories were compiled within paper-based charts. Some information was available on electronic records but not all HCPs accessed electronic records in their usual workflows. Though some documents were easier to access within nurses’ usual work areas (e.g. medication administration documentations at medication carts, assessment records, nurses’ notes, risk screening tool documents), comprehensive medical and social histories were stored in the main charts, which
were located in chart racks in the central desk spaces. The central desk spaces were away from where nurses spent the bulk of their time (see Figure 5-1).

Figure 5-1: Fieldnote (recreated), illustration of Site A unit and Site B unit

Unit layouts recreated from FNs. Site A (left, FN (p. 8)) shows a portion of a cardiac medicine specialty unit, which had designated critical care beds as well. Site B (right, FN (p. 88)) shows a portion of a general medical unit. Both re-created sketches are included here to illustrate the nurses’ work areas and their positioning to patient care spaces (i.e. patient rooms). Both areas had chart racks in the “main desk area” where patient’s full health histories were stored.
During day shifts, I observed nurses rarely working in main desk areas. Instead, nurses carried out a vast majority of their work near medication carts or near the charting areas, which were in proximity to the rooms of their patient assignments. Nurses’ personal items such as water bottles, note pads, and stethoscopes were also kept in these spaces, which was also where I kept my items when I was buddied with nurses. As documented in my fieldnote journal, on one particularly busy observation experience on a medical unit at Site B, I described the scene as “chaotic” and emphasized how much time it took to simply find the chart. The chart was an important resource because it contained significant information about the patient’s history:

FN (p. 135). Unit had no [unit clerk\(^{58}\)] - no show. Felt like chaos. Phones ringing, charts everywhere. The charge nurse actually ended up pulling an RN later to be [unit clerk] UC because it was [disorienting].

The unit's nursing [station] for gathering and also has all the computers and meds is closed off for constructions. [This construction] takes up [a great deal of] space and totally closed off for dust control so now only 1 entry into station and it resembled a bar.

At one point I looked down and there was approximately 20 people [crammed] into small space. [Medical] students everywhere, it looked chaotic.

* Minimal computers (hard to check [blood work] for [patients], moving a lot i.e. nurses who can't sit in [station] to peruse

* Minimal sitting space!

\(^{58}\) A “unit clerk” is a person who provides reception services in an acute care unit. For example, a unit clerk provides essential services including answering the telephone, receiving packages and mail, and directing location and wayfinding inquiries.
* Nursing doc[uments] separate form main chart (practical application—if [medical doctor] MD orders UC can process to pharmacy quickly)—consequences of that, minimal MD looking at nursing docs

* Med carts are small work area for nurses

* Charts and [nursing documentation] binders (i.e. nurs[ing] docs) always hard to find—huge time lost in hunting for this stuff

On evenings and night shifts, I spent more time with nurses at the central desk area, though nurses still spent the bulk of their time away from these centralized spaces as they engaged directly with patients. In effect, the central paper-based patient chart, which was the best source of a complete health history, was kept separately from nurses’ main work areas. As there was also only one chart per patient it was in high demand and often used by other colleagues. Of note, both study sites were also teaching hospitals, which meant there were large numbers of students seeking the chart. On day shifts in particular, many interdisciplinary consultants and their students (all disciplines) sought access to the chart; at times, it was hard to find.

As the paper-based patient charts were used by many interdisciplinary professionals, it became difficult to locate and read. I experienced feelings of frustration as I observed my buddy-nurse-study participants search for misplaced documents and charts. Through my commitment to reflexivity and paying attention to the feelings I experienced with data collection, in the fieldnote below I recorded an observation about the nurses’ patient report and handover and noted the amount of time it took to find an important patient information document:

FN (p. 134) [observation with BM018]: Report in teams; 3 [nurses][per]team.

Each [nurse] reviews from kardex-type doc. Short verbal report in break room from night shift [nurse] - talks about pain control, etc. Quick.
Missing [medication administration record (MAR)] binder - took approx 10 minutes to locate. Report finished at 0735h

As I also documented in this fieldnote, the time between nurses’ report and starting patient care was limited which meant the window of time before nurses had to engage in direct patient care made it difficult to both hear and retain large volumes of patient information. Nurses had few minutes from the time they arrived to start work, until the time they engaged patients in direct care (e.g. safety checks, morning assessments, medication administration, preparation and organization for diagnostic tests, etc.). Time available to hear and assimilate patients’ information was further complicated by issues such as misplaced paper-based patient charts. This did not mean the charts were actually missing; in most instances, misplaced charts were in use by someone else who was working in another area.

To manage the issues of limited time between the start of nurses’ shifts and patient care needs, and the issues of high-demand and in-use patient charts, information during handover was *focused* and the cause of the acute admission was forefront; for example, “patient admitted with cellulitis.” Likewise, tasks where specific actions were scheduled (e.g. diabetes and blood sugar checks were commonly emphasized) or where particular problems needed intervention (e.g. pain and timing of next analgesic), were also foregrounded. I made several observations related to the way that the admitting Emergency Department (ED) diagnosis and particular tasks were emphasized and foregrounded. In the excerpt below, I documented a participant’s emphasis on the ED admission (e.g. “failure to thrive”) on nurses’ handover sheets:

FN (p. 118-121) [observation with BM013]: Handover, unit-wide report sheet.
Contains initial [emergency room diagnosis] only (e.g. 'failure to thrive', [or] 'heart failure', [or] 'chronic obstructive pulmonary disease').

[The night shift team] put the [vital signs], [fluid volume status], [intravenous access lines] etc on the report sheet then photocopied and shared.

Targeted [neurovital sign] assessment [related to] [large] [cerebral vascular accident].

Emphasis: Older pts integrated [comprehensive and multi-system] care plans into routine nursing documentation. “Compliance” [comprehensive and multi-system care plan] mentioned in [morning] team rounds...

My note above about the “comprehensive and multi-system” care plan referred to a nursing documentation tool where information about patients’ others diagnoses (e.g. chronic illnesses) and related care needs were intended to be organized. The unit leadership had attended the team rounds that morning with the goal of emphasizing nurses’ roles in completing this more comprehensive documentation tool. The unit was experiencing difficulties getting the documentation tool integrated into practice and “compliance” was an issue. As a result, there was little shift in how the single ED-related diagnosis was emphasized.

In another observation experience I asked my observation buddy, “what types of patients do you have today?” Again, the participant focused on the ED diagnosis:

FN (p. 100): BM015 pulls out a paper with [Emergency Department] descriptions (e.g. [acute coronary syndrome (ACS)]). The info from [night shift] handover are directions—
[activity as tolerated (AAT\textsuperscript{59})] and the immediate risks and tasks (e.g. [vital signs every four hours]).

There was an ACS patient with a history of HF. [I] asked about thinking of ACS admission [in relation to] a HF [history]—not a clear connection between these.

BM015 told me, patients with HF “already know about their HF.” Assumptions about knowledge.

Asking the same question “what patients do you have today?” in another observation experience, I similarly noted the use of “cheat sheet”, which was a piece of paper used as a way of focusing and shortening a patient’s medical history. The emphasis was on tasks from the ED admission:

FN (p. 90) [observation with BM012]: I asked what illness/[diagnoses the patients] had. [BM012] didn’t know was using a ”cheat sheet”, but info limited. Focused on the skill aspect e.g. [the patient in] bed 1 has a [subcutaneous] butterfly, [the patient in] bed 2 has a [diagnostic computed tomography (CT) scan coming up].

I asked what CT for, [participant replied]: "pleural effusion."

[I then] asked what pleural effusion [was related to] but [BM012] wasn’t sure.

[Later, BM012] told me [about plan to enter a critical care training program]. Has been working for a year and also said "didn't want to forget what it's like to work in medicine."

When [I asked BM012] to explain, [response]: “busy [workload] and acuity. [Patients] come and go for a lot of tests.”

\textsuperscript{59} “AAT” is a commonly-used acronym in acute care nursing practices. “AAT” means patients have no limits on their mobility. This information is emphasized in nursing handover because it is often one of the earliest clinical decisions and judgment a nurse needs to make, particularly at the beginning of a day-shift because patients commonly request to mobilize to use the toilet, sit up for breakfast, perform personal hygiene, etc. Not all patients are permitted to freely mobilize; a patient’s mobility may be restricted for clinical reasons.
In the three fieldnote observations above (FN (p. 118-121), FN (p. 100), FN (p. 90)), the initial ED diagnoses were foregrounded, as were nursing tasks related to that particular ED diagnoses. Tasks that were immediate—for example, mobility instructions, vital signs and assessment needs, upcoming diagnostic tests—were especially emphasized. To accommodate this focused approach to patients’ clinical information, parallel (i.e. related, but different and separate from the main chart) information tools were created by the nurses in order to exchange this truncated information. For example, instead of the main chart, nurses relied on methods such as “Kardex-type system”, which was a type of flip-board with a small card for each patient; handwritten notes; and personal “cheat sheets.”

Excerpts from my fieldnotes above also illuminates a tacit and taken-for-granted way of thinking (i.e. a schema) about the way HCPs prioritized patients’ needs during an acute care hospital admission. Specifically, there was an emphasis on the main and presenting diagnosis from the ED and an emphasis on the clinical tasks related to that specific diagnosis. Both emphases reflected schemas that the role of HCPs working in these areas is to focus on and treat the presenting problem. Of note, while many patients with HF may present to hospital with exacerbated HF as the primary issue (and thus, HF would be foregrounded in the ED admission diagnosis), many do not. Instead, HCPs caring for patients presenting with a non-HF issue such as pneumonia, who also have HF as a concurrent comorbidity, likely needed to review the medical history for HF to become seen. Complete medical histories including patients’
comorbidities (e.g. HF) were available on the chart; however, charts were hard to find and were a difficult resource to actually use—especially for nurses.

5.2.1.4. Resources in acute care units in hospitals that point to structured practices. As was apparent from the data I presented in the sections above, resources in acute care contexts were important in understanding HF-EOL planning and care in hospitals (e.g. general medical units, cardiac units, etc.). Health care professionals working in these settings faced resource-related challenges including fluctuating acuity and workload in relation to complex staffing realities (e.g. turnover, collective clinical inexperience), information constraints (e.g. misplaced or in-use patient charts, truncated information), and equipment shortages (e.g. unable to complete a patient’s weight due to a missing scale). The clinically complex patient populations who presented to hospitals with acute illnesses, were cared for in the context of these resource-related challenges. Thus, the practices (e.g. not carrying out a daily weight) were structured with schemas (e.g. not knowing about HF or the need for a daily weight because it was not communicated during handover) and/or resources (e.g. not having a scale or ready access to patient charts).

Other features within these contexts (e.g. clinicians’ workload, meaning, limits to their time), collective clinical experience, mechanisms to access patient information, and the layout, of the clinical unit) made HF hard to see—that is, resource-related challenges in these practice contexts contributed to layers of HF invisibility and challenged HCPs’ awareness of HF. In the next section, I will examine data and findings that captured more schema-related aspects of
these contexts and in particular in relation to what knowledge HCPs need to know to work in acute care settings, which I explore by first explaining HCPs’ common assumptions about what it means to have HF.

5.2.2. Clinicians’ understandings of HF illness concepts and recognizing HF as a life-limiting illness: Issues of awareness and invisibility around HF-EOL planning and care. Participants told me about how HF knowledge concepts were under-known and widely misunderstood across acute care settings, particularly inpatient units. As I emphasized in Chapter Two, for patients with HF in particular, HCPs’ clinical thinking and decisions ought to reflect recommended evidence-informed therapeutic HF interventions such as administration of medications, targeted physical assessments to detect decompensated HF, and patient/family education. Thus, when HF was overlooked or unrecognized, where recommended therapeutic interventions were under-known, or when needed equipment was unavailable, the clinical decisions and practices that followed contravened recommended practices or were missed entirely. For example, the missed daily weight I observed FN (p. 134-137) above was an important therapeutic activity and a recommended practice that was affected by structured clinical practices.

As I learned from my experiences studying with participants who practiced predominantly in cardiac specialty acute care practice areas, HCPs’ existing knowledge and beliefs about HF were said to be shaped by what one participant called a “curative model of health care.” This “curative model” was effectively described in an excerpt from this participant,
who was a cardiac nurse with a leadership role. They explained how a strong cure-focused lens influenced HCPs' impressions of HF as a curable illness and also obscured seeing HF as a life-limiting illness:

AC006: I think there is definitely a bit of a knowledge gap. I find, I hear, even though we know that the trajectory of a patient, is palliative, um, symptom management...I think that we are poor at that, right now.

I think that our understanding is increasing. I think our physicians, are very much in the curative model of health care and that plays into our own, kind of, beliefs about how we care for patients. And we believe that we can make them feel better. Just change their medication.

So, actually discussing the kind of the end-of-life concerns, and what the patient might experience, and explaining that and talking to them with them. I don't think that we are good at that. And I don't think that there's been a lot of exposure to that thought process here at this site.

So, it is a newer...

JG: Newer. So, you’re saying, exposure to the thought process that HF is terminal?

AC006: Yes.

This cure-focused lens has been important because in acute care broadly, the conceptualization of HF as a life-limiting illness has not been axiomatic.

While the “curative model” was said to influence HCPs' understandings of HF (i.e. meaning, HF is an illness that can be treated: “just change their medication”), alternative
viewpoints, including the *palliative approach* were also described as increasingly influential\(^{60}\).

Noting this participant’s use of “newer” with respect to HCPs making linkages between the relevance of HF and EOL planning and care, I asked for further explanation of what I interpreted as evolving (i.e. changing) conceptualizations about the nature of HF:

JG: What do you think is changing there? Because it sounds like there is something changing...?

AC006: Yeah. I think what happened, first of all for myself is, I saw [an advanced practice nurse] do a presentation back last [month]. And it was about the palliative approach.

And one of the examples that [the speaker] used in [the] presentation was, [the speaker] compared a patient with HF to a patient with cancer.

And the graph for like the cancer patient was very much, patient is declining and declining. It’s a straight line. Whereas with HF patients, they decline and then they do better and then they have another episode and they decline again. And you never know at what point, you know, they might not improve.

And so that kind of opened my eyes up to that.... there were a lot of comments from staff, that they really didn’t ever think of HF patients in those terms. That really, it’s just symptom management, and we’re managing the patient’s symptoms. And we’re not actually curative.

\(^{60}\) In the next chapter I link this point to what I describe recognizing as a “shifting narrative.” An example of a shift related to increased emphasis on integration of the palliative approach. Learning about the palliative approach and understanding how it fit into a clinician’s practice was described by participants as an important and relevant theoretical viewpoint with increasing influence on overall understandings of HF and related care implications for patients and their families. I also pick up on this point in my closing chapters.
As can be seen from the interview data above the participant, who was an experienced cardiac nurse working in a leadership role, attributed a recent shift in their own conceptualization of HF from being treatable to life-limiting, in part, to having heard another clinical practice leader at an education event compare the illness-trajectories of HF with cancer. Attending this formal education session was said to have had a big impact, as was the presentation of HF as analogous with cancer. Assumptions about the word “cancer”, and its tacit meanings relating to serious illness and/or dying and death, came up frequently in my fieldwork.

5.2.2.1. It’s not cancer: The substantial impact of hearing “cancer” as compared to hearing “heart failure.” Heart failure has been compared to malignancy with key differences: dying from HF is often experienced as sudden and unexpected; and, HF is frequently regarded by the public and by many HCPs as being more benign than cancer despite comparable mortality (Mamas et al, 2017; Flynn, Connolly, & Booth, 2008). From the findings in my research study, I also learned that the word “cancer” was emotive, while “heart failure” was much less so (which I discuss further in Chapters Six and Seven). At a societal level, uses of the word cancer were commonly described to be poignant and associated with illness, disability, dying, and death—that is, the word cancer was underpinned by widely held schemas about presumed morbidity and mortality. The term “heart failure”, however, differed. As participants told me, HF did not necessarily evoke comparable responses to “cancer”. Instead, the descriptions about HF that I observed in my fieldwork reflected schemas about harmlessness and manageability. These differences were clinically important because emotive words such as “cancer”, which
carried implicit presumptions about morbidity and mortality for both HCPs and patients/families, brought attention to EOL planning and care considerations. In contrast, uses of the word “heart failure” did not bring about equivalent responses. That is, HCPs, patients, and family members thought about “cancer” and considered EOL planning and care issues. In contrast, “heart failure” was not inherently seen as related to EOL planning and care.

For some HCPs, the meaning of HF shifted when “heart failure” was related to cancer in their education and/or clinical work. In the interview excerpt I cited above, participant AC006 described a recent and transformative experience where a new way of understanding HF was adopted after hearing an advanced practice nurse compare HF and cancer during a discussion about illness trajectory, prognostic outcomes, and a palliative approach to care. Other study participants recalled their encounters with dominant social perceptions of cancer, noting the implicit meanings and how patients and families associated cancer with terminality. For example, disclosing a diagnosis of HF was described as landing with a vastly different impact compared to “cancer”:

JG: What types of preparations would we expect from health care providers helping patients and families understand the terminal, downward trajectory of their illness?

AC002: Yea, education around the, yea the trajectory I guess. Like symptoms. That your heart is, you know, a lot of the times it’s just explaining what heart failure is.

Because, it’s, like it’s...it’s not like, even similar like cancer. When people hear the word cancer, it’s like, “I’m going to die.”

Like heart failure to me is more like, it’s just, I know it’s not, but it sounds like a gray area. It sounds like “oh heart failure, okay.” Like, you can just...

JG: Work with it?
AC002: Work with it! You know what I mean?

I think a lot, it doesn’t have the same reputation as like a death sentence of like a cancer or something.

Maybe because it takes, at times, a little longer? And people can, I mean, live with heart failure for a while, say, managing their symptoms and stuff.

This participant explained their perception that patients and their family members experience a distinct difference between receiving a diagnosis of cancer compared to HF. Heart failure was described as less dire, less serious, and less fatal (“when people hear the word cancer, it’s like ‘I’m going to die’. Like HF to me is more like...it sounds like a gray area. It sounds like ‘oh HF, okay.’”). The use of the term “heart failure” was also framed as having much less inherent impact—that is, it did not mean the same thing as the word cancer. As HF did not hold the same inherent assumptions about mortality, HCPs had to explicate what it meant to have a HF diagnosis and engage patients and their families differently than what was needed with cancer.

In other words, “heart failure” did not figuratively speak for itself as a serious life-limiting illness. Instead, HF had a live-with (i.e. manageable) “reputation.” The participant (AC002) speaking in the excerpt above shared further insights about their experiences helping patients understand HF. Heart failure was said to be known as a chronic and manageable illness, that “you can just live with”:

AC002: Like I said, I just don’t think heart failure has, the, the only thing I can think of is like...it’s reputation. Like it’s not, you know like, you know you think of like something that’s going to kill you. You know, like a brain tumor or like, you’re in an accident or something.

It’s like heart failure, just like diabetes can kill you but when you hear about someone with diabetes, it’s kind of like, “hmm whatever.” That’s like a chronic illness, you can just live with.
And like heart failure is probably worse than diabetes but... [laugh]. Like I feel like it's categorized as like that kind of an illness. You know what I mean?

JG: Who's categorizing it?

AC002: I don't know.

JG: Who makes it like that?

AC002: I don't know.

This participant emphasized events associated with imminent death and included “a brain tumor” or an “accident.” Heart failure, however, was seen as different and likened to diabetes; this likening conveyed chronicity and manageability, which was reflected by many other participants. As AC002 and other participants expressed, they were not sure why HF was seen “like that”. The idea of chronicity and manageability added another layer of invisibility around seeing EOL planning and care issues as relevant or related to the HF patient/family population.

The idea of HF as an illness that people can live with was explained similarly by another participant. This participant, who had practice experiences nursing in palliative, cardiac, and critical care, explained their experiences of looking after someone who learned they have cancer compared to HF:

JG: Do you see parallels with people with cancer diagnosis and people with heart failure diagnosis?

BC003: I do but I don’t think [heart failure is] as clearly identified

JG: By who?

BC003: All of us as health care individuals. I think we as a big group, I’m lumping everyone together, I think we as a group generally think cancer, for the most part, if it gets bad enough, it’s incurable and you’re going to die.

Heart failure is something you live with. But you live with diabetes so “you’ll be okay. We’ll give you medicines, you’ll be okay.”
The reality is, I’ve witnessed in this week alone, two individuals have died of diabetes as it relates to an illness process. It’s not something that I think about on a daily basis. I think of something like diabetes as livable.

HF, it’s livable. You can carry on having a job. You can have a family. You might not run on the soccer field but, you can survive.

Possibly an interesting point is that we don’t realize HF could be very much like cancer. Could be...if clearly identified early on...could be something that we could be, as a population, could recognize um, does sometimes have an end point quicker than others. And, if we just have those conversations earlier, maybe people could make priorities of what matters to them.

You know, they can think about what it is that they really wanted from their life before they don’t have that opportunity anymore. Because when we see people coming through the emergency department, in pulmonary edema, messy...and family members are distraught and it’s traumatizing and they end up dying on the ventilator. It’s too late by then.

What this research participant and many others made clear is that manageable illnesses such as HF and diabetes were framed as “something you live with” whereas cancer was “incurable and you’re going to die.” Of note, this participant also highlighted the positive opportunities that arise for people who understand their diagnosis as “incurable” and life-limiting. For instance, the participant explicated awareness of death as a chance to reprioritize one’s life and pursue “what matters to them.”

5.2.2.1.1. The impact of hearing “cancer”: How implicit assumptions about cancer obscured concurrent comorbidities. The infamy and impact of the word cancer was also said to obscure other diagnoses including HF; that is, invisibility arose where cancer took priority over another illness, even if the cancer was comparatively more benign. A participant with a multi-site leadership role described their experience supporting a patient and family with multiple comorbidities:

NP014: So, I think part of the issue is also with HF, you already know this, is that it’s like
they have a little bit of HF. A little bit of HF and a little bit of all these things. And it’s like, hmm, we’re not quite clear about what they’re dying from.

And so... I remember a family meeting just not that long ago here at [this site].

The [patient] had dementia as well as a number of other things. Big family meeting. And [the patient] also had a history of cancer. [The family] found out that the bone metastases were causing more pain. [The patient] actually wasn’t dying from that cancer, the bone metastases...people last for a long time. But when the family heard the cancer was in [the patient’s] bones, it was like night and day. They were like, [the patient] has got cancer again? Like it never went away. But that’s what they latched on to.

So, in the scope of a little bit of lung, heart, and brain failure...like those are the big things. The cancer was like something that was totally minor, but that’s what they latched onto.

Because people hear cancer and they think death. They don’t hear HF and...think death.

In the excerpt above, the participant recollected an experience where, despite a significant multi-comorbid medical history that included HF, information about metastases of a previously diagnosed cancer was said to overshadow any other cause of death. The participant speaking in this excerpt strongly emphasized the impact of hearing “cancer” and its association with death (“because people hear cancer and they think death. They don’t hear HF and they don’t think death”), which is consistent with what I observed and heard from most other study participants.

Health care professionals disclosing a diagnosis of “cancer” and engaging patients and their family members in conversations about illness and EOL issues, may have greater mutual interpersonal understandings because there are implicit, tacit, and widespread social understanding of cancer—in these scenarios, the relevance and appropriateness of EOL planning and care was clearer because there were commonly held schemas about cancer meaning dying and death. In other words, using the word “cancer” conjured assumptions about disability and death—and, widely shared schemas undergirding “cancer” brought attention to the
illness itself, and to the illness as life-limiting. In contrast, HCPs involved in disclosing HF navigated implicit assumptions about survivability and manageability. Though HF has similarly mortality outcomes to cancer, it was described has having schemas that conveyed chronicity and manageability which shifted HCPs’ (and patients’/families’) attention from the life-limiting nature—that is, EOL planning and care were not necessarily seen as relevant.

5.2.2.2. Relevance and appropriateness as a necessary and foundational schema for HCPs to engage in EOL planning and care. Logically, for HCPs to engage patients and their families in EOL planning and care, they first need to first see the relevance of EOL planning and care for a particular illness. As I have indicated in the analysis discussed above, unlike cancer, HF was not inherently associated with mortality—thus for HCPs and patients and families alike, awareness of HF as a life-limiting illness was diminished. Additionally, likely stemming from the reportedly dominant curative view of HF in acute practice settings (for example, as described by AC006 in an excerpt above), general mortality outcomes associated with HF were under-stated and not well known, particularly among nurses and social workers.

61 This assertion is supported by my data analyses throughout this dissertation as well as my many years in clinical practice and working within various nursing contexts. I have not been able to locate empirical or theoretical literature that makes the claim explicitly.
This under-appreciation of the mortality risks associated with HF undergirded what many research participants pointed to and one participant, for example, articulated as a “big problem”:

JG: Can you tell me what you meant by “HF is a big problem?” Like what is, what is the big problem with HF?

AC020: So, I think because [HF] is on the rise. Just more and more people are developing HF and are living longer with it.

But because [patients are] not always very well managed, because people don’t know that it's life-limiting...what is the statistic? Fifty-percent die within five years of diagnosis?

People don’t know that, right? Even when I would even quiz during my education sessions like, how many will die within, you know, five years or whatever? People would say like, I don't know like, 10 percent? 20?

People don’t...really get that it really is [emphasis in original] life-limiting and this is like nurses, right?

Issues of awareness—that is, nurses and other HCPs not seeing HF as a significant illness and nurses not recognizing or understanding HF-EOL planning and care as relevant for patients with HF because they did not understand associated mortality—created structured conditions under which HF-EOL planning and care was overlooked. These layers of invisibility, that is diminished awareness of HF at all, and diminished awareness of HF as a life-limiting illness, interfaced with what participants described as HCPs' views about acute settings as inappropiate places for HF-EOL planning and care. This interfacing also structured how HF-EOL planning and care were overlooked and/or missed entirely.

As one participant (AC001) explained to me, some HCPs regarded acute care contexts as unsuitable and/or inappropriate for many HF-EOL planning and care activities, including self-management and illness education, for example. The environment of acute care itself was
identified as a suboptimal setting to “deal with that” (i.e. EOL planning) for patients with HF and their family members. In the excerpt below, participant AC001 used the word “appropriate” to emphasize limitations of acute settings and to explain why illness trajectory conversations and education are not done:

JG: For those that aren’t in the [heart failure] clinic...those who are admitted currently in acute care, do people get conversations about their trajectory? Is there any teaching about...?

AC001: No. Because in acute care is not really an appropriate time to deal with that.

JG: Oh. Tell me about that

AC001: I, I feel that the patient needs to grasp what they need to do at home and how this has happened to them.

Then they need to do the self-management strategy and decide if they’re going to take care of themselves. Then they are going to come up to the HF clinic and they are going to learn about this.

But we need them to get a handle on it first.

While the participant does describe some aspects of patient/family illness education as important (including “getting a handle” on HF, meaning, accepting the diagnosis and making changes to home life), other aspects of EOL planning and care (e.g. prognostic expectations, EOL care considerations) are situated as subsequent learning objectives that would take place in an outpatient setting (e.g. a heart function clinic).

Other participants similarly described acute care settings as suboptimal, placing heavy emphasis on the outpatient encounter for establishing self-management routines. For example, a participant who practiced medicine in several settings including inpatient and outpatient areas,
explained how the focus and goal in acute care is on getting the HF patient “better”, which meant getting the patient well enough to go home:

AC021: In the acute setting, we probably don’t go into too much detail long term. We will definitely go into that detail in the [outpatient program].

If someone comes in with a low ejection fraction [which is a measure of a person’s cardiac function] we often tell them, “we need to get you better. Okay, your heart is weak, we need to do this and this. We’ll get an angiogram. Whatever. Start you on these medications. Get you on some Lasix. Make you feel better”.

Once they’re better, and they’re kind of at their baseline, we have the other, you know [considerations], we meet them every day during the rotation [when the physician is acting as the most responsible physician – usually one-week], but we then, before they go, we’re going to refer to [the outpatient program] and we’ll take it from there.

And then in the [outpatient program], they then explain, “okay you’re on these medications”, and we kind of go for more details. “These drugs will do this. These drugs will do that. This drug with do that. And if we don’t help, these are the consequences of dysrhythmia”.

“These are the consequences of HF long-term”. All that.

JG: Right.

AC021: And so, [the education is] a lot more deep. But not in the acute clinical setting...Usually, most of us don’t go into a lot of detail in that short time.

JG: For time?

AC021: Time. Plus, again, because of the acuity of the situation, many patients–there’s only so much...when you throw so much information at them, that they can kind of grasp. Because a lot of this is coming pretty complicated.

And this is honestly across the board. Someone comes in with a heart attack, I usually don’t go into details. I usually just [say], “okay you had a heart attack, you didn’t get enough blood to this part of the heart. We need to do this to open up the vessel”.

This participant’s focus on getting patients better, and their explication of how education and interventions are aimed at the presenting diagnosis, aligns with what most participants told me about how acute care education and priorities are emphasized for clinicians as well—that is, the focus on identifying the presenting acute issue, treating it, and getting the patient home.
5.2.3. A summary of findings about issues of awareness and invisibility of HF in acute care settings. As I came to appreciate over the duration of my research fieldwork, not only do HCPs need to be aware of HF and its relevance to EOL planning and care, the acute care hospital environment (from the physical space to clinicians’ perceptions of what their work actually entails) also needs to be seen by HCPs as appropriate practice areas for HF-EOL planning and care. That is, HCPs need to be aware of HF and its relevance to EOL and need to regard acute care practice contexts are areas where EOL planning and care can and should take place, at least to some extent. As I described at the beginning of this chapter within acute care contexts acuity, workload, staff experience, and diverse patient populations, for example, contributed to layers of invisibility that structured practices such that nurses were less aware of HF.

The context of acute care settings related to invisibility in other ways as well; for instance, study participants described how HCPs did not necessarily understand HF illness concepts or recognize HF as a life-limiting illness and thus did not always see EOL planning and care considerations as relevant, or recognize possible benefits of HF-EOL planning and care. Participants also described how some HCPs viewed acute care contexts as inappropriate settings to engage patients and their families in EOL planning and care because of particular contextual characteristics (e.g. noise, crowded layout). Broadly, issues of awareness—that is, HCPs not seeing HF, HCPs not recognizing or understanding EOL planning and care as possibly having benefit for patients with HF, and/or HCPs viewing acute settings as
inappropriate for EOL planning and care—structured practices in ways that fragmented EOL planning and care because EOL planning and care was not necessarily considered in the first place.

Awareness of HF at all, and awareness of HF mortality in particular, also related to acute HCP’s knowledge—that is, participants explained issues of HF and EOL planning and care vis-à-vis a compilation of particular knowledge bases, skills, and competencies\(^{62}\) and framed this compilation such as necessary to engage patients and their families in HF-EOL work. I will turn now to explain how I learned through my research and fieldwork that in the absence of particular knowledge bases, skills, and competencies, HF-EOL planning and care were not done.

\(^{62}\) I am drawing from Hafferty, Gaufberg, and O'Donnell's (2015) definition of competencies as “the behavioral outcomes of educational practices” (p. 132).
5.3. Knowledge, Skills, and Competencies in Acute Contexts: Perceptions about Disciplinary Scope and Role and the Positioning of Experts for EOL Planning and Care

I first recognized perceptions and assumptions about clinical knowledge while listening to study participants’ frequent, implicit, and explicit statements about “expert” others such as “you should talk to [so and so]...” Self-imposed, clear statements qualifying participants as not experts were also common; for example, “I don’t know much about...” Often, participants would steer me elsewhere to a place, which was often a palliative care program. Participants would also steer me towards a colleague who was recognized as being responsible for practicing EOL planning and care. I came to understand that participants were regarding these places and colleagues as having particular experiences (e.g. an established clinical practice in palliative care), authority (e.g. a palliative care physician or a cardiologist), and/or expertise (e.g. nursing and/or medical practice leaders). That is, some places and colleagues were positioned

63 With the terms “perceived and “perceptions”, I mean to convey the ways of understanding something.

64 With the term “assumptions”, I mean to convey the acceptance of something as true or certain without necessarily having verification. In using terms such as knowledge, skills, competencies, perceptions and assumptions, I am not intending to make evaluative judgements about the practice of individual nurses or other HCPs. Rather, I am attempting to illustrate challenges such as those Sewell (1992) pointed to about agents practicing in complex organizational contexts (see also Chapter Three).
as experts in EOL planning and care, whereas other areas and colleagues were not. In the excerpt below for example, the participant who was an experienced cardiac and critical care nurse described communication during dying as being “better” in a different setting (i.e. specialist palliative care—the “palliative list”) with “someone who is more trained in this area”:

AC002: I was looking after a guy with HF just like a few weeks ago and he was like super end-stage, like, not on the palliative list yet, but like, [the critical care team] were applying to it in like the next couple days.

And [the patient] was just like terrified and [the patient] would wake up a night like “I’m just thinking of all these regrets in my life” and I, I said, “well let’s talk about it.”

But I, sometimes I feel like maybe I’m not qualified to give more. I don’t know...

It just, just like, feels like maybe they should talk to a counselor or, you know what I mean? Like I don’t always feel prepared to talk about those kinds of things.

Whereas it’s not like that’s not a part of nursing because it is.

But especially when someone’s like actually close to death, I feel like, well maybe they need someone who is more [pause] trained in this area [laughs]. Better than I am.

There were both implicit and explicit statements about perceived skills and qualifications in this excerpt (“maybe I’m not qualified to give more...”). Particular communication skills were also conveyed (“like maybe they should talk to a counselor...I don’t always feel prepared to talk about those kinds of things”), as were assumptions about the existence and value of communication training. (And also, of note the participant conveyed an implicit notion of what it meant to be on the “palliative list”, which I explore in the next chapter as I discuss my second major area of findings What HCPs said and heard.)

In addition to communication, participant AC002 identified how they were thinking about the other domains of knowledge, skills, and competencies needed to “deal with EOL.” For
example, the participant described their unfamiliarity and uncertainty around particular drugs used for pain management at EOL and explained their perceptions and assumptions about palliative care clinicians having particular experience and expertise:

AC002: Well I... I just always feel like if they're up there [in palliative care], those nurses are trained to deal with end of life. More than I am. So, I guess sometimes I do feel like, maybe, needs that they have that I don't necessarily know that they have would maybe be met. Better.

JG: So, through your experience particularly in critical care, would you say that you've seen a lot of people die? In critical care?

AC002: Yep. More than anywhere else that I've worked.

JG: And what makes a palliative care nurse uniquely trained?

AC002: Well I think just their experience. Like say, you know, will have a patient referred to palliative, and say they're waiting for a bed. And palliative will come and write orders, like comfort medications like hydromorphone or something, with like a range.

And just like any medication, the more experience you have with it, the more decisions you can make. So, say like, [give] this guy like 0.25 of hydromorphine and see if that helps. Whereas like a palliative would be like, “I've used this a lot.” Be like, “this is usually a dose that works.” You know what I mean? Whereas for me I feel like I’m kind of guessing. Even though I have a range, I'm still like kind of guessing. Like, “maybe this works.”

The participant’s mention of “training” above pointed to assumptions about specific knowledges and skills associated with this work\(^{65}\), which I heard from many participants. In particular,

\(^{65}\) I do not mean to convey that this is only an assumption. Indeed, writings from the literature point to various knowledge domains related to EOL planning and care, which I will discuss in Chapter Eight (Keely & Generous, 2017; LeBlanc, 2015; Pesut et al, 2014;).
participant AC002 focused on knowledge domains involving communication skills and EOL-related symptom management. The explication of a “better place” to die also struck me as especially significant. While the participant identified their own professional experiences being with many people who died in critical care, they simultaneously conveyed expressions of a lack of confidence and uncertainty. The participant contrasted their own practices against palliative-specialist clinicians who were said to be “trained to deal with end of life”—that is, they were positioned as experts and thus were also positioned as the ones to do the EOL-related work.

Participants’ thinking about scopes of practice and disciplinary expectations were informed by related perceptions about skills, competencies, and expertise including what seen as optional and what was not, and the positioning of experts—meaning, what participants believed they were expected to do and what they believed was part of their work (i.e. what their role was). In this longer excerpt below, the speaker used examples of daily weights, intravenous fluid administration, and patient/family education and communication to share their experiences of HCPs’ perceptions about scope and role in relation to HF-EOL planning and care:

AC020: So...with HF being as much as of a...big problem as it is, as you well know, one of the key pieces...I was talking, initially very informally, with [a nursing leadership group], [asking] about how do they feel that the HF care is in their area? And the patient education? How well are the nurses prepared? We have a lot of new nurses, new grads. [The nurse educators] said that the knowledge is there around the pathophysiology of that, much of the time. But when it comes to actually putting that into practice, they felt that there were, you know, really big gaps. We know that we have, I don’t know the numbers off the top of my head but, high readmission rates...for HF.

What people have said is that [nurses] know the pathophysiology but you wouldn’t believe how few, even cardiac patients, get a daily weight. Whether it’s in a [cardiac unit] or a medical unit.
And I asked the nurses, you know, and I said to them, “this is just conversation—no judgment, no anything—do you, do you do daily weight on your patients?” And most of them said that they would do a daily weight if it was a HF admission. But not just a history of HF.

And when I explained to them, “do you know that patients who have HF, who live with HF in the community, I mean I hate to say supposed to be, but you know, we encourage them and teach them to measure their daily weight as one of the easiest and really, really most reliable ways before they start to feel crummy. Like before [they get sick].”

And [the nurses] were kind of like, “no, really?” And some said that they only do daily weights on their patients if they’re on 80 or more of Lasix in a day. Like they had sort of these different kinds of thresholds and whatever. And they were quite surprised when I said, “you know we should actually be doing daily weights on any patient with a history of HF.”

And I said, “you know, understanding that of course, you guys are overworked...and you know, et cetera. I do understand that. But when you can, and if you can fit it into your day and find the time to do, ideally in the morning but you know.” Then I said, “it’s just one of the easiest ways.”

Think about when people come into the hospital. We’re giving them you know, different food. Different medications. IV fluid. You know, we might be fluid overloading them and I, without even sort of realizing it. And I said, “when you talk about fluid restrictions, I asked about, you know are you sort of doing it?” And they were kind of “no.” [said in a low tone in original] Looked at me kind of blankly.

And I said, “you know, IV antibiotics, if it’s in a 250ml mini-bag. And they’re getting three times a day for example, that is a lot [emphasis in original] of fluid. In addition to their oral fluids. In addition to, then they go for surgery.” You know, things like this, right? So, they go for surgery and they, you know, load them up with fluid. So, I think it was pretty eye opening because some of them were like, “Oh. I hadn’t thought of that.” You know?

I kind of showed them some of the numbers about people who, even if it’s not a HF admission, um, HF keeps people in the hospital for longer. Even if they’ve been admitted for a hip. Or for, whatever. A UTI. It doesn’t matter. If they have HF, they stay in the hospital longer and they come back more frequently. So just kind of going through, I

66 Lasix is a trade name for a drug called furosemide. Furosemide is a type of diuretic that is mainstay in a pharmacological management plan for a patient with HF (Arnold et al., 2006).
showed them some of the educational resources that are available from the [provincial heart failure resources].

And so, I showed them that they are available on the [health authority] patient education catalogue. I don’t think a single one out of maybe 85 that I’ve taught so far, even knew that they were there.

And yea, I think there’s a bit of, “it’s not really my job to be teaching about HF,” [Patients/families] could go to the cardiac clinic. The kind of, it’s not my job mentality.

And I don’t mean that in a “they’re lazy” kind of way, but it’s like, well but somebody else does that. Or I’m not a HF expert. And I’m like, well that’s why I’m here to tell you, that, as a matter of fact, you know it. And you can.

And I said, in much the same way that you, you “do your patient teaching before discharge education et cetera about whatever else it might be. About using their inhalers properly and things like... Signs of wound infection... if, if a person has a history of HF, this is, it needs to be reinforced at every visit, that this is what they need.”

And not in a, “well because this is our rule” but because “this is one of the easiest ways to keep yourself out of the hospital”.

The participant’s extensive and expert account in the excerpt above emphasized the linkage between self-identified perceived knowledge and competencies, and perceived disciplinary role and scope. As was emphasized similarly by other participants, notions of expertise were also salient; HCPs held assumptions and were reliant on what they perceived to be other more expert, more competent, more confident HCPs who would engage patients and their family members in communication about the HF illness via patient education (“somebody else does that”). That is, HCPs had self-assessed their illness knowledge as inadequate and positioned as experts. Positioning shaped both awareness and willingness to actively engage patients and their family members in HF in EOL planning and care and structured practices because they influenced actually doing it.
5.3.1. Interpretations of self-assessed knowledge deficits in relation to perceptions about practice expectations. While I encountered participants’ frequent self-assessments of their own and others’ knowledge deficits related to HF-EOL planning and care regularly, these knowledge deficits were not necessarily seen as problematic by most participants. Instead, self-assessed knowledge deficits were interpreted in relation to practice expectations and roles. In acute care, these practice expectations were mainly focused on the physiological needs most directly associated with the acute admission, which was often the ED admission (as I explored earlier). For instance, in the excerpt below a participant who practiced in cardiac nursing and critical care explained how they focus on developing “mandatory” aspects of practice:

JG: And you’ve said you’ve seen a lot of people die in critical care. Do you think there hasn’t been an emphasis, on like your education to this point about what that entails?

AC002: There’s lots of education out there and I just haven’t sought it out. And it’s...So I know it’s available so. It’s out there but it’s not...it’s not like, it’s not like there’s...I’ve...noticed like they’ll have like a conference or whatever about dying and I just never signed up for it before. It’s not like it’s like a mandatory part of our practice to take it.

JG: Does that surprise you?

AC002: I guess maybe, it would be helpful. But I mean for where I am in my life. I just, I just don’t have time for any like extracurricular work things. So... Yea. I do the mandatory stuff [laughing] and that’s about it.

And even if it’s... I mean sometimes something is super interesting and I’m at like work and I can go to like a nursing rounds or something. I’ll go to it. But if it’s like, if I have to come in on a day off, it’s just... I just don’t have time.

While this participant recognized their practice role supporting patients and their families with EOL planning and care activities, and also described self-assessed knowledge deficits related
to this practice domain, gaining the knowledge, skills, and competencies required was seen as optional. That is, this work fell outside of what they believed they actually needed-to-know.

Other participants talked about HF-EOL planning and care conversations as being the type of work that needed clinical experience (i.e. a length of time in practice) thus conveying that HCPs with less clinical and/or life experience may be expected to delegate (i.e. not do) EOL planning and care activities, such as EOL-related conversations. Participant AC006 below, for example, distinguished between the clinical expectations related to engaging patients in conversations about EOL (i.e. EOL planning), and other nursing duties such as monitoring vital signs and doing assessments. The participant emphasized EOL planning conversations as “experience driven practice”, which was a reference to both length of time in practice and personal life experience:

JG: What’s your sense of how nurses understand [EOL conversations] as an expectation of their practice?

AC006: I think that depends on the experience and the background of the nurse. A portion of that is probably personal belief as well. Kind of coming out of whatever has happened within their own family. Because I think it's very much an experience driven practice.

JG: Right. So, then [expectations to have EOL conversations] would seem different from then, for example around the expectation around monitoring vital signs?

AC006: Yes.

JG: So, one would be seen as critical [needed/necessary]?

AC006: Yes.

JG: And one may have something other than critical [needed/necessary]?

AC006: Yes. And I think part of that is because nursing, kind of looks like the patient as they are right now.
And sometimes, I think some of that other stuff gets left, because it can happen outside the hospital. It doesn't have to happen inside.

Where it can happen, once a patient is more stable, or I think there’s other variables associated to it. Whereas vital signs are a little bit more cut-and-dry.

Within the excerpt above I interpreted two assumptions. First, the participant is describing how a HCP’s own personal experience could relate to their ability to engage patients and their families in EOL planning and care activities. And second, the participant emphasizes the focus of acute care as “right now”, meaning the management of the acute condition, and subsequent hospital discharge. Within this focus, vital signs and the “more cut-and-dry” clinical work were conveyed as needed (i.e. necessary) knowledge. That is, there was a schema (i.e. a belief and an implicit understanding) about what was needed and necessary for acute practice; less “cut-and-dry” knowledge was thus positioned as optional. Such optional positioning included HF-EOL planning and care because “it can happen outside the hospital.”

This important finding of schemas about needed and necessary knowledge for acute practice also related to the findings from the previous section on awareness of HF. In section 5.2, I presented data from fieldnote observations illuminating the way that patient information was organized in acute care units—in particular, I showed how presenting diagnoses, which were often the ED diagnoses, were foregrounded as were related assessments and nursing tasks. I also learned that schemas underpinning the particular importance of presenting diagnoses influenced how nurses and other HCPs perceived what was necessary in terms of the knowledge, skills, and competencies to practice in inpatient units (e.g. acute medical units, acute cardiology units). For example, I asked a participant to share their understanding of how
HF pathophysiology was understood in acute medical units. The participant explained that pathophysiological knowledge was less important than rapid assessments, developing "intuition," and being able to identify deteriorating physical status:

JG: Perhaps you could talk more specifically about the expectations for understanding of the pathophysiology of diseases, all the different kinds of pharmaceuticals... just that you are exposed to a large number of illnesses and...

BM008: So. I worked on [one of] the medicine units for many years. Which is on the [this floor] here. So, I don’t think there is a huge need. I think it’s more about having intuition and like doing rapid assessments and that kind of thing.

I don’t think that if like, if I went around and asked for patho, that somebody would be able to explain any of that to me.

And also, and even just having just rolled out um the stroke stuff for the nurses [on another unit], just for the ECGs, first thing we did is we talked about anatomy and patho and, and it was difficult. [The nurses] definitely required a refresher. And for some people it was really new knowledge.

JG: So, the emphasis then is on that rapid assessment, early identification of like deterioration? Is that right?

BM008: Yep.

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67 I was inquiring about pathophysiology because in general, having a foundational understanding of the basic pathophysiology of HF is valuable for being able to also talk about the illness course, the self-management concepts, the medications used, etc.

68 This participant did not explicitly define their meaning of the term “intuition”. In practice, the term “intuition” often refers to a sense of just knowing when something needs to be acted on and knowing how to act. There are broader discussions about the concept of intuition that are beyond the scope and aim here and thus I have no included.
This excerpt illuminates how particular types of knowledge were seen to be needed (e.g. rapid assessment), whereas other domains of knowledge were seen as less necessary (e.g. pathophysiology).

5.3.2. Why HF is a “big problem”: Perceptions about the knowledge needed and beliefs about permissions. At the outset of this study, I was impressed and optimistic by what I observed and heard as participants’ dedication and eagerness to provide excellent EOL planning and care for all patients and families, including those with HF. Paradoxically, EOL planning and care for patients with HF was concurrently described as a “big problem.” As I explained in my analyses in the first sections of this chapter, I came to understand HF-EOL care as a “big problem” in part because HCPs did not always appreciate the mortality associated with HF and thus EOL planning and care was not always done (or not done well) for patients and/or their family members.

Another part of the “big problem” however, stemmed from what I identified as the ways HCPs perceived about their own roles in HF-EOL planning and care, as participant AC020 emphasized in the excerpt above. Perceptions about roles, and thoughts about necessary knowledge, underpinned beliefs about the pursuit and acquisition (or not) of the types of necessary knowledge, skills, and competencies seen as required. Overall, that this meant what HCPs believed was their work influenced what they sought to know for their practices. Thus, work situated outside what HCPs thought was needed (i.e. those activities not specifically related to the acute admission and non-mandatory aspects of practice) was the work that was
positioned as belonging to expert others. With the emphasis on the acute cause of admission in ED, patient care activities that fell with EOL planning and care such as communication and illness education, were seen as non-essential and thus were positioned as the work of these expert others. While these experts were clinicians who were seen as having particular “training” (e.g. counselors, clinicians with skills in symptom management) extensive clinical practice or life experience, they were also HCPs regarded as having particular authorities or permissions.

5.3.2.1. Permissions and authorities: Implicit and explicit understandings about disciplinary scope and roles. Importantly, participants’ thinking about others’ skills, competencies, and expertise around EOL planning and care also informed participants’ own (and others’) perceptions about having the right authorities and/or permissions to do HF-EOL work. For instance, one participant expressed their concerns about inadvertently overstepping tacit and implicit professional boundaries by engaging patients and/or their family members in conversations about HF illness and EOL. This participant who practiced nursing in general medicine, described what it meant to be just a “regular RN” in relation to EOL planning and care:

BM017: If I am a nursing clinician [like a person well known in the practice area], as a profession, then of course I will. But as for my profession, just regular RN, it’s hard.

JG: Why? Why is it hard?

BM017: I don’t know if it’s me but, but, um...[pause] we [nurses] are having a little bit of this common thought that we’re not the ones who’s...[pause], um, who is bringing up that kind of issue.

Like at the first time to the family. Yea, so if there’s a terminal care order, then yea. I can tell them. It’s already initiated so that means that we can talk to the family.
We still...you know, they’re, between a hierarchy [of physicians and nurses]. [laughs]

One of my patients deteriorated and they were thinking about comfort care versus palliative. And then that night like our colleagues told me, you should call the Hospitalist to get him here to tell the patient’s family that he’s not going to make it. Yea. That wasn’t my role.

In the interview excerpt above, the presence of a “terminal care order” meant that a physician had previously disclosed the illness and EOL information and thus provided permission for the participant (who was a nurse) to discuss this content with the patient and family. The participant also explained how an interprofessional “hierarchy” existed, which has inherent disciplinary authorities and power. In this case, physicians were viewed as holding power and were thus seen as being in control of the information shared. Thus, in this situation and many others I observed or had recounted to me, both perceived and actual disciplinary expectations, responsibilities, and boundaries shaped participants’ understanding of implicit practice rules and knowledge about what was allowed. That is, these perceived and actual disciplinary expectations structured the way knowledge was seen to be needed and aligned within the need-to-know versus what was seen to be optional or belonging to experts or those with disciplinary authority, such as physicians.

Assumptions about colleagues’ particular knowledge and skill base were also evident and these assumptions formed expectations about what colleagues would and would not do. For example, a participant who practiced as a cardiologist in various inpatient and outpatient settings described their impressions of how generalist physicians and nurses were expected to think about HF-specific interventions such as daily weights. They described having different
expectations of nurses on a cardiac unit versus a general setting such as a general medicine unit:

AC021: The [most responsible physician69]...they should say, “Oh look at this history, he’s got HF, “hey let’s do daily weights on this patient.”

The expectation of the cardiac unit would be very different. Because the cardiac nurses themselves would not expect you to need to order weights to get a weight done.

Just a little bit of historical background, when I first came here, they weren’t doing any of that.

JG: Interesting

AC021: And [the team leaders] really pushed for [daily weights to be completed]...so now [the nursing team does daily weights]

Now, even if we don’t order it, if the patient comes in with HF, the nurse will automatically [weight the patient daily]. So, the nurse will now. But it took education.

Of note, the participant speaking in the excerpt above noted that the “automatic” daily weight came about after an education and quality improvement initiative. The need for this initiative draws attention to HF-knowledge deficits that existed in the cardiac specialty as well as in the general acute medical settings. However, such deficits were improved with initiatives supported by practice leaders.

69 The phrase “most responsible physician” refers to the physician in hospital who is overseeing the patients care and is acting as the person primarily responsible for treatments and decisions.
Another participant who was also a cardiology physician with broad practice experiences across many inpatient and outpatient settings, similarly described how interprofessional expectations shaped practices around other aspects of HF-EOL planning and care, including illness education and self-management. In the excerpt below, the participant explained what is “reasonable to expect” from nursing staff on the general medical units:

BC019: You know I think as a consulting cardiologist, you’ll see the patient, you know relatively briefly for 1, 2, 3 visits maybe at most that week.

And you’ll introduce some of these concepts but you know, [I’m] not optimistic that me explaining once how to do daily weights with patients in the hospital setting is really going to stick and [the nursing and medical staff are] going to take it to heart

JG: So, who do you, who does that then? Like where would that responsibility lie?

BC019: Well. It should...it’s not necessarily reasonable to expect that it would rely with the nursing staff on the unit. Because they’re not cardiac or heart failure trained nurses.

And so they may not have the correct expertise or knowledge to really counsel patients on how to do self-management. Um. And you don’t want wrong information either. So you know, it should be probably with the physician caring for the patient or with the consultant cardiology.

I included both of the excerpts above because they illuminate how practices were interpreted within implicit expectations and assumptions about disciplinary roles in relation to the practice context. That is, self-assessed knowledge deficits related to EOL planning and care, as well as deficits assessed by others, were not inherently visible or intentional. Instead, they were situated in relation to the context and in relation to implicit assumptions about what was within nurses’ roles in the particular setting. How participants thought about scope and role was beyond simply thinking about how others’ work; instead, these perceptions actually structured the way people practiced—meaning, their enacted practices.
5.3.3. Perceptions about scope and role and relationship to decisions and enacted practices. Throughout my fieldwork, consistent findings of differing expectations and “optional” practices shaped my understanding that despite dying and death being a relatively familiar occurrence in acute care, supporting patients with HF (and their family members) to prepare for death, and caring for the dying, were seen as special areas of clinical work. This understanding was important because it helped me to interpret what HCPs actually did—that is, how they enacted their practices. For example, in the excerpt below a participant who practiced cardiac nursing in a leadership role illuminated the relationship between HCPs’ knowledge of HF concepts, their understanding of how such concepts are translated into practice, and the enacted clinical practices:

BC011: I ran into this situation the other day...I was looking at the medications and I was talking with the nurse. And [the patient] was on, you know, a beta-blocker\textsuperscript{70}, an ACE. And [the nurse] was like, “oh I held the metoprolol because [the patient’s] heart rate was low” and I said, “oh, well how low was it?” And [the nurse] said, “58”. And I said, and I was like “oh, well that’s not really low. Was he symptomatic?” [And the nurse said] “Well no. But it’s just going to drop it lower, right?”

And so, I took that opportunity to say, “well you know, this patient needs their medication. [This patient] has been on this medication at home. You know, it’s not something that we would just hold for the entire day. You know, until the evening. You would check it again”.

\textsuperscript{70} In Chapter Two, I explained the pharmacology in HF noting that beta-blockers, ACE inhibitors, aldosterone receptor agonists, and diuretics are therapeutic mainstays (Gibson & Raphael, 2014; Gibson & Nordby, 2014).
And I guess, [the nurse’s] magic number in their head was about you know, sixty beats per minute. So, anything below...so it’s taking those [teaching] opportunities as well. Not just a formal in-service with a group. But it’s, it’s doing those little teachable moments with individual nurses as well.

JG: What’s your sense of like the knowledge level then?

BC011: I would say [emphasis in original] just because...looking back on my own experience, um, as a bedside nurse. And then coming into this role. I would say that the learning curve for heart failure was huge for me.

And just going wow, you know, like I didn’t really realize how big of a deal heart failure was. And just, when you have a patient on the ward that you’re looking after who has heart failure, it’s like, yea, you don’t necessarily...I [emphasis in original] didn’t necessarily think about it as a big deal as a chronic illness.

Right? And I think...I think there are some nurses who would fall into that as well. Just, just, you know, connecting that with now my experience and working with nurses who don’t necessarily know, um, a lot of depth of what heart failure is.

As BC011 conveyed, there was an implicit and underlying premise that knowledge shaped HCPs’ enacted clinical practices vis-à-vis both an understanding of HF concepts, and the ability and inclination to translate the concepts into care actions. This premise was similarly reflected by other participants as well.

Collectively, perceptions about HCPs’ own needed knowledge which was self-assessed and related to different domains of knowledge for EOL planning and care, as well as positioning of experts and understandings about disciplinary scope, role, and permissions, structured practices about which activities (e.g. tasks, assessments, education) were done and by whom. These structured practices related to a schema about professional knowledge that I came to call “need-to-know” which reflected a hierarchy and prioritization of knowledge, where some knowledge was seen to be needed and highly prioritized (e.g. the “cut-and-dry” content that was
described by participant AC006), whereas other knowledge was seen as optional (e.g. daily weights in medical units as described by AC021).

5.3.4. Structured practices from need-to-know schemas: How knowledge was prioritized in acute care. The phrase “need-to-know” was frequently used by participants and its meaning was both implicit and explicit. For example, need-to-know schema informed HCPs’ understandings and conceptualizations of their own and others’ roles and responsibilities in different aspects of clinical work. Throughout my data collection and in several excerpts in this Chapter, for nurses in particular, skills and competencies related to actions such as “rapid patient assessments” and early identification of changing clinical status were explicitly “needed” for acute care practice. In contrast, other knowledge and competencies were regarded as having a lower priority and or being optional, or not needed—“it can happen outside the hospital”.

Overall, I identified that there was a relationship between expectations about disciplinary scope and roles, and self-assessed knowledge deficits and actions, including professional development as well as enacted clinical activities. In the diagram below, I illustrate how I came to think about and understand particular types of knowledge in relation to this need-to-know schema and in relation to knowledge hierarchies (see Figure 5-2).
Forming the base of this knowledge/skill pyramid is what was “needed”, including the vital signs and acute rapid assessments; visually, this is represented as the largest portion because it was described as belonging to all clinicians in acute care and was seen as standard. Moving upward, more nuanced HF illness knowledge (e.g. awareness of HF and the need to do a daily weight) was presented as within the scope of HCPs with special skill and/or more experience (e.g. AC001 talking about using life experience as a foundation for conversations about self-management and lifestyle). Ideas about specialization seemed to be positioned closely in here (for example, participants AC021 and BC019 speaking in the excerpts above described discovering that daily weights were done in specialty cardiac settings and made
efforts to correct the practice gap first in the specialty areas). Moving further upward, I positioned communication skills at the highest level because communication was most often described as needing particular skills and experience and was also associated with positions of leadership or authority (e.g. clinical nurse specialists, specialist physicians—thus, also meaning fewer people).

While the illustration may imply a somewhat categorical progression from what is seen as “need-to-know” to what is seen as the work of experts, I think in practice there is more fluidity between these areas and the groupings are likely less discrete. For example, participant AC001 told me how their own personal experiences with cardiac illnesses in their family led to them having a special interest in understanding on the disease trajectory and EOL issues, which has also led to greater confidence talking to patients and their family members in the work context. I included the diagram above because it became an important analytical step towards how ultimately came to understand both the existence of a knowledge hierarchy, as well as how this hierarchy structured particular practices related to EOL planning and care.

5.4. Chapter Summary

As the findings from this chapter indicate, the professional work of engaging patients with HF in EOL planning and care was rooted in HCPs’ beliefs about clinical knowledge and competencies—that is, beliefs about whether or not the HCP was competent and/or sufficiently knowledgeable and allowed to engage in HF-EOL planning and care. Such beliefs about clinical knowledge and competencies related to broad domains of knowledge that included, for
example, HF illness and EOL concepts and common patient population characteristics (e.g. pathophysiology, common treatments, general outcomes, comorbidity burden, symptom management, dying and death); patient/family education (e.g. self-management support); and, communication skills for patient education about HF and difficult (i.e. serious) conversations involving specific EOL issues (e.g. personal goals and wishes). These knowledge domains constituted an important contextual feature of acute care because they undergirded HCPs’ perceptions of clinical competencies, disciplinary scope and expectations, and related permissions and authorities. Importantly, these knowledge domains also related to HCPs’ understandings that EOL planning and care was relevant for patients with HF. Together, these domains fit within a schema called need-to-know schema, which structured the way HCPs seek and develop particular knowledge, skills, and competencies.

In the next chapter, I explore how knowledge undergirded how participants understood words and phrases differently and as having different meanings—that is, I will build from this chapter about What HCPs saw and knew present the second major area of findings about What HCPs said and heard.
Chapter 6

What Health Care Professionals Said and Heard about End of Life in Acute Care Settings: Implicit and Shifting Narratives within Commonly Words Used to Talk about End of Life Planning and Care and Structured Practices

In my acute care fieldwork, I noted that particular words and phrases had nuanced meanings and conveyed stories. For example, in the previous chapter, I explored how “heart failure” did not mean the same thing as “cancer.” While HF was thought to represent chronicity, it also meant manageability and “something you can live with.” In contrast, to have cancer meant something quite different to both HPCs and to patients and their families; to have cancer meant a person was dying and death was anticipated. For instance, in acute care I observed that the word cancer functioned like a resource that interfaced with agents’ schemas about cancer, which reflected beliefs about dying and death. These schemas about cancer also structured participants’ enacted responses. For example, the word “cancer” meant dying and thus EOL planning and care came to be seen as relevant and appropriate.

The term cancer also acted as more than a diagnosis—it was symbolic of dying and death. Agents’ meanings about “cancer” reflected agents’ own schemas (e.g. beliefs, assumptions, perceptions). “Cancer” also acted like a story, which stemmed from what I am
calling *narratives*, which were underpinned by schemas about meanings. Not all words had narratives but different EOL-related words did, including “cancer.” As I will show in this chapter, words that I identified as having this narrative attribute were powerful words because they told implicit and explicit stories *well past* their intended definitions.

In this sixth chapter I explore the second major area of findings, which focuses on meanings of particular words that were used in interprofessional communication: *What HCPs said and heard*. Findings about what was said and heard and my interpretations about the undergirding schemas were discoverable in part because of the way I used dialogic data collection methods including observations and interviewing. With these dialogic methods, study participants both showed and told me about their experiences supporting patients with HF in EOL planning and care. During observation and interviews, I heard examples of EOL-related words and phrases used regularly. In most instances, the meanings of these words were implied and tacit so I purposefully invited participants to explicate what these words meant in

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71 While some authors use the words “narrative” and “story” synonymously, Charon (2001) emphasized their distinction between the two: “A story—a state of affairs or a set of events—is recounted by the patient in his or her acts of narrating, resulting in a complicated narrative of illness told in words, gestures, physical findings, and silences and burdened not only with the objective information about illness but also with the fears, hopes, and implications associated with it” (p. 1898). Narratives are a process, which can be thought of as set of schemas, through which stories are created. Thus, I treat these two terms (i.e. narratives and stories) as distinct in this dissertation.
semi-structured interviews that often took place later. In other instances, these words were said and described within participants’ stories and recollections of their clinical practice experiences. At its core, dialogic interaction invites participants to share an explicit—meaning, articulated—narrative about aspects of EOL planning and care broadly, as well as about EOL-related words specifically. It was within these narratives that I sought to understand the underpinning schemas.

6.1. How I am Using the Term “Narrative”

Before I proceed, I will clarify how I am using the term “narrative” as it is employed with different uses throughout the health care and research methodological literature. I am using “narrative” to refer to a relational process and practice of storytelling—meaning, there is an exchange between two agents where a message is sent and a message is received (Charon, 2001; Charon, 2006; Fitzpatrick, 2017; Fitzpatrick, 2018; Mattingly, 1994; Montello, 2014; Roberts, 2012; Sandelowski, 1991; Sharf, Harter, Yamasaki, & Haidet, 2011). Telling stories and hearing stories are inherent within human communication: “... each of us, to varying degrees, makes use of our narrative tendencies in a wide array of communicative activities, including how we talk about health, illness, and medicine” (Sharf et al., p. 36).

The idea of “narratives tendencies” points to narrative as a process and practice that agents use to produce stories. Sandelowski (1991) used the word “immersed” to amplify the idea of human narrative tendency and to illustrate the near omniscient quality of narratives presence: “human beings are immersed in narrative, telling themselves stories in a virtually
uninterrupted monologue and tirelessly listening to and recognizing their own stories and the
stories of others” (p. 162). Sandelowski’s description of “telling themselves” points to an implicit
and internal characteristic of narrative; in contrast, “listening” points to an explicit and outward
characteristic. In other words, narratives can be viewed as being compiled of both implicit and
explicit aspects that reveal ideas about causation, solutions, and future states; they become part
of a story and provide a way of making sense of circumstances or events (Casey, Proudfoot, &
Corbally, 2016; Sharf et al.).

The narrative process produces stories that have several commonly shared
ccharacteristics. With the goal of making sense of circumstances, narratives are often organized
temporally (i.e. in relation to time\textsuperscript{72}); though as Tropea (2012) explained, “narrative time is not
linear; it is characterized by turning points, moments of tension, conflict, and suspense” (p. 941).
The narrative in a story is then presented as an associated series of events; connections as
antecedents and consequences are shown between locations of past, present, and future
(Charon, 2006; Roberts, 2012; Sharf et al., 2011; Tropea, 2012)—that is to say, narratives have

\footnotesize\textsuperscript{72} Charon (2006) attributes the idea of “temporality” to Paul Ricœur, which I do not discuss in
this dissertation as it beyond the scope of my aim.
plotlines\textsuperscript{73}, which means agents may interpret stories as predictive. Narrative stories are also often situated within a setting (i.e. context, a particular place) and agents (i.e. characters) and agency is foregrounded. Narratives may also reflect overarching sets of values or ideas (i.e. schemas) which may be stated or implied (Charon, 2001; Charon, 2006; Montello, 2014; Roberts, 2012; Roscoe, 2012). Throughout this chapter I draw attention to significant differences in how HCPs’ understood the meanings of particular EOL-related words. I also describe how agents enacted clinical decisions differently depending on their own interpretations of the meanings of the narratives they created—that is, I will show how different schemas underpinning narratives created different stories with different meanings, which interfaced with particular EOL-related words and structured the practices that were enacted.

6.2. Overview of Chapter Six

I open this chapter with a discussion on my own narratives about particular EOL-related words as a researcher. Within this first section, I briefly revisit key points from Chapter Five about knowledge and notions of expertise. I also return to the theoretical framework and explore how Sewell (1992) considered language in relation to structures. I explicate how agents’

\textsuperscript{73} Mattingly’s (1994) “therapeutic emplotment” refers to the action perspective of narrative; that is: “to say narratives are lived before they are told” (p. 811).
narratives can differ because they are underpinned by unique and individualized schemas. Linking back to my findings in Chapter Five, I explore how individuals’ schemas reflect understandings about what people know—which can change with new knowledge. I then expound on how Sewell considered words as resources such that when they interface with schemas, different structured conditions, including actions, can result. This important theoretical undergirding supports a key point in my research findings: EOL-related words have meanings that extend past their definitions; such extension relates to the way agents’ narratives, informed by a multitude of schemas, become HCPs’ stories; and, these meanings structure and shape the way words are used and how clinical practices are enacted.

I then present my findings about EOL-related words and phrases. Specifically, I explain what I came to learn about the notion of being palliative and being “DNR” (DNR refers to a resuscitation preference, which I explain more below). Drawing from study data that captured participants’ uses of the word “palliative”, I present and discuss undergirding schemas. I also emphasize how these schemas then underlie and inform narratives and meanings; that is, I illuminate how uses of these words conveyed stories about patients. I close the chapter by examining how I came to appreciate the relationships between narratives, meanings, and actions and I illuminate how differing understandings resulted in different decision-making and practices.
6.3. What is End-of-Life Care? Considering My Own Narrative

At the outset of this study, I mistakenly assumed the words I was using to describe the purpose and aim of this study would be mutually understood by others. Inadvertently, I failed to recognize schemas underlying my own narrative of EOL planning and care including conceptual definitions, underpinnings, and embedded assumptions. From my earliest fieldwork experiences, I had documented these lessons and insights in my reflexive journal and became increasingly aware of the way the words I was using were not easily understood by others.

I had to confront and seek to understand my own narrative and address divergent views regarding uses of terms from my earliest experiences gaining access to the study sites. For example, I created study information materials with a short title: “The HF-EOL Study” (see Appendices A, B, C, and D). I sent these materials to various contacts including managers, clinical leaders, and clinicians who had been recommended as key people and possible study participants. Some respondents interpreted the short title I chose and told me they assumed I was specifically focused on the experiences of *active dying*—meaning the days immediately preceding death. I received replies advising me of where else to go for my research, including non-acute care settings and specific palliative care units where many patients were commonly deemed to be dying. I documented instances of these early encounters in fieldnotes, reflecting on how the language I was using was creating confusion:

FN (p. 32): Am I not asking in the right way?

EOL on the letter needs a change. [Participants do not] know there is an EOL trajectory here...
Using “EOL” in conversations with HCPs is [problematic] as no one [is recognizing] they do anything with dying and [HCPs] [are not] seeing patients with HF as on this EOL trajectory?

I found myself repeatedly needing to respond with more explication about how I was regarding the term “EOL” in relation to upstream activities (e.g. planning) and in relation to other functions and features within acute care practice settings (e.g. illness teaching, self-management, symptom management, and prevention of re-hospitalization).

In setting out my study focus in Chapter One, I defined EOL as the final period of life marked by the beginning of active dying, continuing until death, and including bereavement. I also argued that, based on a well-developed body of literature about HF and EOL, that patient/family experiences in the EOL period are shaped by activities that take place, or are missed, much earlier in an illness trajectory. Thus, to encompass this linkage between upstream planning and EOL experiences, I have used the phrase “EOL planning and care” throughout this dissertation and in my research fieldwork to denote my definition—a definition that I came to learn was broader than the understandings I observed at play in my research fieldwork.

On reflection, I came to appreciate my own narrative and plotlines—that is, my temporally organized understanding of the phrase “EOL planning and care”, which was a key insight from my reflexive process. For example, for patients with HF (and their family members), the beginning of a plotline in my narrative for the term “EOL care” starts at diagnosis and includes and emphasizes “planning” aspects, including patient education and communication with HCPs. Underlying schemas are also embedded. For example, I have beliefs and
assumptions about quality (for example, that patients’ own preferences ought to inform their EOL experiences), access (for example, that quality EOL care should available regardless of illness type or care setting), and disciplinary roles (for example, that all HCPs working with patients with life-limiting illnesses such as HF have some degree of professional responsibility in EOL planning and care). I also brought beliefs about how to approach the care for this patient population generally.

Indeed, I selected the terms to describe the study population and research problem came about as I commenced my research after investing considerable time studying the nuanced differentiation of concepts including, for example, the *palliative care model*, the palliative care specialty, and the *palliative approach to care* (I explained and distinguished these concepts in Chapter Two). My own narrative also *shifted* with input and feedback from my supervisory committee, who are experts in HF and EOL and palliative care and who pushed my understanding of these concepts. Though I had not recognized it initially, I had developed my own narratives with underlying schemas through the process of writing a detailed dissertation study proposal. My narratives also evolved through the process of preparation for this research and from personal experiences as a nurse and later a clinical leader and manager working with patients with HF in a range of acute care practice settings including adult critical care and outpatient clinics.

As I faced difficulties conveying the purpose of my study to potential study participants, I became increasingly attuned to definitional differences. I proceeded to more carefully explore
and seek to explain the ways I was using specific terms in my conversations. In almost all instances, I had to do additional clarification work during initial verbal meetings (in-person and via telephone) by providing more context for the study and explication of terms. Some study site leaders (e.g. contact “1”, Figure 4-1) and initial study participants sought more detailed background information about how I was conceptualizing and understanding the relationships between upstream care activities and experiences at EOL. From these early encounters, I looked at who used particular words and how they were understood. I then started asking study participants how particular understandings of these terms were developed (e.g. “How do you understand the following words?” How did you come to understand that word/phrase in that way?”). My assumption about shared meanings of clinical language was naïve and incorrect; one of the key findings from this study illuminates both similar and dissimilar understandings of commonly used, EOL-related words and phrases in acute care practice settings. This finding of individualized understandings of EOL-related words and phrases is supported theoretically, which I explain in what follows.

6.4. Sewell’s Conceptualization of Language within Structures

Taking Sewell’s (1992) conceptualization of structures as resources and schemas, value sets or ideas represented with narratives should be regarded as being composed of underlying schema (as discussed in Chapter Three). It also follows that words can be thought of as resources, and thus the interface of schemas underpinning the words-as-resources can be said to produce structural conditions that shape decisions and actions. This is an important
theoretical underpinning because it supports the finding that narratives become enacted practices and thus should be considered as having clinical as well as theoretical implications.

Sewell (1992) addressed language (i.e. words and phrases) in his theoretical explication of structure. Sewell described language and linguistic structures as preponderant and having depth\(^{74}\). Characteristically deep structures can be identified in a wide variety of contextual spheres and tend to be implicitly applied and have taken-for-granted assumptions. Deep structures also underlie common procedures or social processes, including language. Words can also be conceptualized as *resources*. This linkage highlights how schemas underlie and inform narratives, and narratives interface with words; structured actions result. How words are understood when these words interface with schemas shapes or structures the care experiences for patients and their family members. Schemas are dynamic and prone to change and shift. Evolutions in the conceptualization of palliative care, for example, have manifested with the presence of differing schemas. I will begin my explication of such schemas by discussing uses of the common phrase: “s/he/they are palliative.”

\(^{74}\) Sewell (1992) used “depth” as a way to describe dimension of some structures in relation to others. For example, Sewell said that language structures are deep because they underlie other structures.
6.5. Narrative Dimensions of Common Words and Phrases Used by HCPs to Discuss EOL in Acute Settings

As I observed and heard during my research and fieldwork, several words and phrases related to advanced illness and EOL and were used in acute care practice settings. These words functioned as a way to share highly nuanced and detailed information about patients and their family members. I refer generally to these words and phrases as “EOL-related words.” The term “palliative”, for example, was commonly used in acute care. Likewise, words and phrases about patients’ preferences for resuscitation75 (e.g. “full code”) were also commonly used.

6.5.1. What did it mean to “be” palliative? Explicating implicit schemas and narratives. I encountered the term “palliative” early on in my data collection process. For example, I recorded observational data in a fieldnote following one of my first observational buddy experiences with a participant. I was in an office with a participant who practiced nursing as a cardiac specialist in a leadership and education role. Another colleague approached this nurse with the intention to refer the patient for a consultation from this specialty role:

75 Resuscitation refers emergency interventions used for patients who experience cardiac or respiratory arrest. Such interventions include cardiopulmonary resuscitation (CPR), defibrillation, intubation and mechanical ventilation, among others.
FN (p. 20): A nurse came to see [the study participant] with a referral. [My buddy] said, “that patient is palliative.”

The nurse replied, “oh really?”

My attention was drawn to the way that a patient’s direction of care was verbally communicated among HCPs with the phrase “that patient is palliative”—as though “palliative” was a characteristic. I observed the other HCP who was involved express surprise (“oh really?”) in that encounter and no further clarification of the word “palliative” was exchanged. In this instance, being palliative implicitly meant the patient was not going to be seen by a particular HCP who was the nurse I was observing, or by a particular physician (i.e. a cardiologist), or in a particular clinic. The particular clinic was an outpatient setting designed to support optimization of medication for HF patients, which the patient would not attend because “the patient [was] palliative”.

In that encounter, being palliative also meant that instead of being seen by a particular HCP in a particular setting which was the specialist HF nurse in an acute setting, that patient was to be seen by another HCP, meaning a palliative specialist, in another setting, meaning not an acute treatment-focused care area. This implication also seemed to be mutually understood in the interaction. This was one of my earliest observation experiences and was also where I first recognized how being palliative (“that patient is palliative”) conveyed nuanced details about access to services and resources.

To be palliative was also used to convey prognostic information. For example, a participant who had a broad nursing background in multiple practice areas including general
medicine, cardiology, and critical care, compared and contrasted care experiences for patients with HF among different clinical settings. Of note, the participant explained “palliative patients” as being closer to death and more expected to die:

JG: ...both of the types of patients you described in like a medical area and in a cardiac [critical care] unit, where are they in terms of their disease trajectory?

AC002: Well, I guess, in both areas—they could be near the end. Just kind of depends on what their goals of care are I guess. Because I know we have had people on the medical unit, like pass away, you know...be kind of a palliative patient in end stage heart failure. I would almost feel like with those patients, it was more expected.

Whereas in the [cardiac critical care area], you know, if they’re...a lot of the patients are, if they’re in end-stage heart failure, trying everything they can and then they make the decision to like, you know, there’s nothing further we can do. And then they would maybe be transferred somewhere else.

The people who pass away [in critical care], I would say are sometimes more likely [to pass away] than [cardiac medicine unit] and [which is] more unexpected.

Like the fieldnote (FN (p. 20)) excerpt above, the word palliative became a characteristic (“be kind of a palliative patient”). To be palliative conveyed a person’s closeness to death (“like pass away, you know, be kind of a palliative patient in end stage heart failure”—that is, there was an underpinning schema that “palliative” meant close to death. Being palliative also functioned as a designation to communicate that death has become expected (in the previous chapter, for example, participant AC002 also described a patient as being nearly on the “palliative list”). I came to appreciate that being palliative commonly conveyed closeness to death (i.e. proximity and immediacy). That is, to be palliative was to be proximal to death.

Uses of the word “palliative” when it meant being close to death were conveyed similarly by other participants. In the excerpt below, a participant who practiced as a social worker told
me about how describing (or labelling) a patient as palliative was in some instances reserved until the illness course gained certainty and the team was confident about conveying nearness to death. The patient referred to below had HF, had been in hospital for a prolonged period, and their clinical status was deteriorating despite medical efforts including cure-focused treatments and interventions:

AC004: [I asked the cardiologist] “like, do you think they are palliative?”

And often [cardiologists] tell me, with HF, it’s very hard to know. For them. Like, where are they are at. And often I find, that they tell me, “no he’s not palliative yet... I can’t tell how long he has.”

In this excerpt, the word palliative functioned as a decision point, associated with an understanding that the person’s proximity to death was near (“no he’s not palliative yet”).

Assumptions (i.e. schemas) about predictability were also embedded and underlying this narrative. Patients who had an uncertain prognosis (“I can’t tell how long he has”) were not always regarded as palliative “yet.” As the palliative label was associated with nearness to death, the term also conveyed a type of care for the dying (i.e. days/weeks remain before death)—that is, a type of care with minimal curative-focused treatments and interventions, though the patient was not “yet” at that point.

Another participant who practiced as a cardiac and critical care nurse, similarly described “palliative” as a decision point that indicated nearness to death:

AC002: “I was looking after a guy with heart failure just like a few weeks ago and he was like super end-stage, like, not on the palliative list yet, but like, [the health care team] were applying to it in like the next couple days.”
The term palliative here functioned as a set of procedures, applied during the EOL period (meaning active dying), and was reserved for the final moments of life—that is, for the care that should follow after “super end-stage.” Of note, the palliative title was not always easily ascribed even when a patient was assessed to be medically unwell and was likely to benefit from the integration of palliative principles and palliative specialists in their care.

To some participants, being palliative related to a narrative reflecting finality and exhausted options, and perhaps a degree of abandonment, from schemas about “giving up” on the goal of diagnosing, treating, and curing. That is, to be palliative conveyed a story that meant “there is nothing further we can do”—that is, nothing further in terms of curative/treatment interventions, and possible palliative interventions were not identified. A participant who was practicing in cardiology explained their disciplinary background and the challenge of expending treatment options:

AC021: Your first day in med school, it’s saving lives. Get them better. Palliative care is assisting dying. And that concept is a struggle for any physician. It’s hard to say I’m not going to do anything.

And it’s one of the things that we learn in our training, that near the end of our training of...we need to learn when to say, I’m not going to do anything more. There’s nothing more I can do here. So, I could see that as being a problem. It’s innate in us.

We need the patient to be this close to death and they wouldn’t give up. None of us would. That’s why we went into this, to save lives. To make people better.

But, yes, there, we have to realize that there comes a point where we need to start talking about [end of life].

The other problem with that, is, from our end, is sometimes you don’t know.
The shift towards palliative here was framed within the idea that there was nothing left to do ("It’s hard to say I’m not going to do anything...There’s nothing more I can do here").

Dependence on certainty was also evident; the participant conveyed disinclination to use a palliative label without strong confidence that treatment/curative efforts were expended. At risk with use of the term, was inadvertently conveying giving up or abandoning a foundational value (i.e. “saving lives”).

Functionally, to be palliative conveyed information about ways some HCPs, services, and interventions were offered and others were not. Palliative also conveyed prognostic meanings and meant or conveyed nearness to death. These meanings told stories to others (e.g. “giving up” and “there is nothing further to do”); as I elaborate on in the next section, these stories were understood differently depending on the agent and evoked different reactions.

6.5.1.1. Managing others’ understandings and reactions to what it meant to be palliative: Strategies to clarify and control others’ interpretations. Participant AC021 used the word “hard” in the excerpt above to articulate the difficulty of implying and/or explicitly conveying impressions to others that the participant was not going to do anything further (i.e. that there is nothing left to do). This difficulty was described as both nonphysical and psychological. That is, it was taking place in the mind as a subjective and mental experience with emotional components—I called this emotion, which I explore further in Chapter Seven.

Patients’ and family members’ responses were based on their own understandings and interpretations of a word such as “palliative”, and were also described by participants as difficult
and challenging at times. For example, a participant who practiced medicine in cardiology described their experience managing others’ (colleagues, patients, and families) responses to uses of the word palliative:

AC021: A lot of it, it’s, that sense that if I’m saying palliative, then I’m giving up. Versus, there is a lot to say for palliative can work side-by-side with what you’re doing as well. To a certain degree.

And that is an education thing more than anything. But having said that, most of us are not there. Most of us do not know or appreciate that. Because it’s subtle. And a lot of us are…and families as well. I have to be very brave to go into a room full of family members and tell them we’re going to consult palliative care.

JG: Because it means what?

AC021: Because they’re thinking he’s going to die tomorrow. Or today. Right? They’re immediately, “what? You said that you’re going to do this and that? Why are we getting palliative? We want chest tubes.” Right? So that’s a whole other can of worms, right?

Um. But um. And I’ll often, and we often have to say that, and I… I, would pre-phrase it… “I’m about to say a word now, I don’t want you guys to misunderstand, but when we have palliative care, it doesn’t mean he’s going to die tomorrow but I just want to see if they can help with comfort” and this and that. It’s…it’s a lot of misconception… around what palliative…around what palliative can and will do.

In this excerpt above, participant AC021 expressed concern about patients’/families’ perceptions of the word “palliative”—that is, concern about managing reactions to an underlying schema of palliative meaning imminent death, or conveying that HCPs are “giving up.” This finding illuminated the existence of implicit meanings about the word palliative at a societal level, which influenced patients and their families. In response to these implicit meanings and their diverse interpretations, participants described needing to clarify misunderstandings and unintended messaging, and manage others’ strong emotions (e.g. grief, sadness, anger). Study participants also described strategies they used to manage patients’/families’ responses to
“palliative.” For example, in the excerpt above, participant AC021 explained how they used a “pre-phrase” to aid in clarifying intended meanings and purpose: “I’m about to say a word now, I don’t want you guys to misunderstand…”

Bravery was also described as necessary for patients’/families’ responses. Anticipating patients’/families’ responses, and the common thinking that these responses from patients and their family members were potentially difficult, participants told me that HCPs need bravery. In an excerpt above, for example, participant AC021 explained how bravery was needed at decision-points where palliative care consultation discussed (“I have to be brave to go into a room full of family members and tell them we’re going to consult palliative care”). This bravery related to different dimensions of difficulty including the experience of confronting HCPs’ own psychological responses, responding to emotional responses and demonstrations from others, as well as the act of engaging in a conversation where illness expectations (i.e. estimating prognosis, outlining the morbidity trajectory) were discussed (i.e. having conversations about dying and death and being in the presence of death). Collectively, these strategies also point to the significance of emotion, which I take up in the next chapter where I talk about the third major area of findings: How HCPs felt and acted.

“Palliative” was an example of an EOL-related word that HCPs used to describe issues such as treatment preferences, to denote a particular place where dying patients go, to impart the inclusion and exclusion of specialist HCPs, and to convey someone’s closeness to death. Of note, these meanings were extended beyond a definition of “palliative.” Patients deemed to be
palliative were commonly those receiving non-interventional/non-treatment/non-curative focused care. The word palliative was also used to convey implicit stories about information such as procedural details and treatment plans, interventions, and patients’ care preferences. The word palliative also became a personal character attribute—HCPs discussed the notion of being palliative as if it were a trait or personal characteristic: “that person is palliative.” Overall, the word palliative had a wide range of different meanings and despite this range of meanings and uses, explications of the intended meaning were rare. In my hours of fieldwork observations, I did not encounter any instance where the term “palliative” was clarified during interprofessional communication exchanges. Instead, these narrative meanings were consistently implicit and yet conveyed nuanced information.

Some meanings of the word palliative seemed to be common and understood by many, whereas other meanings were uncommon and less understood. Collectively, the schemas shared and understood by many constituted what I inferred to be commonly underlying the dominant narrative, which also appeared to reflect schemas that aligned within a classic and traditional understanding of the palliative care model. Such classical and traditional understandings entailed meanings such as immediate nearness to death; inclusion and exclusion of particular HCPs; settings where care should be provided; and a shift from a treatment and cure-focus to a non-treatment, non-cure focus. Conceptually, the schemas undergirding the dominant narrative of “palliative” most closely captured understandings of palliative as reflected in the traditional palliative care model as described in Chapter Two (see
Figure 2-2). That is, where curative treatment was understood as characterizing the focus
during the majority of a disease trajectory until an abrupt shift occurs and palliative care (i.e.
support-focused) was initiated. Death is assumed to follow shortly thereafter. These classic and
traditional understandings contrasted against alternative understandings which reflected shifts in
the narrative.

6.5.1.2. Shifting narratives: Dissemination of the concept of a palliative approach

and concomitant influences on schemas and narrative meanings. While some meanings of
the word “palliative” were common and understood by many, there were other schemas
underlying narrative meanings of the word palliative and what it meant to be palliative. As I
learned from participants, these different meanings were in part related to recent educational
initiatives and research studies that were taking place. Participants described how this new
knowledge had shaped what the word “palliative” meant for them. Likewise, these education
and knowledge-building sessions also shaped what “heart failure” meant. As I explored in
Chapter Five, in some of these education sessions, “HF” was framed in relation to “cancer”
which was highly influential on participants’ narratives about what it meant to have HF.

In contrast to what I recognized to be commonly understood schemas underlying
“palliative” and the dominant narrative, the less commonly understood schemas made up what I
called shifting narrative. This shifting narrative reflected meanings derived conceptually from the
palliative approach philosophy, which I explained in Chapter Two. I wrote a fieldnote entry about
what I observed to be some evolutions in the way participants were using and understanding
the palliative term:

FN (p. 60): Language: palliative, defined as the last, last, last phase (as understood in
practice), seems to be equated to active dying.

[I am seeing] evolutions in this term also— references to palliative approach [from
participants]?

I heard these evolutions in other observations and interviews as well. For example, a participant
with several years of experience nursing on medical units explained their current understanding
of “palliative”; this participant used additional “classifying” terms to further differentiate specific
treatment preferences, care goals, and prescribed medical orders/directions:

BM015: When I think palliative care, the first thing that comes to mind is our palliative
care consult team. That’s the people, well, that they come in like to assess, which
patients would be appropriate.

JG: Appropriate for what?

BM015: So, um, it would be for being referred to. So, it would be if that patient actually
fits their guidelines...And so they would come in and they would assess the patient, ask
what their goals are, and how they can help them. With either comfort or, or to get to, to
get to their goal.

JG: Who helps patients determine what their goals are?

BM015: Um. They would just... I think the patient would need to decide that for
themselves. But the options would be presented by a doctor.

JG: Which doctor typically? Is that like a palliative care doctor or is that like the acute
medicine?

BM015: It’s usually...in acute medicine they are usually under the hospitalist or um, or a
[another medical unit] team. And then so that would just be their [primary physician]. It
would be like, where things are going, what their plans are, and then to continue with
medical treatment or you could go for more symptom management. Or it would be some
combination or something like that. And palliative team would be offered sometimes for
that as well.

JG: If, when we say that a patient is palliative, does that mean then that they’re
consulted by the palliative care team and that these patients are followed by them?
BM015: Yea. It means that, well to me, like there’s with palliative, it’s the... it’s kind of, it could be someone who’s just in their final days with something that’s happened really quickly like a stroke or something.

Or it could mean that like someone that has like cancer diagnosis. But they know that the end is within sight. And they just want to start setting up things that they could even be seen by... like the palliative practitioner in the community. Like to have that resource there.

JG: And how does it work for treatment? So, can you have somebody who has palliative care but also has active treatment?

BM015: Well so for us, it’s, usually we try to classify it. As in like, “oh they’re acute medicine treatment,” or “they’re either comfort care or terminal care.”

So, for us, like medicine treatment, even if they have the cancer diagnosis and, and the palliative team like consults with them usually for things like pain control and things like that. Then... we’d still be like giving them antibiotics, checking their vitals, if anything happens, then we would still like um, it depends on what they want but either move to [a unit that can manage higher acuity patients] or [an intensive care unit] or something like that.

This participant used three additional terms (i.e. acute medicine treatment, comfort care, terminal care) as an attempt to provide clearer explanations and differentiation of both procedural care (e.g. vital signs, antibiotics) and overall goals (e.g. comfort, being out of hospital). I asked for further clarification about the meaning of “terminal” and “comfort care”:

JG: So you said the words “terminal” or “comfort care”...so how is that different and how does that fit with palliative care?

BM015: ... I’m not sure these are like actual terminology or not, but for our ward’s understanding, comfort care is... more...like, you still give the medical treatment. Like still antibiotics if they need. But their main goal is comfort.

So, make sure that they’re comfortable. Either with like, emotional like having family there or if they don’t want their family there that’s up to them too... If any medical treatment causes them discomfort and they, if they don’t want that then we don’t give that.

JG: And terminal care is different?

BM015: Terminal is more of like their goal is just to be comfortable. We don’t do any medical treatments because the end should be coming really soon.

JG: And how soon is soon?
BM015: Well. For...I know this might be a bit specific but in our medical ward we have a specific end of life bed that anyone in the hospital [can use]. The bed is designated for someone that is going to pass in the next 72 hours.

So, for us we normally have a designated end of life patient that is going to go within 72 hours. We just give them a little space with privacy...that way they can like have more family there. That is a little off to the side so that they don't get jostled with all the medical rush.

Of note, the description of palliative from this study participant expanded the use of the term for both patients “in the final days” and for those where “the end is within sight.” The participant also explained the notion of concurrent treatment and supportive-focused care (“... what their plans are, and then to continue with medical treatment or you could go for more symptom management. Or it would be some combination or something like that”).

Participant BM015’s use of these classifications to differentiate “palliative patients” illuminated underlying assumptions, which differed from how I heard others using the term palliative with schemas underlying the dominant narrative (i.e. the classic and traditional palliative care model). For example, being palliative as a consequence of having “nothing further to be done” was contrasted here with BM015’s explication that some patients continued with medical treatment, including interventions and escalation of clinical care environments (e.g. critical care), depending on the patients’ personal goals and preferences. An implicit though discernable schema underlying the classifications described by this study participant was the belief that palliative principles can be integrated alongside curative-treatment-focused care. This concurrent view aligns within the conceptualization of a palliative approach to care.

At both study sites, and across all the different clinical practice areas where I carried out data collection, participants told me about how recent education had influenced their thinking
about the meaning of “palliative.” That is, knowledge development activities concomitant with my research fieldwork were creating evolutions in participants understandings of this particular term, which also reflected my own process, as I described in an earlier section of this chapter. For example, a participant explained how a recent education event influenced their understanding of palliative care:

   JG: So, to begin, what does it mean if I say end of life? What does that mean to you?

   BM017: Oh. That’s a good question. Um...[pause]. When I like, during my practice, I’ve seen a lot of people having...heart failure. But they ended up having sort of no choice. But other than they deteriorate every single day. And then they choose to be in a comfortable way...to me, that’s end of life.

   ... it’s hard to say it’s **palliative** [emphasis in original] to me. But end of life is really going to be comfort care.

   JG: So, end of life then, would you say that’s the active dying stage?

   BM017: [nodding]

   JG: And then how does that differ from palliative care?

   BM017: ...that one, I really um, talk about it... talked about it with [our nurse educator] because there are huge discrepancies between palliative and end of life.

   JG: Yea, so tell me about that.

   BM017: So, palliative care is you get the full treatment but it’s sort of reversing the symptoms. And um... make yourself comfortable. But comfort care, to me, end of life equals to comfort care. Um...means that you focus on your pain management and you focus, you’re preparing to just, to pass away.

   JG: So, then the goal of care is comfort but in palliative, you still will see that there’s treatment that’s offered?

   BM017: Of course, yea.

In this excerpt, the participant’s conceptualization of “comfort care” was equated with “EOL care” (“comfort care, to me, end of life equals comfort care...you’re preparing to just, to pass
away”). Alternative assumptions about the idea of being palliative are also apparent. For example, the presentation of palliative care as “you get the full treatment” with symptom-alleviation emphasis, illuminated an underlying schema that palliative was a concurrent strategy to treatment interventions. Such concurrence reframed the experience of being palliative as appropriate within acute care practice settings for those who understood acute care as the locations where treatment-focused care was provided.

Understandings of the word palliative, and the related service implications including referrals, were also evolving. A participant introduced above as having a clinical practice in social work, explained their experience navigating what I came to recognize as reluctance to call a patient palliative:

JG: So, the reluctance for physicians to call a patient palliative, relates to...?

AC004: I’m not sure what it is. I don’t know if they feel, okay that’s it, I’ve given up. Um, it’s the end of their life. I don’t really, I’m not sure.

I haven’t had that conversation but I do get, [pause] I get the sense that they are uncomfortable with that piece. And they try very hard not to get to that point. Where they have to have that conversation or... [pause] and when they do, this person is really, like, very sick. Very sick. And they normally die within their admission.

JG: Do you ever see someone get called “palliative” without having a palliative specialist follow them? Like do they always need to have a palliative program come on board or can a patient be palliative without...?

AC004: I think that’s the change. Because before, yes, we needed that referral [to a palliative care specialist]. Maybe a year, maybe 6 months now, or a year has [changed]. Yes, we had to refer to the palliative program [in the past].

And often [the palliative specialist team] would come back to us and say, “I’m sorry, we cannot. He’s a cardiac patient. We don’t know how long they have. Therefore, they don’t qualify for the program.” Which is, at that time, I think it was like a year less to live. To determine that, and a lot of our patients don’t have that...
So, I think the changes they’ve made to the palliative program recently, so now, one of our docs...he made a referral to the palliative program and I said, “how did you do that?” and he said, “I only refer for medication palliative stuff.” So [patients] can be covered.

...In the past this meant, so a doc says, “this, this person will last a year,” so you have access to home care, to equipment, like medical beds, and all sorts of things. Right? So, that’s what it meant a year ago. Now it’s sort of changed I think a little bit more. And I’m still trying to...figure it out.

Within this exchange, the speaker recalled a change in the way that patients came to be known as palliative. They explained particular changes with the way the referral to palliative specialists has shaped access to services and resources such as expertise, medications, and equipment.

I asked if a patient would be called “palliative” without having a palliative specialist team consulted. This participant responded by highlighting a practice change. Where previously a patient may have been called “palliative” after the involvement of palliative specialists, in current practice, palliative specialist consults occurred without necessarily designating someone as palliative. Within this conceptualization, the term palliative encompassed a broader definition where palliative specialists supported complex issues related to advanced illness (e.g. symptom control, home support needs) without fully changing the direction of care (i.e. from treatment-focused to supportive). Consultation to palliative specialists also was described to occur independently from diagnosis, prognosis, and anticipation of immanent death.

As is apparent in the excerpts above, participants raised many different EOL-related terms (e.g. terminal care, comfort care, end of life) when talking about EOL planning and care. While I focused specifically on meanings underpinning the word “palliative”, I did not fully explore these other terms of their implicit meanings, though it would likely be worthwhile for future study and is a recommendation I note in Chapter Nine. However, I will explore terms
about resuscitation preferences (e.g. “code status”) as they were important and frequently used within interprofessional communications.

6.5.2. What does it mean to “be” a particular resuscitation direction? Explicating schemas and narratives associated with preferences for resuscitation or code status.

Medical directions about resuscitation were widely regarded as essential medical instructions in acute clinical practice settings (i.e. “code status”\textsuperscript{76}). Like being palliative, being a particular code status, which referred to a particular resuscitation direction, also held meaning that was past the simple definition of the resuscitation direction. Code status was a significant feature in all the acute care inpatient units I observed; indeed, in many instances it was the first piece of medical information shared among HCPs after a patient’s name (for example, “Mrs. G. She’s full code...”). And, in the same way that “palliative” was used to convey a story (i.e. as having an implicit narrative underpinned by schemas that created different meanings), code status designations (e.g. “full code”) also conveyed information with narratives.

I will explain what a resuscitation direction actually is and to what it was intended to refer as I will compare and contrast schemas and narratives related to the different designations. To

\textsuperscript{76} “Code status” is a commonly used phrase. “Code” refers to the action of “calling a code blue”, which is the emergency response procedure used to summon a variety of HCPs trained in cardiac and respiratory resuscitation interventions.
this end, I start by explaining what I learned about what resuscitation directions actually were and then I discuss what I found they actually meant and how they were taken up and enacted.

6.5.2.1. Explaining “code status”: A descriptive account of resuscitation

directions. As I have noted above, resuscitation instructions were foregrounded in my observations of participants’ communication exchanges and “code status” was frequently shared between participants and other HCPs. All participants described these patient care orders as foundational and necessary; they were designed at an organizational-level across the health authority to provide instructions about emergency interventions (e.g. immediate involvement of a critical care team), including a range of resuscitation efforts (e.g. CPR, ventilation support) for patients who experience sudden and life-threatening physical conditions (e.g. cardiac arrest, respiratory arrest). As I heard from participant NP014, who had special expertise in ACP initiatives including resuscitation directions, in theory, code status (i.e. the medical directions for resuscitation) was envisioned to be the product of more detailed and repeated conversations with patients about their broader values, wishes, and treatment goals. According to NP014, such conversations included, for example, ACP and goals of care. Both were intended to take place in different settings, including hospitals.

As I learned from participant NP014, ideally, ACP conversations were thought as best taking place prior to new or sudden illness by a capable individual who is not acutely ill. This information is then meant to be shared with others who may become involved in medical decision-making, should the individual be unable to make their own decisions. In contrast,
goals-of-care conversations were described by NP014 as useful for someone who experienced changes in their health status, necessitating more specific directions about treatment and care goals, preferences, and wishes. Code status conversations and decisions were thought of as ideally informed by details shared during ACP and goals-of-care conversations. I illustrated relationships between code status, goals-of-care conversations, and ACP in a fieldnote drawing that I created while talking to this participant (see Figure 6-1):

FN (p. 115) [digital illustration recreated from sketch]

![Figure 6-1: Fieldnote (recreated from sketch), code status and ACP relationships](image)

In short, the aim of code status conversations was to identify *specific directions* about emergency interventions including resuscitation.

In NP014’s view, conversations about code status and ACP were also envisioned in theory to be a *multidisciplinary* responsibility; however, there were also specific disciplinary responsibilities related to which professional was permitted to actually sign a form with resuscitation directives:

NP014: So, how I see it now, is that it’s everybody’s, everybody can have the
discussions. And, and so, the question was also about the broader sense, I don’t know if when the [resuscitation directives] policy was developed, people think often that [resuscitation directives] is advance care planning.

We think of advance care planning as a broad umbrella and [resuscitation directives] is just one little piece of the form that needs to be a one-pager that acute care can use mostly [laughing] to summarize what are we supposed to do around the changing condition of the client. Or what’s happening with the client or how much we do for them.

So, I, I think that the broader advance care planning can happen with anyone. So, it’s certainly with families. And, and their loved ones. That’s where it starts. And then their family doctors and physicians. But I think that [occupational therapist] or [physiotherapist] and any allied health staff can have conversations with the patients around their wishes or goals. Might be the dietitian. So that’s how I see it. But I don’t know if all of the disciplines see this as part of their role.

As NP014 outlined, the responsibility to engage patients in conversations that informed scope-of-treatment and resuscitations decisions belonged to all HCPs; however, physicians were ultimately responsible for determining and documenting code status direction, both legally as well as within assumed disciplinary roles as discussed in Chapter Five.

Participants who practiced at the bedside described processes around resuscitation conversations similarly. For example, a participant who practiced cardiac nursing described the relationships between ACP and resuscitation preferences conversations:

JG: With the [resuscitation directions form] who has got the signing authority there? Who does that belong to?

AC006: The physicians.

JG: Exclusively?

AC006: Um hm [affirming response]

JG: But the ACP documents, the form is different, it's multidisciplinary?

AC006: Yes.

JG: How, do you understand, what is your understanding of how the [resuscitation directions] actually relates to the ACP form?
AC006: I think the [resuscitation directions form] is created kind of, out of the conversation of your advance care planning. But, they are separate, even though they’re linked, they’re separate documents.

And, the only connection the [resuscitation directions form] really has is that it should be, kind of, derived from the conversations done during advance care planning.

From theoretical relationship between resuscitation directions and ACP—meaning, that ACP-type conversations inform resuscitation directions—two documentation tools were created for resuscitation directions and related communication: the resuscitation directions form (i.e. code status form) and an ACP form. The resuscitation/code status form contained specific medical directions narrowly related to emergency resuscitation efforts and interventions. In contrast, the ACP form was designed for HCPs to document and include details from conversations that informed the resuscitation direction. Participant NP014 used the term “married” to describe the intended relationship between the ACP form and the code status form and explained that they were designed to function as a unit.

6.5.2.1.1. A disconnect between theory and practice: How the forms were actually used in practice. While designed to function together, in my observations and from interviews with participants, the ACP form and resuscitation directions form were rarely both completed. As the resuscitation form was required in accordance with the institutional policy, it was completed consistently. The ACP form, however, was not required or consistently completed. I recorded a fieldnote from an observation experience with AC004, who was a social worker who practiced in the cardiac units. Participant AC004 attempted to show me a completed ACP form that they had done for a patient; however, the form was missing and we could not locate it:
FN (p. 45 – 47). [Resuscitation form] is in effect [and required] throughout [the health authority] and [has] regional use.

Very detailed, [however][limited] use in clinical practice.

[As per AC004] used by [social workers] only, and only occasionally. Not read by anyone else either.

ACP planning notes [written recently by AC004]. AC004 tried to find one to show me but the form was missing [from the chart].

AC004 told me that ACP discussions should inform the [resuscitation directions]. [I] asked who else triggers those [conversations]? [Social workers and bedside nurses]. rarely [physicians] per AC004.

Participants also told me about the disconnect between the intended uses of these two forms, compared to what was actually done. A participant who practiced nursing in cardiac and critical care explained both the theory and the reality, noting that the ACP form was almost never actually done:

JG: What type of infrastructure exists for then, how nurses or any discipline, would document [information about ACP conversations]? To share it?

AC006: We do have an advance care planning form. It’s supposed to be discussed with patient on admission throughout their stay.

Um, and it’s supposed to, kind of direct our [resuscitation directions] form. For their code status. Um. But I find it's not used well in [health authority].

And I think a lot of staff, when a patient arrives on the unit, they already have [resuscitation directions form] filled out [from the community or from a previous admission], so they don't have those conversations with the patient.

But it’s actually an ongoing kind of assessment and evaluation of what the patient understands.

JG: So, lots of “supposed to’s” when you’re describing the ACP form?


Conversations with participants in the excerpts above (AC006, AC004, NP014) indicated that these participants understood both the intention of the forms and process—that is, ACP
ought to inform other decisions, including resuscitation directions—but recognized a disconnect in practice. Other participants were less familiar with the theoretical relationship between ACP and resuscitation directions. For example, a participant who practiced nursing in medical units told me that they had never seen an ACP form used in practice:

JG: And have you ever seen an advance care plan?

BM012: Um. I think... I saw it in school. But I haven’t seen one on our unit. In practice, yea.

JG: Have you ever been involved in making one?

BM012: For a hospitalized patient? Hm. No. But I’ve, I’ve given people like notary numbers and that kind of thing. I’ve never been a part of the actual process.

This disconnect is significant because as I will show in the next section, HCPs held upstream assumptions from an actual resuscitation event and understandings about what it meant to be any particular code status. These assumptions informed practice decisions and actions. I summarized this relationship in a fieldnote, following an interview with participant AC002:

FN (p. 81): "full code" status linked to acute care [units]. Relevant because supposed to be underpinned by a 'goals-of-care' conversations.


“Full code” was assumed to mean full treatment outside of resuscitation. This assumption was common and informed upstream thinking—it also points to how code status designations (e.g. “full code” “no code”) sometimes had conflated narrative aspects, which I will explore next.

6.5.3. What it meant to “be” a resuscitation direction: Explicating schemas and implicit narratives. Different descriptors were used to convey directions for resuscitation among HCPs. Although I did not observe or hear any explications with the frequently used
terms “full code”, “no code”, and “DNR” (do not resuscitate), I observed these terms to be tacitly understood among users. As was explained to me upon request, “full code” indicated maximal resuscitation options meaning medical interventions should be used in the event of sudden cardiac or respiratory arrest (or sudden change in physical condition). In contrast, “no code” or “DNR” (which is a commonly used acronym for the phrase “do not resuscitate”) meant that minimal interventions and no resuscitation-specific actions (e.g. CPR, artificial ventilation) were to be performed.

Code status directions functioned past their intended purpose. For instance, “making him a DNR” conveyed much more than emergency instructions for resuscitation. Making someone a DNR, or becoming a DNR, or choosing to become a DNR, signified a transition in the overall goals of care. A participant explained how teams engage in conversations about EOL issues including resuscitation directions (i.e. code status) using a clinical anecdote from their experiences as a social worker in acute cardiac units:

AC004: Sometimes I find nursing too...like they find [patent's care plans] distressing. Um, when, like we have a good fellow here, [Mr. X], he's been here like three weeks or so and he's just not improving.

Like he seems to be worse, but yea...

So, nursing was sort of prompting, “like gee, should we continue on? Like, should we, you know...?”

But usually at rounds, like it just gets–they are focusing on the medical piece. What needs to be done and so, I don’t know if they forget or what, but I try to do rounds as well and so that’s when I will then jump in and, I have had a conversation with the wife and she did say, “...you know, yes, when he came in he was a full code, because he was fantastic before this. But now, look at him, and it’s been two weeks and he’s still confused, and so sick.”
What’s the point of doing all these crazy interventions, he’s suffering, he’s not... you know? So, let’s, let’s change that and let’s make him a DNR. Because that’s not what he would want.

I’ve had these discussions with him and he would not want to be a vegetable.

I asked for clarification about what it means to become a DNR:

JG: What does it mean to become a DNR?

AC004: Yea, so it just means, no CPR and no intubation specifically. We still treat the symptoms, pain management, um, hydration, nutrition, that sort of thing.

The first excerpt implicitly conveyed becoming DNR as a shift in care (i.e. from “crazy interventions” and “suffering” to something else). Values, preferences (“he would not want to be a vegetable”), goals of care (i.e. “he’s suffering” therefore, “let’s change that and make him a DNR”), and closeness to death were also embedded within code status statements. There was also an implied relationship where DNR tacitly conveyed a patient’s wish to maximize quality of life through avoidance of suffering via therapies aimed at reducing symptoms such as pain. Implicit within the QOL descriptions were also values and judgments (e.g. “he would not want to be a vegetable”).

Other participants described assumptions other clinicians made when they heard a patient was a “DNR.” For example, the participant speaking in the excerpt below practiced as a nurse in medical units. They shared an experience where their patient needed a specialty assessment and possibly a different care environment but faced barriers stemming from health care team members’ assumptions about the patient’s previously expressed and specific preference for no CPR:

BM008: Sometimes too, the physicians, towards the...going through times of crisis, um, change the code status so that critical care will actually come and see that patient.
Because then critical care will come and be like “okay they’re a [do not resuscitate, no critical care]. I’m not coming”.

So, they’ll change [the code status] just to have that consult done.

JG: Because the patient needs a higher level of care but doesn’t necessarily need the CPR? But they need that higher level of intervention?

BM008: Right. It could just be, some monitoring or it could just be for [non-invasive ventilation]. Just to get them through this crisis.

But the internist won’t come. Because they’re a [do not resuscitate, no critical care]. And even sometimes [Respiratory Therapist] doesn’t come.

JG: So, what I’m thinking from that statement, is that, though we have written directions, like on the [CPR directives form], there is a gray area in practice?

BM008: For sure. Absolutely.

As is apparent from BM008, being DNR was undergirded by a schema with assumptions about how a preference for resuscitation related to broader care directions including potentially non-resuscitative crises such as needing a higher level of care, including nursing care or closer monitoring. These situations can arise patients require interventions for what are often thought to be reversible conditions such as arrhythmias. Being DNR conveyed implicit, though not necessarily valid, understandings that preferences for minimal resuscitation inventions were assumed to also reflect preferences for minimal treatment and intervention-focused care outside of resuscitation.

Other participants described “DNR” as being the resuscitation preference at the end of life when, as is implied, most treatments and interventions are no longer wanted:

JG: When you see doctors [talk to patients about their code status], how does that look? Or when you do it yourself, what do you do?
BM012: Well. On the nursing side, I never have to ask. Patients will, will express. Because by that point, we’ve gotten so close. You know, family feels comfortable. Patient feels comfortable.

They’ll say, “you know, I’ve, I’ve reached a point where I no longer want to do this.” Or, “I feel like I’m coming to the end of my life.” Or whatever the case may be. Or they’ll say like, “I don’t want to go out like this,” kind of thing.

As I came to understand, most participants used code status terms with underlying assumptions that becoming and being a particular code status (e.g. DNR), shifted goals of care and decisions upstream outside of resuscitation. Value statements were also apparent in participants’ descriptions about resuscitation preferences; that is, a value indicating that in the setting of nearness to death, “quality of life” is paramount and goals of care should adjust to avoid perceptions of suffering. As participants often positioned suffering in relation to continued cure-focused treatments and interventions, such treatments and interventions would be withheld and/or withdrawn to alleviate suffering. This recognition of values is important. In Chapter Seven I explore how recognition of values relates to a third major area of findings How HCPs felt and acted.
In summary, medical orders about resuscitation (i.e. code status) were intended to direct the narrow and focused medical actions for the uncommon\textsuperscript{77} event of cardiac or respiratory failure. In acute care practice however, resuscitation decisions were used to communicate much more nuanced information extending beyond simple resuscitation directions. Instead, resuscitation directions and “code status” were highly symbolic and were used to reflect broader patient care goals, directions, and actions. Resuscitation information was also conveyed like a character attribute (e.g. “he is a...”) with implied care directions, where patients in acute care clinical practice settings were commonly said to be full code or to be no code. In this way, code status, like “palliative”, had underlying schemas with implicit and explicit narrative qualities.

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\textsuperscript{77} Though cardiac and respiratory arrest events are significant and memorable, they are actually uncommon and infrequent. Eroglu, Onur, Urgan et al. (2014) retrospectively looked at five consecutive months of “code blue” events, which is an overhead emergency call that indicates to critical care teams that a patient has experienced respiratory or cardiac arrest and requires resuscitation interventions such as CPR or mechanical ventilation (or other interventions).

The authors counted a total of 89 “code blue” activation events within this five-month period at a hospital that served 72,000 patients per month. The authors also reported only 8 patients in the five-month period were actually requiring resuscitation interventions. The authors concluded: “81 (91\%) [of activations] were wrong code blue activations in our hospital” (p. 21).
6.6. How Clinical Decisions and Enacted Practices were Structured from Implicit Schemas and Narratives

Health care professionals made decisions and enacted care based on their understandings of EOL-related terms. Terms such as “palliative,” “DNR,” “full code,” and “EOL” reflected significant meanings. Because these terms functioned within interprofessional communication as a way through which nuanced information was shared (e.g. medical orders/directions, expectations, and patient/family goals), the implicit information shared often went past the terms’ actual definitions. Instead, these words reflected nuanced and tacit meanings, which were not always mutually understood among HCPs and were rarely explained—these words functioned as narratives with stories made-up by the users.

Other EOL-related words and phrases were also used to convey information about patients. For example, participant BM017 identified other terms and attempted to better qualify and articulate their intended messages: “medicine treatment,” “comfort care,” “terminal care,” or “making someone comfortable,” were additional phrases used in communication exchanges between HCPs. These other terms were not commonly explicated by the HCPs using them; yet the words also conveyed nuanced and complex information about patients to other HCPs. A participant with a practice in cardiac nursing described their experiences navigating the idea of “making someone comfortable.” This participant described clinical decisions and actions (e.g. clinical decisions related to diuresis and other medications) that arose from how particular HCPs understood the meanings of these words:
BC019: ...they sort of do sort of stress and emphasize comfort. Right? And making sure the patient is comfortable.

I think sometimes it’s misunderstood in how to make an end-of-life cardiac patient comfortable. Cause sometimes they think, “oh we should stop all their meds, we should you know?”

And really, you know, you do want to continue to diurese\(^78\). And you do want to continue to afterload reduction\(^79\) because those things are going to improve their dyspnea. And so just because they’re palliative doesn’t mean you withdraw their active therapies.

In this excerpt, participant BC019 highlighted different understandings associated with making someone comfortable and shared insights about how to some HCPs, these words implied actions such as withholding cardiac medications. In contrast, this participant interpreted “comfortable” as continuing symptom-controlling medications and some “active therapies,” provided they aligned with the patient’s care goals.

Other participants also described linkages between clinical thinking, decisions, and actions in relation to how meanings were derived from different EOL-related words. In the

\(^{78}\) As I explained in Chapter Two, “diurese” refers to a pharmacologically-induced state of diuresing. Medications such as furosemide (Lasix) are commonly used in HF to induce diuresis with the aim of decreasing overall circulating fluid volume.

\(^{79}\) As I explained in Chapter Two, “afterload reduction” means to reduce the amount of vascular pressure that a weakened ventricle needs to beat against in order to eject blood. Afterload reduction is an important hemodynamic goal in HF with systolic dysfunction (HF-REF) because in this type of HF, the ventricular muscle is weakened and blood will back up into the lungs or body, depending on whether the right or left ventricle is affected, when afterload is too high. Blood backing up into the body or lungs can cause unpleasant physical symptoms including dyspnea and edema (Gibson & Nordby, 2014).
fieldnote below, I describe a conversation I had with a participant who practiced cardiology and critical care medicine. This participant described their experiences navigating unintended patient care actions after calling a patient “palliative”:

FN (p. 61). Talked to [NC022] today... highlighted a couple points that I hadn’t considered:

1. When doctors say, “palliate” a patient, [others] don’t understand (e.g. [described how a nurse had discontinued the [oxygen] when [oxygen] was needed),

2. Quick CPR conversations vs. values conversations–based on time available,

3. “No one likes to give bad news.” Closely [related to: no one really knows who will survive [critical care] (e.g. prognostication so difficult).

This participant told me that they use the word “palliative” with both colleagues, patients, and family members cautiously in order to avoid unintended interpretations. Specifically, this participant described experiences where others have enacted an unintended direction such as withdrawing or withholding other supportive therapies (e.g. oxygen) in the context of different understandings of “palliative.” Of note, the third point about giving “bad news” highlights the emotional element in this work, which I will explore in Chapter Seven.

To some HCPs, the word palliative does not preclude the use of medical interventions and/or treatment-focused care (i.e. “active therapies”). A previously introduced study participant who states below, “to me, palliative means you do everything,” describes a clinical situation where their understanding and intention using particular words (i.e. “palliative” vs. “comfort care”), mismatched that of another HCP:

JG: And in clinical practice, knowing that definition...you said that there were big discrepancies, where do you see it?
BM017: ...she was a really old [patient]. So, a massive [pulmonary embolism]. She was on heparin infusion. And then it ended up, [they] had a massive GI bleeding. There was some point that this is too old [patient], does she need this massive heparin infusion and the bleeding? So, they decided to make [the patient] comfort care.

But they referred her to palliative care team first and then there was no order for comfort care. So, [the patient] was still palliative to me. That was even not my patient but I was helping my partner. But [they were] on a break. So, I was the primary nurse for the patient.

And then [the patient] started [experiencing oxygen desaturation]. It was like 70% on room air.80

So, um, to me, palliative means you do everything. What you can do...except for like, you know, for example, for cancer patients, chemo, radiation, it doesn’t mean that it’s palliative. So...I hooked [the patient] up to high flow [oxygen]. I called [the Respiratory Therapist]. I did everything I could do.

But then the site leader...came and [they] said, “oh she is, he’s um, comfort care. Why did you put up a high flow?”

But I showed [them] the chart and, “look at this, this is palliative team care...and, I mean referral...and there is a progress note from the [physician], may go to comfort care.” And everybody is saying that “[the patient] is comfort care.” But there was no terminal care order.

To me comfort care means end...like we have to actually get the order to have the terminal care. Which is like [supportive medication], [supportive medication], or [analgesic medication] [every hour], right?

So, um, and then, I told [the site leader] that it’s my nursing decision to give [they] oxygen to make [them] comfortable. Even though [they are] going to, [the patient] is going to pass away within a few hours. And then yea, [the site leader] said, “yea...”

You can see everywhere in medicine floor, or other floors, that there’s huge discrepancies.

JG: When you... if you would have seen a comfort care order, that would have been more clear to you?

80 For most individuals, a normal oxygen saturation level is higher than 92%.
BM017: Absolutely 

JG: That the treatment [emphasis in original] part has stopped?

BM017: Absolutely. Treatment part has stopped.

JG: And then there is pre-printed orders? To give you that... and certain procedures to... pain control and stuff?

BM017: Exactly. So, without that comfort care order, you’re left wondering how much [emphasis in original] treatment is left even if still palliative. So, there’s a palliative order, you know comfort is an emphasis but there’s still treatment.

As becomes clear in the excerpt above, assumptions and interpretations about terms and phrases can confuse the decision-making and lead to contested clinical actions (e.g. starting high-flow oxygen therapy as compared to the fieldnote above where participant NC022 recalls a colleague removing oxygen as a consequence of the use of the word “palliative”). That is, meanings of EOL-related words were understood dissimilarly from one agent to another; contested (and unintended) practices resulted.

Contested practice illustrates how participants’ own narratives, and their understanding of language and schemas underlying code status designations, influenced judgment and clinical decisions. For example, HCPs’ assumptions about what it meant to be DNR shaped assumptions about patients’ care preferences outside of resuscitation. Assumptions about what it meant to be DNR also shaped actual patient care decisions and actions. An important point is illuminated from this finding: that patients who are identified as “DNR” (i.e. they have expressed a preference not to receive CPR and/or mechanical ventilation) may receive less intervention than they desire and/or HCPs may be less inclined to consider treatment and intervention options (including options that focus on symptom management) outside of cardiac/respiratory
arrest situations. Conversely, assumptions about what it meant to be full code, may limit access to palliative specialist referrals and/or integration of palliative approach principles and related actions including supportive communication.

6.6.1. A prism effect: Illustrating how different words can result in an array of meanings. As I examined, analyzed, and interpreted relationships between implicit and shifting narratives and enacted practices, I came to think about EOL-related words as having had a prism-like effect. Much like a ray of light passes through a prism to produce an array of colors, metaphorically, a multitude of schemas and narratives passed through EOL-related words (e.g. “palliative”), which cast an array of meanings.

In the diagrams below, I illustrate how the word “palliative” reflected a range of schemas and cast a range of interpretations, depending on the individual agent’s own narrative. I used colors to point at differences in how participants expressed schemas differently. In Figure 6-4, I drew samples of the schemas I heard underlying the dominant narrative of “palliative (e.g. there is nothing left to do, palliative is a place other than acute care where patients go to die). I also illustrated what I heard about how this narrative was (and could be) translated into enacted practices (e.g. withdrawing therapies such as oxygen, consulting palliative care specialists).
I contrasted schemas underlying the dominant narrative illustrated in Figure 6-4 with other schemas I heard underlying the shifting narrative of “palliative”. These other schemas were reflected in a narrative that resembled the palliative approach (see Figure 6-5). Here, (Figure 6-5) I drew the word “palliative” with examples of schemas reflecting palliative as a concurrent care strategy alongside treatment-focused approaches; as an approach that guides decisions based on individuals’ preferences in the context of a life-limiting illness trajectory; and others. When these schemas were interpreted through the prism reflecting the resource “palliative” and this shifting narrative, different possible interpretations and enacted practices resulted (e.g.
integration of palliative care principles into existing acute-focused care, and early communication about EOL planning and care issues considered for patients and their families).

Figure 6-5: Palliative prism and the palliative approach to care (shifting narrative)

Sewell (1992) reminds us to also consider the enactment of schemas as unpredictable. In Chapter Five, participants shared their knowledge-building experiences with initiatives that have been aimed at integrating a palliative approach in acute care practices (e.g. in medical units), which resulted in new knowledge and new ways of understanding the term “palliative.” In effect, those knowledge initiatives introduced new schemas that now underlie different and divergent narratives. As I also noted in the sections above, the EOL-related words that I examined were rarely explicated by users (in fact, were only really done so following my explicit
requesting of participants to do so) and yet, I observed these words to be assumed as mutually understood in countless interprofessional exchanges. Without clear explication of the narratives underpinning the words used in practice to talk about EOL planning and care, meanings and actions vary. In Figure 6-6, I illustrate how these varied schemas can be thought of as scattered without explication of these terms (see Figure 6-6).

Figure 6-6: Scattered narratives, unpredictable interpretations.

In summary, schemas underlie narratives, which belong to agents and are therefore diverse. Narratives, which are composed of schemas, interrelated with words, which can be
thought of as resources. Throughout this chapter I focused attention to differences in how HCPs understood the meanings of EOL-related words. And importantly, I described how agents thought and enacted clinical decisions and practices differently, depending on their own interpretations of the meanings of narratives. A significant implication follows from this divergence and is an important one that I return to in Chapter Nine: within acute care settings, what HCPs say and intend to convey, can mismatch what is heard, understood, and enacted by other HCPs. That is, thinking about how HCPs become willing to engage patients and their family members in EOL planning and care, and how they move to actually doing it, initiatives aimed at improving EOL planning and care ought to consider existing assumptions about the language used to talk about EOL.

6.7. Chapter Summary

Acute care units where patients with HF access EOL planning and care contained complex, conflicting, and evolving narratives about EOL-related words. Within health care teams, important and widely used EOL-related words and phrases were underpinned by schemas, which underlie narratives; these words came to mean different things to different agents because they were created from various schemas. Among HCPs, terms and phrases such as “palliative” and code status designations (e.g. “full code”) were used past their definitions; instead, complex and nuanced information was communicated about EOL issues including goals of care, preferences and values, recommendations, and medical directions. Proximity to death and prognosis (“nothing further we can do”) were also conveyed through the
narratives in EOL-related terms and phrases. Importantly, varied uses of these terms influenced clinical care differently, depending on how the agents interpreted meanings. In the absence of mutual understanding and meanings of words used in clinical practice settings to discuss a range of EOL issues, contested and unintended practice decisions may result.

In the next chapter, I delve into the emotions of HF-EOL planning and care work and present findings related to the third major area—How HCPs felt and acted. At a societal level generally, EOL and death are commonly regarded as grievous and sad; however, as I will explore in Chapter Seven, HCPs’ emotional experiences are more complex and nuanced. Instead, the qualities of HCPs’ emotions are related to HCPs’ own perceptions, preferences, and values in relation to what they understand as patients’ and family member’s experiences.
Chapter 7
How Health Care Professionals Felt and Acted: Coping with Difficult Emotions and Value Incongruence in the Work of EOL Planning and Care

In Chapter Six, I explored a major area of findings about *What HCPs said and heard*. I examined uses of EOL-related words and phrases, analyzed their underpinning schemas, and explored how narratives undergirded meanings and structured practices. Though several EOL-related words and phrases were exchanged between HCPs, I focused on two types of words/phrases in particular: “palliative” and words/phrases related to “code status.” As the findings from the previous chapter have illuminated, various HCPs used and interpreted words differently. Importantly, these interpretations varied, which structured clinical decisions and practices differently, depending on the individual agent’s interpretation.

In this seventh chapter, I build from the notion of “bad news” that I introduced in Chapter Six (e.g. FN (p. 61) where participant NC022 told me: “no one likes to give bad news”). I look at aspects inherent in “bad news” and share what I learned about HCPs’ own internal experiences of EOL planning and care, the emotional and value-based dimensions in relation to EOL planning and care work, and how these aspects structured practices. I look at a third major area of findings about *How HCPs felt and acted*. Here, I shift focus and explore *feelings* in EOL planning and care. In this analysis, I am drawing from Hochschild’s (2003) definition of “feelings”
and regarding feelings and emotions\(^{81}\) as related. That is, I use the phrase “feel” (and “to feel”) to mean experiences of an emotion. In contrast, I use the term “emotions” to describe the subjective responses and meaning-making that individuals experience from inputs, which can include feelings as well as sensory inputs (e.g. pain, hot, cold, soft, and hard).

In the content forthcoming, I explain what I identified about complexities and structural implications in the emotional and value-based\(^{82}\) dimensions of HF-EOL planning and care work.

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\(^{81}\) Various definitions of “emotion” and “feelings” can be found in the literature. The brief definitional work here is not intended to be exhaustive; instead I provide it here for greater clarity around how I use these terms in this dissertation.

Damasio (2000), writing as a neuroscientist, recognized feelings and emotions as connected by distinct based on their neurologic and physiologic involvements. In Damasio’s view, “feelings” refers to the neurological awareness of stimuli (e.g. fear) whereas “emotions” are the complex physiologic body responses from such stimuli (e.g. racing heart, muscle contracting). In Plutchik’s (1980) view, “feelings” is a narrower term that describes sensory inputs (e.g. cold, hot, smooth, rough), whereas “emotions” are what feelings bring-about. That is, according to Plutchik, “emotions” refers to the subjective responses (e.g. sad, mad, rage, joy, fear) in response to sensory inputs.

Hochschild (2003) approached these terms different and defined them with more synonymy: “we feel. But what is a feeling? I would define feeling, like emotion, as a sense, like the sense of hearing or sight. In a general way, we experience it when bodily sensations are joined with what we see or imagine” (p. 17). As I draw on Hochschild’s work about emotional labor where I discuss my findings in Chapter Eight, I see the relevance of Hochschild’s interpretation to this dissertation and thus draw from Hochchild’s definitions of “feelings” and “emotions.”

\(^{82}\) In this dissertation, I propose that “values” refers to the ideas and things that an individual sees as having intrinsic worth or inherent desirability. Jiwani (2017) defines values similarly: “a value is simply understood as something that is important” (p. 5)). “Beliefs” are ideas that individuals regard as true.
In using the affective term “feelings”, I point at two internal dimensions: thoughts/schemas (i.e. non-physical, psychological), which suggests individuality and inherent variability, though I also recognize that within a constructionist epistemological perspective\textsuperscript{83} shared experiences in similar social circumstances are also possible; and, emotions. Health care professionals’ experiences of these internal processes (i.e. thoughts and emotions) are complex and contingent on the context and circumstances where they arise, including, for example, the HCPs’ self-assessed knowledge, experience, and personal sense of comfort and competence in the experience.

7.1. Overview of Chapter Seven

End-of-life planning and care exist with a significant emotional dimension for HCPs; thus, I open this chapter by explaining how I first came to recognize emotional dimensions of HF-EOL planning and care work. Drawing from my findings, I present what I identified as explanations of and expressions of emotion. These emotional expressions included explicit descriptions about experiences with difficult feelings such as awkwardness, fear, and worry. I use excerpts from my

\textsuperscript{83} As I have outlined in Chapter Three, I understand constructionism from Crotty (1998). According to Crotty, constructionism “is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (p. 42).
data to situate these emotional expressions in relation to examples and recollections of clinical practice scenarios—my aim here is to show what I learned about which aspects of HF-EOL planning and care provoked HCPs’ emotions. I illuminate relationships between HCPs’ experiences of emotions, and their perceptions as well as understandings about patients’ preferences, goals, and care decisions. It is my contention that the relationship between HCPs’ values and preferences, and perceptions about patients’ care, constitutes an important aspect of HCPs’ emotional experiences of HF-EOL planning and care. This relationship also connects to what I learned about the ways HCPs used strategies to control emotion in HF-EOL work, thus I present my analysis of these strategies and how they structure particular HF-EOL planning and care practices.

7.2. Emotional Dimensions of EOL Planning and Care

The emotional nature of HF-EOL planning and care work became apparent to me early on in my research fieldwork. I had spent several hours shadowing a study participant who was an experienced cardiac nurse with HF expertise. I accompanied this participant to a patient/family meeting, which was organized as part of the preparations for a planned discharge of a patient the following day, and following that patient’s multi-day, HF-related hospital admission. At the outset, the aim of the meeting was to connect with the patient and their family members, review introductory HF illness education and self-management strategies, and discuss the discharge and follow-up plan. While this had been the patient’s first HF admission, the patient had previously been hospitalized for other non-cardiac reasons. When we arrived, it
became quickly apparent that the patient and their family members were unaware of the HF diagnosis at all.

FN (p. 106-107): I asked [the participant] later if this [i.e. no HF teaching done] was common as [patient] had been admitted [more than five] days with HF [and] no previous teaching done.

This observation stood out to me as significant in two ways. First, I had been expecting that the patient would have at least a minimal understanding of their situation. And secondly, I observed how the study participant (BC011) was able to quickly adjust their approach and delivery. This participant was expecting to reinforce HF education. Instead, the conversation and education content altered substantially and the participant found themselves in the role of being, what the participant later called: “the bearer of bad news”.

We met again after the observation experiences as participant BC011 also participated in a semi-structured interview. The encounter I have described above stood out for me, so I invited the participant to share their impressions about the experience. The conversation began with a discussion about disciplinary scope and roles:

JG: When I was in a shadow [observation shifts] with you we had a situation where the patient was for the first-time hearing that they had HF. And they had been in hospital for several days.

And, I just wanted to get a sense of like where your role is in relation to other people. Are you the only person that, that does this work? Is there an expectation that other people will also do [HF education] work? That is, talking to people about the illness?

BC011: Well like there is an expectation that the doctor will have talked to them about their illness. But that doesn’t always occur. I don’t tend to find that in my experience, that nursing staff always talk to the patients about their illness. Like the [nurse who is assigned to look after the patient for that shift].

Yea, so there is, there should be an expectation that [colleagues] are talking to the patient about their illness. Other disciplines, not only me.
In my experience when I do speak with the patients I tend to be, the [main communicator], whether they recognize that it’s the first that they’ve heard it or whether they feel like it is the first time that they’ve heard it.

They may have been told it before but maybe they didn’t hear or understand what it was.

I find that [for many of] the patients, that I’m the bearer of bad news.

Several findings became clear from this excerpt and from what I also heard and observed from other participants. There was an implicit assumption about disciplinary scope and roles; in particular, that physicians lead HF-EOL planning and care conversations and that nurses uncommonly engage in this work, and perhaps are only optionally expected to—“there should be an expectation...”. Implicit in this excerpt is also what I recognized as an emotional aspect. Being the “bearer of bad news” is underpinned by an implicit assumption (i.e. schema) and explicit description (e.g. “bad”) that conversations about illness issues are bad news. With an assumption that illness news is inherently “bad” news, participant BC011 and others described these interactions as emotionally difficult.

Many other participants also talked about the emotional dimensions of conversations and planning around more general illness issues, including HF self-management teaching. For example, a participant who practiced cardiac medicine in a range of acute and outpatient settings, shared their understanding about which HCPs speak with patients and their family members about illness and discharge issues and what content is taught:

JG: So, when you go into a cardiology consult service in to those types of areas, what are your assumptions about who is doing that self-management education and helping people go home with discharge planning? What are you assuming is happening there and whose role is that?

BC019: I don’t think anyone wants to take on that role.
I experienced an “a ha” moment as I listened to this participant’s candid response (“I don’t think anyone wants to take on that role”). This participant plainly acknowledged that the work of self-management education and discharge planning, which falls within EOL planning, was widely regarded as undesirable. This acknowledgement and points to the difficult nature of HF-EOL planning work. Over time, I came to better understand how emotions undergirded the perceived difficulty of EOL planning and care.

7.2.1. Navigating HCP’s own and others’ emotions in EOL planning and care. As I have indicated in my analyses above, various aspects of HF-EOL planning and care evoked emotions. I will show here how some participants explained HF-EOL planning and care experiences with descriptive characteristics and terms such as “awkward” and “hard.” Other participants explained how the difficulties of HF-EOL work meant HCPs needed to be “brave”, which I touched on in the previous chapter. These explanations about the emotional difficulties of HF-EOL and why this work was “awkward” and “hard” related to ways HF-EOL work evoked emotion from others including patients, families, and other colleagues, as well as from participants as HCPs themselves.

7.2.1.1. EOL planning and care as “awkward” and “hard.” Conversations about serious illnesses such as HF and about EOL planning and care issues were commonly said to be “awkward” and “hard.” For example, at the end of an interview a participant who was an experienced nurse and who practiced in cardiac and critical care units, offered closing remarks that emphasized their experiences engaging patients and their families in discussions about “it”: 
JG: ...I don’t have any other questions. Do you have anything that you want to add?

AC002: Um. Not that I can think of but yea, definitely, yea like. I just... I find it awkward to talk about end-of-life stuff.

And, I, I’ve had those conversations with patients before but it’s... always like, something’s like triggered it, then I talk about it. I guess I make assumptions that like people don’t want to talk about it.

The awkwardness expressed by this participant was described as related to an implicit assumption and schema that patients and colleagues do not want to talk about illness and EOL issues. This participant’s experience also illuminated how HCPs wait for some reason or trigger (for example, the patient asks) before entering into interactions about EOL planning and care.

Other participants used the word “hard” to characterize emotional and physical aspects of HF-EOL planning and care work. In the excerpt below, a participant who practiced nursing in general medicine units and who also had an education and leadership role, explained the significance of conversations to them that were said to be “hard emotionally”:

BC011: But, but it affects you. Personally. On a personal level. Right? And so, I found that, I wasn’t... over the years, I wasn’t as engaging to the, with the patients, as I maybe would have been at the beginning of my career.

Because it’s just, it’s too overwhelming. And I tended to bring it home with me. And you know, um, I just didn’t, I didn’t want to have those difficult conversations because it was difficult for, for me, to you know, internalize that.

And so, I sort of, put up barriers and walls to limit you know, how far I would, I would engage in that type of conversation with a patient. Right? So.

You know, I think, there’s an element…it’s a hard job. It’s hard emotionally. It’s hard physically. And I think that there’s just a limit to people’s um, what they can, what they can internalize and take. You know?

The participant described these “difficult” conversations as “overwhelming” and articulated an internal limit to the emotional impact HCPs could bear. Strategies used to manage these
emotions were also explained including distancing (“put up barriers and walls”) and controlling the depth of conversations (“to limit how far I would engage”), which point at structured practices (I come back to this finding in section 7.4).

A participant with a clinical practice in cardiac nursing and critical care similarly described their own experiences with colleagues having a “hard time talking about it”:

AC002: I feel like everyone’s a full code unless [patients] say something that they don’t want to be full code. Or something happens that [HCPs say], “there’s not really much else that we can do for this person”.

JG: Whose responsibility is it to clarify with patients or families what a code status is?

AC002: I would say nursing could talk to them about it for sure. But the physician has to actually clarify. And like, be there to hear them say that. And sign it.

JG: Who does that more commonly? Even though, if it also falls to nursing? Who, which, health care provider?

AC002: I would still say the physician. The physician. I, I think it’s hard. I don’t know. A lot of nurses have a hard time talking about it.

JG: Nurses have a hard time you said?

AC002: I think so.

JG: And what do you think is underpinning that?

AC002: Hm. It’s just... uncomfortable I guess. To bring it up.

This participant related conversations about resuscitation to the feeling of being uncomfortable. Such feelings of discomfort were similar to how many other participants described the work of HF-EOL planning and care.

7.2.1.2. Directly addressing mortality is a “hard” aspect of EOL planning and care.

A participant who was a nurse with practice experiences in palliative care, critical care, and cardiac units, clearly explicated the burden of directly addressing someone else’s death. They
shared their perspective about why EOL planning and care meant directly confronting mortality, which was “hard” for some HCPs:

BC003: I think in general, we as health care professionals have a hard time telling people.

If I’m just going to totally generalize, we have a hard time as a group of professionals telling another human that they’re going to die. Based on our experience. Based on the information that we have. We don’t know. We’re not clairvoyant. We don’t have magical powers that tell us exactly when someone is going to pass away.

That much I did learn from palliative care actually.

But I think, as a whole, we have a hard time as a group of professionals telling people...and who wants to deliver that message?

And yet, I have yet to meet one person who says, “pick me, let me go tell that young mom that she is not going to make it another six months.” No one wants to say that.

Challenges navigating both uncertainties overall within the context of certainty about mortality were also illuminated—that is, participants described how difficult it was to deliver information about the certainty of death from HF, while also providing information about the uncertainty of when and how the death will occur (“We don’t have magical powers that tell us exactly when someone is going to pass away”). The participant also conveyed emotional elements associated with disclosing the imminence of death to someone (“no one wants to say that”).

7.2.1.3. How EOL planning and care elicited participants’ and others’ emotions.

Engaging patients and their families in HF-EOL planning and care meant other people’s emotions were also involved, which made up another aspect of how these experiences were “hard” and difficult for some study participants. For example, confronting illness and EOL issues evoked emotions such as anger from others. A participant introduced above as the nurse who
was experienced in palliative, cardiac, and critical care, described their encounters with those
“hard conversations” and what they identified as other people’s “anger”:

BC003: I’ve seen a few physicians have those hard conversations with patients when they realize that what they are about to do likely will not change anything for this person or possibly with make things actually worse. And I respect those conversations.

They don’t always make sense and people get angry. Patients get angry. Families get angry because they just want a cure.

The expressed idea of having “respect” for physicians willing to have those “hard conversations” implicitly conveys how difficult emotional responses from patients/families were also difficult emotional experiences for the HCP involved.

Others’ sad emotions were also evoked from EOL planning and care interactions. In the excerpt below, for example, the participant described how a patient was “bawling” after hearing and understanding their prognosis:

BC003: I still remember this day, this one young man, he couldn’t have been more than maybe 45 years old. And he had some, you know, pre-existing disease process and essentially, he had been in the hospital for two or three admissions in about two years for his heart failure.

But his last one was the worst and he was probably on his second week of being in the [cardiac critical care area] and I remember thinking, he’s never getting out of here.

Like he’s just, every – it was two steps forward, four back for him. For everything you’d do, he’d end up with something wrong. With some other problem.

And I remember one of the surgeons coming in and, after coming to sort of a nursing-round situation, us saying to this physician, as a group of, of team members, “no one has told this young man just how bad this is. No one has told this man, like, has really given him the hard news of what this means for him.”

JG: And by hard news, you mean he’s nearing death?

BC003: Meaning, that there’s a pretty high chance and no one wants to admit that he’s going to die in the next six to twelve months.
And I remember this physician going in and saying to him, and me listening to these two talk from ten feet away—this doctor saying to him, “I’m going to be hard with you and I’m going to tell you that there is about a fifty five percent chance that you’re not going to make it through this year.”

And the man, you could see him sort of doing the math, and saying, “wait a second...there’s a higher probability that I’m going to die than I’m going to live?”

And he broke down. He was bawling and he was like...I don’t know.

In the excerpt above, use of the word “admitting” stood out (“no one wants to admit that he’s going to die”). “Admitting” highlighted an implicit assumption that HCPs may be disinclined to deliver “hard news.” Uncertainty, and the risk of giving incorrect information, also evoked other emotions including fear and worry for patients, patients’ families, and for HCPs.

Anticipating patients’ futures, particularly when these futures were expected to be uncertain, which was presented in relation to HCPs’ perceptions and their beliefs about patients' quality of life, also elicited HCPs’ emotions. An experienced physician with a practice in cardiology and intensive care talked about making decisions “emotionally”:

BC019: ...people often emotionally decide, “oh I think this patient is going to do badly.”

JG: People, you mean, nurses? Health care professionals?

BC019: Health care professionals, yea.

In this participant’s view, “going to do badly” was an emotional reaction. “Going to do badly” was also an idea with an implicit meaning—that is “going to do badly” meant that patient was expected to experience death or considerable morbidity despite available medical interventions.

7.2.1.4. Fears and worries about making mistakes, giving wrong information, and provoking interprofessional conflict. For some participants, conversations about HF illness progression and EOL in the setting of uncertainty evoked feelings of worry around possibly
making a mistake or giving patients/families wrong information. A participant who practiced nursing in a general medicine unit explained their role in preparing someone to understand HF as a terminal illness during an acute care admission. They used the word “afraid” to explicate their feelings of worry about saying the wrong thing:

JG: How do you see your role in preparing someone who has a terminal illness such as heart failure? How do you see, they come into hospital just regular decompensated heart failure, need Lasix, need whatever...what’s your role in helping that patient and the family, what’s your role?

BM017: Oh. I don’t know. I think... I really...do we do? [laughing] Yea, because we’re kind of afraid of talking to the family members about the patients, you know, not actual prognosis, but the future plan.

JG: Who’s, when you say “we are afraid” who do you mean? Nurses, doctors All of us?

BM017: Yea, yea. Of course [all of us].

JG: And what do you think is underlying that fear? Why are we afraid?

BM017: Maybe they’re afraid of making mistakes and then get blamed if something happens. Or they don’t want to be the person that, who’s notifying the family members about this bad news

In this excerpt, “making mistakes” and worrying about being “blamed” was explained in relation to the delivery of HF illness and EOL information. In the setting of illness uncertainty in HF, the information may evolve or change depending on the patient, which meant HCPs had to then also navigate what might be seen as incorrect previous information.

As I explored in Chapter Five, emotions of fear and worry may also relate to interprofessional dynamics including respecting tacit disciplinary expectations, roles, permissions, and boundaries. For example, participant BM015, who practiced as a nurse in medical units talked about being “just a regular RN.” Being a “regular RN” meant that a more
appropriate (i.e. authorized or expert) colleague would need to first bring up EOL planning and care issues. Without this preliminary step, the participant conveyed that they did not have *permission* to engage patients and their families in HF-EOL planning and care and thus interprofessional conflict would be anticipated. In this same interview, this participant elaborated on the *consequence* of overstepping this boundary and explained this conflict further. I asked participant BM015 to tell me about their role in talking to patients with HF about their illness and EOL planning and care considerations:

JG: So how do you see your role in helping [patients] understand [HF illness issues]?  

BC015: Well I think like, what we were talking about before, it’s kind of... we tend to avoid that kind of conversation...  

And then how like people just don’t understand. And I don’t think we really want to approach that to be like, “okay, this is how it’s going to go.” [laughing]  

Because like, I think we just don’t want to talk about [EOL planning and care].  

Because then that’ll make them...[pause] well, in the immediate, because...I know it sounds really bad but because we do twelve-hour shifts. [laughing]  

It’s like, you don’t want to mess up the rest of your day and have them like stressed and panicked.  

And then they’ll be like, “I want to talk to the doctor right now.” Like well, then you have to make the extra call and do the extra walking to get to the call.  

Talk to the doctor, who may or may not be like, well “why did you talk to them about it, like, I don’t have time for this.”  

As becomes clear from the excerpt above, some participants perceived a risk of interprofessional conflict if they carried out EOL planning and care activities without regard for what they understood as tacit boundaries and permissions. The participant also notes how EOL planning and care activities can increase workloads for nurses and colleagues (“then you have
to make the extra call and do the extra walking to get the call. Talk to the doctor, who may or may not be like, well ‘why did you talk to them about it, like I don’t have time for this.’”). The conflicts here points to difficult emotional experiences for the HCPs involved.

**7.2.1.5. Being outside a comfort zone.** Conversations about HF-EOL planning and care issues such as resuscitation directions were described as difficult and were also said to push HCPs to feel “out of their comfort zone.” A participant with a nursing practice in general medicine described how they understood their role in clarifying resuscitation options regarding code status with patients:

BM012: And I think the onus is supposed to be on the doctors but [clarifying code status] falls on the nurses a lot. And I think we often have to, you know, push the doctors.

Like when they, when a patient comes into hospital, it’s often that the doctor won’t even fill out the [resuscitation directions form] until the nurse has flagged it and said, “hello, we have to complete the [resuscitation directions form] for this patient.”

And sometimes they’ll just, whatever, go in and say, “oh full code.” I don’t even know if they always have a conversation that matters. So, I’m not sure. I’m not sure.

JG: So, when you talk about pushing people to fill out the [resuscitation directions] form, would you say that there’s like reluctance then...Or, what’s the hold-up there?

BM012: I don’t know. I don’t know if it’s reluctance. I think sometimes it has to do with just comfort zone, and people not being, some physicians not being comfortable with having that conversation.

The participant’s description of a “conversation that matters” highlighted the complexity of conversations about illness and EOL issues including resuscitation preferences. Needing to “push the doctors” vis-à-vis perceived feelings of “not being comfortable” also illuminated the complex personal emotional output that some HCPs experience.
Navigating disciplinary differences in relation to patient care goals and directions also positioned HCPs such that they needed to assume an advocacy role and engage in an interdisciplinary dialogue, and, at times, conflict. For some, this interprofessional advocacy was said to come easily; for others, this role was difficult, which I interpreted as an aspect of the “comfort zone” noted above by participant BM012. One participant, introduced earlier in my findings and who had clinical experiences in palliative, cardiac, and critical care nursing, shared their experience influencing the care goals, interventions, and directions for a patient near the EOL:

BC003: ...You’re a physician [speaking of a medical colleague], I’m not questioning your judgment skills and your assessment skills. But something doesn’t seem right.

And you know, I thankfully, I’ve had a few years of nursing experience under my belt at that point that I could say with confidence, “this isn’t going the way that I think it should go.”

And the family members are distressed, the patient is clearly distressed. Is there something more that we can do?

To be honest, the physician didn’t really want to hear what I had to say. I believe [they] thought that I was backing [them] into a corner and [they] kind of got defensive with me. And all that I could keep doing is saying, “I respect that you have an opinion, this is your patient, but this is what I’m telling you I’m witnessing and I’m just asking if there is something more that we can do.” Whether that shaped [them] in any way, I don’t know.

...I think the general energy I got from that physician was [they were] reluctant, that [they were] nervous, that I was suggesting something that was a bit far out, possibly, for [them].

I don’t know what [their] clinical experience was. But I was essentially asking [them] to double this patient’s opioids at a minimum and [they weren’t] comfortable with that.

The participant above described how they drew on their clinical experience and expertise to share a professional opinion with the aim of altering the patient’s care. Efforts to influence patient care directions were described as professionally demanding and required
communication skills and the ability to navigate implicit disciplinary expectations and professional boundaries (which may not be explicitly defined).

I identified another important point from this excerpt: this participant was recollecting an account of their experience advocating for a particular EOL care approach; they noted, “this isn’t going to way I think I should go.” Implicitly, this points to beliefs and values—that is, it illuminated HCPs’ perceptions (i.e. thoughts and judgments about, based on values) and preferences (i.e. recommendations for) about their patients. I recognized this as a value-based dimension of EOL planning and care.

7.3. Values-Based Dimensions of EOL Planning and Care: Perceptions, Preferences and Incongruence with Others’ Decisions

As I came to understand, there was a relationship between the emotional dimensions, meaning the experiences of feelings that arose from EOL planning and care work, and values-based dimensions, meaning the personal values and beliefs that informed individuals’
preferences in relation to their perceptions about others’ preferences, of HF-EOL planning and care. Jiwani (2017) defined values in relation to the things that matter to an individual:

Our values can be important to use in two ways: intrinsically or instrumentally.

Something is intrinsically or inherently important to me when it is an end worthy of pursuit—when it is important for its own sake. Something is instrumentally or strategically important when it is a means towards ends of greater value to me (p. 6).

I recognized values in the way participants conveyed their preferences about patients’ care—that is, a HCP’s preferences about a patients’ care flowed from the HCP’s own values about what was inherently important. Particular patient wishes, directions, and actions about resuscitation (i.e. code status) evoked vivid descriptions and strong emotional expressions from participants in particular circumstances.

A participant who was an experienced nurse with a practice in acute medicine and geriatrics, explained how resuscitation wishes and directions elicited others to articulate their preferences and express emotions. This participant shared insights about how colleagues

Of note, in Canada, regulated HCPs are governed by professional Codes of Ethics (see Canadian Nurses Association (2017) or Canadian Medical Association (2018) for examples). Professional values ought to be informed by sources including professional codes of ethics, which take as a starting point for the importance of listening to patients’ preferences.
became conflicted, which I interpreted to have some degree of emotional difficulty, when they disagreed, which I interpreted as having different preferences based on an inherent conflict in values about what they perceived a patient wanted (“Oh my goodness, they’re full code!? What are they doing?”). The participant’s account conveys colleagues’ difficult emotional responses, pointing to feelings of frustration, disagreement, and/or exasperation:

BM008: ...something that, that always kind of irks me [in the] back of my head too is, if [patients] have made at peace with always wanting interventions done or medicines done, [HCPs should be following along] with that and [HCPs should be] happy for [the patient] and [look] at that as a positive.

Because I think in health care a lot of times I hear, “Oh my goodness, they’re full code? What are they doing? They are adamantly dying!”

And so, if you’re okay with the fact that I’m going to do CPR on you and you’re going to be intubated and you’re going to have meds given to you at time of death...if you’re okay with that, I’m happy.

Because you are not going to be okay with me letting you go. Um, and doing the pal...like more of a palliative approach. You’re not going to be happy with that. At that moment.

This excerpt illuminates a disconnect and tension between the individual HCP’s values and preferences. More specifically, “full code” was perceived to be an inappropriate wish or decision, based on the HCP’s own value in relation to the HCP’s subjective assessment of the patient’s quality of life. This value-based assessment was in tension with what the HCP perceived to be the patient’s actual care directive (i.e. “full code”). This disconnect is an example of what I have interpreted as incongruence. Over time, I came to recognize incongruence as component of emotionally difficult experiences. In contrast, I interpreted congruence as alignment between the
individual HCP’s values and preferences, and their perceptions of the actual care, which seemed to lessen emotional difficulties.

I heard what I recognized as incongruence from other participants as well. For example, I asked participant BM008 to elaborate on feeling “irked”, which they mentioned in an excerpt above:

JG: You mentioned something...[something that] irks you, I think you said—when people don’t respect the plan of full interventions? So, who, who do you see not respecting that plan or not being in favor for that plan? You used as an example, “oh that person’s full code” as if there’s a negative...thing there? Whose voice are you speaking about?

BM008: That’s what I hear from, from nursing staff. Or even the doctors. Or, if we call critical care to come and see the patient...you know, it’s sometimes that’s what the internist will say. So, it’s...so our staff.

I do try to mentor [colleagues]. You know what? This is [a patient’s] wish.

You’re doing everything they’ve asked you for. And ultimately, we’re here for the patients. Right? And sometimes cultures play into it as well. And we’re only respecting their culture.

JG: ...Is there like a preferable plan that patients and families should [emphasis in original] have from the perspective of the health care provider? Do you think that there’s a good [emphasis in original] plan?

BM008: Yea! [emphasis in original]

JG: And what is that? What is that?

BM008: Whatever we want them to have.

JG: Yea, what is that?

BM008: It’s whatever we want them to have. What’s easier for us.

As is clear in the excerpt above, the participant points to how HCPs hold values, perceptions, and preferences about patients’ wishes and decisions. The participant explains particular patient wishes and decisions as “easier”—that is, what was easier was “whatever we want them to
have”—which pointed to what Jiwani (2017) called an instrumental value (i.e. it was a means towards ends of greater value, which was the “easier” option). This “easier” experience reflected *congruence*—that is, the degree of *similarity* between what the HCP thought ought to happen, compared to what they thought[^85] was happening[^86]. Overall, HCPs expressed that the more aligned and congruent the situation between HCPs and patients, the “easier” the emotional experience.

Other participants similarly described how HCPs’ own perceptions and preferences related to how easy EOL planning and care situations *could* be. For example, a participant with a medical practice in cardiology and critical care explained how HCPs hold “pre-set ideas” about what is “best” for patients; when the patient/family was “resonating” with these “pre-set ideas”, the communication was more favorable:

[^85]: I am using the word “thought” here intentionally because I want to focus on how these are often HPCs’ perceptions about what is happening, rather than objective accounts of fact. “Perceptions” and “thinking” are more appropriate than “knowing” because perceptions can also relate to ideas about others’ preferences. As was clear from the findings I presented in Chapter Six, in most instances, aside from brief documentation and/or first-hand conversations with a person, a preference is a personal position that does not allow another person to ever fully know. HCPs’ perceptions most often point to assumptions about others’ preferences, rather than actual accounts of a patient’s expressed wish.

[^86]: Jiwani (2017) used the word “integrity” to describe the alignment of individuals’ beliefs and actions (p. 3). I am discussing alignment of individuals’ thoughts (i.e. the processes that precede actions) and thus I proposed new term: “congruence.”
BC019: ...I think both physicians and nurses have a pre-set idea about what they feel is best for the patient. And obviously they, you know, communicate more favorably if the family is resonating with that. Versus if it’s the opposite.

I find nurses are sometimes pessimists about patient’s outcomes. And they say, “aw, what are we doing here?”

Right? And, so you know, when you go against that, or the family goes against that, there is, there is some sort of controversy.

Conflicts arose when “pre-set ideas” (i.e. preferences and judgments) were said to be dissimilar from actual care (i.e. perceptions about what is actually happening). The participant used the word “controversy” to name this type of conflict (e.g. between HCPs and between HCPs and patients/families). This data thus points to an implicit idea that a HCP’s own values and preferences about someone else, were interpreted in relation to the HCP’s own perceptions (i.e. schemas and beliefs about what a patient should want or receive) about someone else’s preferences—thus illuminating this important finding about congruence.

7.3.1. How the interface of other values and tensions can reconcile incongruences. In the excerpt above, participant BM008 explored how their own process of incongruence in relation to their own values, preferences, and perceptions and how some situations came to be reconciled. This reconciliation stemmed from what participant BM008 described as perceived as the team adhering to the patient’s wishes (“if you’re okay with that, I’m happy”). Such alignment with the patient’s wishes illuminates how values interfaced with other values and how tensions were not always simple. In that excerpt above, while participant BM008 explained ease when patients choose “whatever we want them to have”, participant BM008 also explained their value for patients’ autonomy and choice—reflecting an intrinsic
value, meaning something that is important for its own sake (Jiwani, 2017). As the value for autonomy was perceived to be upheld, participant BM008 described the situation as a more straightforward emotional experience.

These instances of value tensions and incongruence, and reconciliation of such incongruences, were described by other participants as well. For example, participant NZ016, who was a critical care nurse with a leadership role similarly described how they personally valued honoring patients’ autonomy and wishes, and explained how acting in a way that was perceived to be upholding a patient’s wishes and preferences, mitigated their own difficult emotions (“at least we did what he actually wanted us to do”):

NZ016: And I say, people get all kinds of things, all day long, that maybe they don’t...isn’t clinically indicated. And some people take a longer time to get there [to a point where they no longer choose life-saving interventions and treatment]. And some people don’t ever get there.

And when we first started...advance care planning, one of the stories that has been told through the years, is a fella, I think he was in his 40s. And he just was very insistent that he be resuscitated no matter what happened.

And the chances [of him surviving] were absolutely zip, zero. Like they were minus. And you know the team really made a decision that actually they were going to do it [resuscitate him].

Because it was his wish. And he was really strong on that. And, the family knew but they still supported him.

And you know, could that have played out differently? It could have. And I’m the first one to say they didn’t have to [emphasis in original] from a legal perspective. But they did honor and cherish, you know.

And he, his heart stopped when he was in the car with his daughter right after dialysis. And she took him back to the hospital. And they tried and it didn’t work.

And everyone said, you know what? At least we did what he actually wanted us to do. So, I think that [kind of] situation is always going to happen.
And I’m, I think that on the inside, you know that gut stuff, I feel very good about something like that.

What I don’t feel good about is when we haven’t had these conversations.

As became clear to me from participant BM008 and NZ016’s excerpts, for some HCPs, the difficulty of their own emotions, stemming for incongruence between their own values and related preferences, and their perceptions about others’ preferences, were assuaged when other important intrinsic values were upheld. In this example above, participant NZ016 described an easier emotional experience because they believed the patient’s autonomy was upheld.

Other participants also described HCPs’ preferences and perceptions about patients’ care and situations where incongruence was reconciled. For example, a participant who practiced nursing in general medical units described the treatment-focused orientation of acute medical settings (“we’re always trying to get them better”) in relation to usual care options and goals. In the excerpt below, the participant unveiled their own thinking and judgments about others’ treatment decisions. This participant also described their experience when a value for respect for patient’s wishes was in conflict with their value for quality of life:

BM012: ...Like in other parts of the world [patients] let certain things go [and die]. Like okay, they’re already going through so much. They’ve got kidney failure. They’ve got [lung disease]. They’ve got this, that, the other thing. There’s so much going on [with the patient and there are no cures] but [HCPs are] still trying to make [the patient] as best that they can be...I think that, [HCPs] don’t have like a stop. Until the person says stop.

JG: And the person you mean, the patient?

B012: The patient. Yea. We will keep going until the patient says stop. And we will respect those wishes. Which is amazing. But it also means that, that sometimes we’re like, we’re kind of beating at a dead horse.
Or you know, somebody can be 90 years old and we’re still trying to do everything that we can for them. Which is cool if the person is you know, able to get better and get to baseline. But are we fixing anything?

Or are we doing anybody any justice by making this person who’s bedridden, no legs, chronic renal failure, on dialysis. You know, like where’s the line? That’s what I’m kind of getting at.

This excerpt illuminated an intrinsic value for honoring patients’ autonomy and providing care that is seen to be what patients choose (“we will keep going until the patient says stop. And we will respect those wishes. Which is amazing”). It also illuminates a tension between a value to *do good* and to provide patients with what HCPs view as a high quality of life (“but it also means that, sometimes... we’re kind of beating at a dead horse”). The participant raises questions about the purpose and goal of curative-focused treatment when they perceive the patient’s quality of life to be poor. Implicitly, this questioning about purpose in the context of perceived poor quality of life implies some degree of a difficult emotional experience.

The complexity of emotional- and value-based dimensions of EOL planning and care are important because they relate to *strategies* that are used to manage and control emotion. In the next section, I will present findings that show these strategies and discuss how they also created structured EOL planning and care practices.

7.4. Mitigating Complex Emotional Dimensions of EOL Planning and Care: Strategies HCPs use to Manage Discomfort and How These Strategies Structured Practices

Overall, my analyses thus far indicate that HCPs use strategies to navigate the discomfort of difficult conversations about advanced illness and EOL planning and care issues (including resuscitation). I introduced this point where I discussed an excerpt from participant
who talked about ways HCPs distance themselves around EOL planning and care situations (e.g. distancing by “put up barriers and walls”; controlling the depth of conversations with an intention “to limit how far I would engage”). In this section, I will present data from other participants that also points to additional strategies HCPs use to regulate emotion in EOL planning and care.

As some participants described, strategies used included protecting (or “sheltering”) patients and their family members from emotionally difficult information such HF-EOL planning and care. One participant, introduced above as an experienced social worker expressed concern that conversations about serious illness and EOL issues may be misunderstood and misinterpreted by others (including patients, families, and other HCPs) as “giving up.” Indeed, as I explored in Chapter Six, “giving up” may evoke emotion in others. “Giving up” was also presented as an idea HCPs wanted to avoid conveying to patients and their family members and thus particular words that implicitly conveyed “giving up” (for example, the word “palliative”) were used cautiously. In the excerpt below, this participant noted how HF-EOL planning and care can convey “giving up” and explained how this impression can mean the HCP avoids the conversations altogether to “shelter” the patient:

AC004: ...I’m just trying to figure out [pause], how we can have those conversations, is just beyond me. And how we can have that, I guess maybe knowing when to having those conversations?

Like, do we have it right away? Like, do we do it the second time they are coming in with, you know, [HF]? Do we need to start having those conversations?

JG: Do you think there is any harm in having the conversation at the time of diagnosis?
AC004: No [emphasis in original], no! But I think, maybe, that’s the perception.

Like, it’s “oh we’re giving up on this person” and we’re not going to...and maybe the family might misunderstand.

So, let’s not even bother having that conversation. And... around what this means though. I don’t think that happens. We sort of are sheltering, in a way, like, as to what the disease will look like later on. Maybe, yea, I don’t really know.

JG: Do you think these are coming from a place where we are trying to protect people’s feelings?

AC004: I think so, I think so. I don’t think it’s meant because we’re lazy or trying to do harm, maybe we’re thinking, “it’s too soon, this person is totally fine.”

Why are we going to cause all this distress? They still have three or four years maybe.

In an earlier section of this chapter, I illuminated how HCPs have to manage emotions that are brought about by EOL planning and care conversations—that is, these conversations elicited strong emotions from others, such as anger and sadness (for example, as participant BM003 noted in an excerpt above: “Patients get angry. Families get angry because they just want a cure”). Thus, to manage or avoid these emotions, participants described preemptively refraining from discussing illness and EOL issues as a strategy to lighten their own emotional experience and/or protect or “shelter” others (i.e. patients and their families) from difficult emotional experiences (“we sort of are sheltering, in a way...” and “why are we going to cause all this distress? They still have three or four years maybe.”).

Other participants similarly described how distancing strategies were used to avoid emotion. A physician participant who had a clinical practice in cardiology and critical care explained how they approach conversations about code status, which is an important aspect of EOL planning and care in acute practice settings, as I explained in Chapter Six:
JG: When you have a [code status] conversation, how does that... how do you make up what goes into a [code status] conversation?

BC019: Yep. So, I usually for a [code status] conversation, I say “the hospital has a form that we fill out for any patient that is admitted.” Basically, what it is, it’s what’s called a “code status.”

[I ask them] “Are you familiar with this? No? What is means is, in the event of an emergency with your health in the hospital, let’s say your heart fails, or your lungs fails, or essentially you die in hospital, um. The question the hospital wants us to ask is: how to treat you?”

“Most patients, we would send a team of people down to do things like CPR and shock the heart. And place you on a ventilator. But not everyone wants those things done to them, which is why we’re having this conversation.”

And then, I’ll often then personalize it after that.

“You’re elderly. You have advanced COPD or advanced HF. Sometimes these measures aren’t so successful. We can try and do these things but we end up causing a lot of trauma. And we are, are unlikely to get a good outcome. It may mean a long time in hospital on, in the intensive care, on machines to keep you alive. Or just in hospital because you’ve become so weak or debilitated.”

“Would you...what are your thoughts about this?” Obviously for younger patients, if you’re young and it’s reasonable to do these things, I recommend this.

The participant cited above explained how they used a preamble (“the hospital has a form that we fill out for any patient that is admitted”) to ease entry into the conversation. Intentional clarification of ownership vis-à-vis the “hospital’s form” provided explanation and justification for engaging someone in a discussion about the topic of dying (i.e. the “trigger”), resuscitation, and death. This preamble also helped to navigate the assumption that others do not want to discuss this topic. Efforts to ease in, and utilization of a statement to assign responsibility of these conversations onto the institution, were strategies to manage the emotional weight associated with the uncomfortableness of this work. Health care professionals also use careful words in conversations about HF and EOL issues.
7.4.1. Careful words: Controlling emotions with softer language. Particular words were used to discuss issues including diagnoses, illness expectations, prognosis, and EOL with patients and their families. For example, people with HF were routinely referred to outpatient settings called Heart Function Clinics (HFC). The use of the word “function” over “failure” in the naming of the HFC was highlighted by participant AC001, who described the descriptor as “kind of optimistic.” In Chapter Five, I explored findings about the impact of telling someone they had HF compared to telling someone they had an illness such as cancer—participants explained that “cancer” was implicitly understood by others as a life-limiting, serious illness with EOL implications (even when it was not). That is, “cancer” was a word that was the bad news itself. In contrast, HF was not implicitly associated with debilitation or EOL, which meant HCPs had to really explain HF and manage and navigate the uncomfortableness of conversations about illness expectations and EOL. These explanations about HF is where I heard uses of “careful words”, which I came to recognize were softer words.

The words used by HCPs to explain the pathophysiologic process of HF stemmed from efforts to create clear communication; however, in some instances, communication became less clear. I observed and heard the word “weak” used frequently as a simple descriptor to explicate the ventricular dysfunction that characterizes HF. “Weak pump” was another phrase used many times in both observations and participant interviews:

FN (p. 24-32) We talked to [primary nurse] for [patient #2].- given [the ok].
Met [patient] in room - they were sitting at bedside in chair—receptive to hearing HF teaching. AC001 reviewed basic pathophysiology—used common explanation: "heart failure is a scary wording that means a weak pump."

A participant who was an advanced practice nurse with a background in cardiac and critical care nursing explained how patients decipher the word "weak." Understanding the term "failure" in relation to a “stopped” heart was also discussed:

AC020: So, I think that part of the lack of understanding and knowledge about [heart failure]—patients don’t even know they have [heart failure] half the time.

“Well my heart’s a little bit weak.” But they think heart failure—that word, that means my heart stopped. Or like I’m dead.

Or you know, which I’m obviously not so, “I don’t have heart failure.”

And so, I think that, just because it’s, it’s, you know, chronic and progressive, I don’t think that we support people well enough in terms of their education.

Use of words such as “weak” was described as creating confusion for patients (“well my heart’s a little bit weak but they think heart failure—that word, that means my heart stopped. Or like I’m dead...which I’m obviously not so I don’t have HF”). In the excerpt above, the participant attributed patients’ lack of understanding about HF to uses of words such as “weak.”

The word “weak” was common and many other participants also described their experiences with uses of this word in relation to teaching patients and their families about HF. A participant who practiced medicine in cardiac and critical care settings, explained how they approached patient education about HF illness and trajectory:

JG: When a patient is admitted into an acute care setting, what are the goals that you [have as the physician], in helping the patient and their family, if that exists, to understand their illness? What’s your primary goal when you go in and talk to them about their illness?

AC021: I mean, predominantly, keeping in mind that every cardiologist probably approaches it differently, but in general, as physicians, our goal is education. Patients don’t necessarily care to know the intricacies of the medications and the doses.
But yes, we go in basically saying, “you know, your heart is weak and that’s why you’re so short of breath. There’s fluid in your lungs. You know, because the heart is weak and we’re going to treat it by doing this, this, and this. And we need to figure out why your heart is weak so we’re going to do this, and this, and this test.”

“Weak” was used as a strategy to explain symptoms such as dyspnea and pulmonary edema.

Weakness was also used to explain need for treatments and tests. I asked this same physician participant to reflect on how the word weak was used to talk about HF:

JG: What do you think the consequences are for patients and families, in that languaging that we’re using—so the “function” versus the “failure.” The “weakness.” The heart is “weak” versus [failing]. It will get worse versus you may die. What do you think... what are the... why do you think we soften the language and...?

AC021: It’s easy... I think it’s easy for patients to acknowledge the problem.

And they’re not [going to understand] if you go through and tell a patient, “okay you’re going to die if you keep doing this.” It’s a lot more difficult to grasp that. And they immediately...not immediately.

But I find that, how should I say this, shocking a patient isn’t necessarily going to get...You have to kind of slowly feed them like a baby. You know what I mean? Like slowly. And you kind of have to gradually let in that.

JG: The bad news?

AC021: The bad news.

In the excerpt above, the participant explained how “it’s easy” to soften the words because it helped patients acknowledge the problem and avoided “shocking” them. The participant also emphasized the importance of a gradual approach to sharing information so that the patient could “gradually let it in.” Here, careful words, such as “weak” were seen as protective of the therapeutic relationship—that is, careful words mitigated emotions in EOL planning and care and promoted relationships and trust.
Participant AC021 explained how these careful words strengthened therapeutic relationships by managing emotional responses and promoting empathy. Paraphrasing a patient’s hypothetical reaction to communication that was overly direct, participant AC021 described how only a small portion of patients “reach a point where [they] are not listening” and require stronger words, including “die”:

AC021: “[That doctor] was such a jerk, [they] said I was going to die. I’m fine.”

You know what I mean? You need to get that trust and that empathy. You can’t get that person empathy if you go in and give them really hard words and use language that you know [will upset them].

But it does depend on the situation and yes, we’ve said it many, many times. When we have to. And when I said have to, it’s when we reach that point where the patient is not listening. When they’re just not appreciating what is being said. And then you have to use a different type of language where, okay, “you will die if you don’t do this.”

JG: And that works?

AC021: I don’t know if it works. It clears our conscious. You know? We’ve done all we could at that point.

Not all patients “appreciate what is being said.” Thus, for those patients the language was changed and different words were used. Here, I identified schemas underpinning illness-related communications where HCPs held assumptions about particular words (e.g. “die”) and their provocation of counterproductive emotions. The participant also describes how words such as “die” can be used “when the patient is not listening.” Such schemas—that is, assumptions undergirding particular words, interfaced with HCPs themselves who acted as resources (e.g. holders of information, including diagnosis) and structured communication practices: particular
softer words were used with the goal to dampen emotions and control responses—in effect, words were carefully selected to control emotion and messaging.

I also heard frequently about how HF-EOL planning and care conversations were often short. Participants also described patients as commonly “defaulting” to “full code”—which illuminated assumptions that most people want resuscitation efforts in the unlikely event of a cardiac or respiratory arrest. As pointed out by participant AC004 (noted above: “let’s not even bother having that conversation”), conversations about EOL issues such as resuscitation preferences may be avoided. Thus, HCPs assumptions that most patients want resuscitation efforts became important drivers of clinical decision-making, resulting in most patients being prescribed maximal resuscitation treatment in code status orders.

7.4.2. Truncating or avoiding EOL planning and care: Full code as the default. As is indicated in much of the data I have discussed above, I heard frequently about full code (i.e. “full resuscitation”) as being prevalent and the “default” for patients with HF. Participants shared beliefs that the actual resuscitation directives for most patients admitted in acute units indicated to do CPR and use mechanical ventilation. For example, a participant who had a clinical background in general medicine nursing described their observations about code status and explained how it was the “back-up”:

JG: So, you said you’ve observed that the common [CPR direction] is full code?
BM012: Uh hm. [agreeing]
JG: So, do you have any ideas about...
BM012: Because it’s the back-up. It’s the back-up, right? It’s whether, if there’s not full, if there’s no code status then automatically they’re a full code, right?

JG: Okay. So, if there’s no [CPR direction form] completed, then by default, the patient is full code until the conversation can be had?

BM012: Uh hmm [agreeing tone].

As I came to understand, “full code” was the back-up because there were several implicit assumptions (i.e. schemas) at play including beliefs that patients had an expected preference of full resuscitation unless otherwise stated. There were also assumptions that “full code” was best practice (meaning, best professional standard) and was also thought to be associated with the least potentially liability. Indeed, “full code” is also reversible, meaning it can be stopped; in contrast, “no code” is not reversible and thus the decision is final.

A participant with a practice in cardiology medicine explained their understanding of why full code was thought to be common. Societal beliefs relating to cure culture and assumptions about the current capabilities of medicine were highlighted. Communication skills and professional experience were also explained:

BC019: ... most medicine, at least in the medicine ward that I worked in, most medicine units are, have a large contingent of medical students and residents. And they’re doing largely unsupervised code status discussions.

And I don’t think they have a lot of expertise to do and navigate that discussion effectively. And so, you know. I think a lot of patients without understanding the implications, would want everything done. And want to hope for a good recovery. And so, I think that’s one problem.

Um. Another problem is just that I think our culture is um, such that, you know, people think that, you know, we can fix things. And everything is reversible

JG: Our culture, you mean health care professionals or like Western...?

BC019: I mean Western culture.
JG: So, then the expectation then from your perception is that patients, families, presenting also have an expectation?


Cultural norms about medical interventions, specifically related to expectations of life-saving, were linked to broader societal schemas (“Another problem is just that I think our culture... you know, people think that... we can fix things. And everything is reversible”). Such thinking pointed to the existence of schemas where HCPs assume most patients want full resuscitation efforts. The participant also emphasized how undeveloped and/or novice communication skills also characterized the quality of explanations and recommendations made to patients about resuscitation options (“I think a lot of patients without understanding the implications, would want everything done”).

Participant BC019 emphasized the importance of communication skills because EOL planning and care conversations, including resuscitation directives, were complex, difficult, and intended to be associated with other conversations such as ACP. As such, there was also an assumption that these conversations were inherently time-consuming. A participant who was a critical care nurse in a leadership role described their experiences with conversations about EOL issues including resuscitation. The participant highlighted complexity and depth in communications about EOL issues such as “code status”:

NZ005: ...we have the [name of CPR directions] form, which is the [name of form explained]. Which is basically a DNR form.

It’s not great though. It’s very much, you know, CPR or no CPR. Critical care or no critical care. Intubation.
I think there’s a few other specific interventions listed. The physician progress note is usually where I see it documented. But again, it’s not a... it’s not a great, you know, progress note.

It’s, you know, “EOL conversation,” check. Decision: DNR. Like it’s really not a good communication tool.

JG: So, the depth of the conversation is missing?

NZ005: Yup. And I think that, the depth and breadth of what was discussed. You know. DNR check.

Like okay so you just signed a form. But were the family actually engaged with that? Did they read? Were they blind-sided? Were they too stunned to say? Like I think there’s just so much missing.

Sometimes, going through social work notes, you’ll see a better accounting of what actually happened. But again, sometimes social work doesn’t understand the lingo either. So, then you wonder how much the family has understood.

But no, there isn’t a clear...and I think with that hand-over from physician to physician week-to-week, I think that’s one of the challenges. So, the plan gets changed because no one has a clear understanding of what was involved in that conversation. Or...who was there.

I think that’s another big part that’s...you might see “discussed with wife”. But was it the wife and her four kids and their pastor? Or was it just the wife?

And depending on what culture, that’s actually unacceptable in a lot of cultures, just to be talking to one person. You need to be talking to the whole family. So.

This participant highlighted the relational aspects of these conversations. The skill set underpinning the communication about care goals and decisions were also emphasized (“But were the family actually engaged with that? Did they read? Where they blind-sided? Were they too stunned to say? But was it the wife and her four kids and their pastor?). Together, assumptions about patients’ preferences for full resuscitation, and commonplace occurrences of incomplete or inadequate conversations about resuscitation, likely underpin why “full code” was perceived to be so widespread in acute care areas.
Overall, participants described the prevalence of “full code” in acute care areas as a likely consequence of incomplete or inadequate communication about HF-EOL issues including resuscitation status. As I explained in Chapter Six, medical instructions about resuscitation (i.e. code status) were designed to address the medical care and interventions specifically related to unlikely instances of sudden arrest. However, patients’ code statuses (e.g. full code, DNR) were treated as character attributes and were exchanged among HCPs as highly nuanced and implicit statements that encompassed much more than specific instructions for resuscitation. Therefore, the dominance of being “full code” meant much more than simply providing maximal medical interventions in the unlikely scenario of cardiac or respiratory arrest. Instead, the dominance of “full code” implied maximal interventions upstream and cure-focused care goals. This is an important implication that I will return to in Chapter Nine; this upstream implication may align with patients’ wishes but it also may not— thus, HCPs’ assumptions about patient’s preferences ought to be understood and explored more fully by improving communication with patients and their family members.

The emotional and value-based dimensions of EOL planning and care are an important finding in this dissertation because they are associated with structured practices, such as distancing or controlling conversations. In other words, thinking about values and emotions as schemas, and thinking about HCPs themselves as resources (e.g. keepers of information that may be important to patients and their families), enacted clinical practices can be understood as structured through the use of particular strategies that mitigate and manage HCPs’ discomfort.
7.5. Chapter Summary

My research findings in Chapter Seven showed that EOL planning and care had emotional and value-based dimensions for HCPs. Emotional dimensions were associated with various aspects of EOL planning and care. For example, EOL planning and care meant HCPs needed to respond to patients’/families’ emotion, including grief or sadness or anger. Likewise, EOL planning and care were seen to elicit HCPs’ own emotions of grief or sadness, which then needed to be managed within the professional context. The nature of the information exchanged also elicited emotion. Fear and worry, for example, arose in situations where HCPs had concerns about misleading, misspeaking, or giving incorrect information.

The emotional-dimensions of HF-EOL planning and care were complex because they also related to HCPs’ perceptions and understandings about others’ preferences, goals, and care decisions—which points to the value-based dimension of EOL planning and care. When HCPs’ values and preferences were in alignment with their perceptions about patients’ wishes, there was congruence—where congruence was described as the degree of similarity between what HCPs thought ought to happen compared to what they thought was actually happening. Conversely, I referred to misalignments between values and perceptions and others’ preferences as incongruence, which was an important finding because these situations evoked stronger, and often more difficult, emotions.

The emotional- and value-based dimensions of HF-EOL planning and care structured clinical practices. For example, I presented findings that illuminated how particular words were...
used to navigate emotion in HF-EOL planning and care and thus structured EOL-related communication. Strategies such as avoidance and distracting were also noted, which diminished the quality and fulsome of EOL planning and care conversations. In Chapter Eight, which follows, I will discuss my findings from Chapters Five, Six, and Seven in relation to what I came to appreciate as an overarching theme among my three major areas of findings.
Chapter 8
Discussion of the Three Major Areas of My Findings

In Chapters Five, Six, and Seven, I presented and discussed three major areas of findings from my study: What HCPs saw and knew, What HCPs said and heard, and How HCPs felt and acted. While I wrote about these three major areas within separate chapters, I also pointed at the relatedness between them. For example, within the area of findings about What HCPs saw and knew, I examined issues of HF awareness and knowledge. Issues of awareness and knowledge related to differences in how HCPs understood and used particular EOL-related words (e.g. “palliative”)—that is, What HCPs said and heard. Relationships between the areas of findings about What HCPs said and How HCPs felt were also apparent. For example, I identified how HCPs used strategies such as choosing particular words over others to manage and control feelings and words (e.g. “failure” vs. “function”, “weak”), showing a relationship between what was said and felt.

Over the course of my study, I came to greater understandings about the relationships between my three areas of findings. Though not causally related, there are important connections and associations between the three major themes in my findings. In particular, I recognized how the three areas of my findings related to an overarching idea of willingness and actually doing. At the outset of my research study, I was informed by having reviewed a large volume of literature about HF and EOL, which I presented and discussed in Chapter Two. This review included a report by the Institute of Medicine (2015) called Dying in America: Improving
Quality and Honoring Individual Preferences Near the End of Life. The report opens with quote from Goethe:

"Knowing is not enough; we must apply. Willing is not enough; we must do."

—Johann Wolfgang von Goethe, (1749-1832) German Philosopher

This quote conveys that knowledge must be applied and willingness must become doing; it struck me that this call to application and action not only touched on my three areas of findings but also unified much of what has been described in the literature about HF-EOL planning and care.

As I described in Chapters One and Two, issues with HF and EOL have been discussed in the literature and many authors have provided various evidence-informed explanations for the persistent challenges of HF-EOL planning and care for patients and their family members. Initiatives aimed at addressing issues of HCPs knowing, being willing, and the actual doing of EOL planning and care are also well documented and are increasingly emphasized; for example, as I discuss in Chapter Nine, there are various provincial and national-level initiatives currently underway which are aimed at improving EOL experiences via an expanded application and integration of a palliative approach to care (Pallium Foundation of Canada, 2018; Quality End-of-Life Care Coalition of Canada, 2019). While we know a considerable amount about HF-EOL planning and care—from patients’ and family members’ care needs during dying to how patients and their family members ought to be supported upstream to articulate their wishes—problems persist and change has been difficult. At the core of the three areas of my findings, is
what I see as an overarching theme: it has been difficult to translate what is known into willingness and actually doing. Indeed, my research findings indicate structured practices that will need to be considered for successful uptake of initiatives aimed at HCP being willing and actually doing HF-EOL planning and care, including initiatives aimed to greater integration of the palliative approach to care.

In the following discussion about my findings, I explore structured practices in the acute care settings in hospitals where I carried out my fieldwork, in relation to what is known from the existing body of HF and EOL-related literature. In keeping with my philosophical and disciplinary commitments towards transformation and change, I also endeavor to explore how my findings can be understood and addressed towards the goal of achieving change. Willingness and doing is more than simply wanting and acting; instead, willingness and actually doing should be considered in relation to many more interrelated ideas that undergird HCPs engagement of patients and their family members in HF-EOL planning and care. By exploring acute care contexts where patients with HF access EOL planning and care and the structured practices, I believe that I have been able to point to some significant implications for practice and research, which I cover in Chapter Nine. I support many of my forthcoming recommendations and implications from the substance and content in this chapter.

Throughout the preceding three chapters of findings, I used a number of terms and referred to concepts that other researchers and authors have written about similarly in the literature. For example, I used the term “need-to-know” to describe a schema. I will show how
need-to-know relates to other concepts including the *hidden curriculum*. Likewise, what I have called *congruence* reflects and relates to others’ work about *emotional labor* and *moral distress* and therefore warrants explication and discussion. Collectively, the concepts I elaborate on the basis of my findings in Chapters Five, Six, and Seven are particularly salient for HF-EOL planning and care. In many instances, the discussions forthcoming also provide further explanation and theoretical support towards the implications for clinical practice, policy, and research, which I discuss in Chapter Nine. Overall, my findings and the discussions in this chapter add to a growing body of literature about how to improve HF-EOL planning and care experiences for patients and their family members, and possibly for any other patients/families on life-limiting illness trajectories.

**8.1. Overview of Chapter Eight**

I have organized the discussions in relation to the three major areas of my findings: *What HCPs saw and knew*, *What HCPs said and heard*, and *How HCPs felt and acted*. I begin by discussing literature related to my findings about *What HCPs saw and knew*. I explain how other authors have written about issues of knowledge, disciplinary scope, and the positioning of EOL planning and care as the work of experts in acute care settings. I also highlight how other authors have described HCPs’ understandings of their roles and responsibilities with HF-EOL planning and care. To close my discussion of *What HCPs saw and knew*, I explicate the *need-to-know* schema in relation to the concept of a *hidden curriculum*. 
In the next section, I look at literature related to the second major area of my findings: *What HCPs said and heard.* I elaborate on the acute care context and HF-EOL planning and care by exploring what other authors have discovered about the words used in clinical practice and their meanings. I show how my findings about different meanings with particular EOL-related words (e.g. “palliative”, “code status”) have been identified by other authors. I also situate my use of the term “narrative” in relation to other authors’ uses and explain the concepts of *narrative medicine* and *narrative nursing.* This situating with related concepts is important because it provides a substrate from which I have identified implications. For example, I point to how my findings about various meanings of words such as “palliative” illuminates the need for HCPs to develop skills towards the goal of mutual understandings, which I present in Chapter Nine.

In the last section, I discuss the third major area of my findings: *How HCPs felt and acted.* I review what I learned about the *emotional* and *values-based* dimensions of HF-EOL planning and care and I examine my findings in relation to how others have described emotions in health care work. In Chapter Seven I used the phrase *incongruence* to describe misalignment between HCPs’ own values and preferences about patients’ wishes, and HCPs’ own perceptions about what patients actually choose. I also described incongruence as one aspect of HF-EOL planning and care that adds to the emotional difficulty of this work. In this chapter, I explore my findings about *congruence* in relation to similar concepts such as *emotional labor* and *moral distress.* I also show how these related concepts support my findings and indicate
particular implications for interprofessional practice, including the need to more explicitly address the emotional- and value-based dimensions of HF-EOL planning and care work.

8.2. Positioning EOL Planning and Care as the Work of Experts: Reframing Nurses and HCPs’ Roles in EOL Planning and Care in Acute Care Settings

In Chapter Five, I explored an area of findings about *What HCPs saw and knew* and discussed issues of HF-EOL *awareness* and *knowledge* in acute care settings. I learned about how HF illness EOL planning and care were seen as beyond standard and basic practices in acute care settings; instead, they were positioned as being within the domain of clinical *experts* (e.g. palliative care specialists) or HCPs with particular disciplinary-related authorities (e.g. physicians). End-of-life planning and care expertise and work were also thought to belong outside of acute care units (e.g. palliative care units). Within the existing body of HF and EOL literature, it is clear that my research findings are supported by other authors who have looked at various EOL issues in different hospital contexts.

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Chan (2014) also found that nurses and HCPs widely regarded “palliative care” as a “place” where people go to die: “Acute [care] and palliative care were considered to be separate areas of expertise; thus, staff believed that care for acutely ill palliative patients was done best on separate specialist wards. One of the main implications of being palliative is the widely held staff belief that palliative patients did not belong on an acute medical ward, and that palliative care could not be performed on the medical ward” (p. 131).
Strachan, Kryworuchko, Nouvet et al. (2018), for example, described nurses’ roles in communication and decision-making about goals of care in hospitals. These authors used interpretive description in a mixed-methods study and engaged a sample of thirty interdisciplinary HCPs at three tertiary hospitals in three Canadian provinces. Two major themes of findings were identified and discussed. In the first theme, the authors explicated ambiguity in nurses’ roles in conversations about goals of care and decision-making. In the second theme, the authors illuminated the embeddedness of conversations about illness into usual nursing care, which referred to the researcher’s findings that nurses engaged in many informal and thus unrecognized conversations about EOL issues.

Strachan, Kryworuchko, Nouvet et al. (2018) discussed their findings about ambiguity and embeddedness in relation to tacit and implicit understandings about disciplinary scope around EOL planning and care. For example, the authors found that “multiple issues create conditions that impeded nurses’ engagement in EOL communication; these included nurses’ lack of confidence, implicit understandings of existing hierarchical structures in health care teams, and social historical constructions of nurse-patient relationships” (p. 27). Of note, the

88 See Chapter Four for further explanation of Thorne’s (2008b) Interpretive description.
authors also reported that while both physicians and nurses recognized the value of having nurses more directly responsible for EOL planning and care conversations, both groups also acknowledged nurses were “not necessarily important actors in formal decision-making processes” (p. 29).

Strachan, Kryworuchko, Nouvet et al.’s (2018) findings highlight important links to my own findings. Indeed, the participants in my research indicated that HF-EOL planning and care conversations were predominantly physician-led and some EOL-related tasks were restricted to physicians only (e.g. resuscitation directions). My findings also indicated other interdisciplinary HCPs were only expected to engage patients and their family members in EOL-related conversations if they had particular training or authority (e.g. a specialist palliative care nurse89). Strachan, Kryworuchko, Nouvet et al.’s explication of ambiguity supports what I similarly recognized as nurses having an undefined professional role in EOL planning and care

89 Interestingly, Jaarsma et al. (2009) noted that the specialization of “palliative care” may have inadvertently led to diminished capacities of non-palliative specialist HCPs to provide EOL care: “the term palliative care has long been synonymous with the support of those affected by advanced incurable malignancy and therefore cardiologists and cardiac nurses are frequently unfamiliar with the principles and practice of this clinical specialty” (p. 434). Gott et al. (2011) also identified “apparent deskilling” of generalist colleagues as an unintended consequence of palliative specialization: “The perceived responsibility of other HCPs to provide palliative care was seen to be taken away by the very existence of specialist palliative care teams. This was considered to be particularly the case within the acute hospital setting where increased specialization meant that ‘everything is in its little slot’” (p. 237).
conversations. The notion of ambiguity is also highly relevant in how it can also be considered in relation to the *expectations* of nurses and all HCPs—that is, in what is expected of nurses and all HCPs in terms of pursuing the training, skill development, and competencies for HF-EOL planning and care. For example, as I explained in Chapter Five, most participants who contributed to my research located themselves as practicing within a standard and basic level of clinical knowledge which encompassed tacit and implied clinical requirements for practicing in acute care units (e.g. as noted by participant BM008, a necessary skill in acute care settings was “... doing rapid assessments and that kind of thing” and thus was taught, learned, and emphasized). In contrast, only a few participants described themselves as being the experts or specialists who actually carried out HF-EOL planning and care. However, neither groups—meaning, the many participants who identified themselves as *not* experts in HF-EOL planning and care and the few participants who identified themselves as these experts—framed the basic scope of practice as problematic. Instead, scopes of practice and disciplinary expectations were framed in relation to assumptions about what actually needs to be known for acute care practice—that is, the “need-to-know”.

Assumptions about training, competencies, and expectations of HCPs working in acute care related to a schema that I called “need-to-know.” This “need-to-know” schema was an important finding in my research because it shaped HCPs’ thinking about acute care practice expectations and therefore shaped what knowledge, skills, and competencies were pursued. While “rapid assessments” and “vital signs” may satisfy many patient’s needs in acute care
settings including many patients with HF, these domains of knowledge are not necessarily sufficient to meet patient’s (and family member’s) HF-EOL planning and care needs.

8.2.1. “Need-to-know” schema and defining expectations for nurses and all HCPs in HF-EOL planning and care. As was evident from my research and fieldwork, participants in my study held assumptions about what knowledge, skills, and training were expected and necessary and needed to support patients and family members with EOL-related issues. Perceptions and assumptions about the necessity of particular skills for communication are not baseless; indeed, the literature supports the premise that engaging patients and family members in EOL-related communication is complex work that HCPs more easily navigate when they have formal preparation and skills, knowledge, and related competencies (Chan 2014; Keely & Generous, 2017; LeBlanc, 2015; Mikkonen & Hynynen, 2011; Pesut et al., 2014; Wittenberg-Lyles et al.,).

The nature of EOL planning and care conversations are also unique and particular skills and competencies have been outlined and recommended. As Mikkonen and Hynynen (2011) have explained, the skills needed to engage patients and their family members in communications about general HF illness education and self-management support are unique and require a special approach. For example, self-management teaching differs from other types of patient teaching because it is less prescriptive, instructive, and authoritative and best approached through a supportive and person-centered manner. Patients themselves are also paramount to self-management and should be central figures in identifying their goals and
making decisions about their daily life, which may differ from other types of health care communication and teaching (e.g. printed health education materials) (Mikkonen & Hynynen, 2011). Thus, for HCPs, EOL planning activities, such as illness and self-management education are optimal when they include strategies such as supporting others to develop problem-solving skills, the use of motivational interviewing and counselling techniques, and fostering interactive participation.

LeBlanc (2015) also noted that EOL planning and care conversations are unique from other types of health communication and thus warrant unique considerations and skills. In LeBlanc’s view, EOL planning and care conversations involves emotions, asymmetrical power relationships, and imbalanced exchanges of information. Indeed, asymmetrical power and controlled information exchanges (e.g. the careful words described by AC021) and strategies (e.g. truncated EOL-related conversations as described by BC019) were evident in my findings. This existing literature has implications for my findings because it illuminates the need to both

90 Other authors have similarly explicated the communication skills needed to support patients and their family members with EOL-related issues (Keely & Generous, 2017; Wittenberg-Lyles et al., 2012). Keeley and Generous identified HCPs as having a crucial role in supporting patients’ and families’ in communication. Noting the highly specialized and individualized nature of conversations about EOL planning and care issues, Keeley and Generous recommended HCPs develop particular communication and facilitation skills for this area of practice.
recognize this power imbalance as well as to strengthen the skills HCPs need to effectively communicate in these asymmetrical encounters.

Two key points can be summarized the discussion above. First, there is the need for all HCPs to regard EOL planning and care and communication as aligned within their professional roles and as “need-to-know” content—that is, to align the existing expectations in acute care practices with patients’ HF-EOL planning and care needs. And second, the value of developing the knowledge, skills, and competencies for HF illness and EOL-related communication needs to be explicit and emphasized. As I found in this study, and has been supported by other authors (Yuen, Reid, & Fetters, 2011; LeBlanc, 2015), communication skills are commonly implicitly and explicitly devalued. Indeed, devaluing is made more complex because it is occurring in the context of also being seen as optional and not within standard practice. This devaluing is also likely occurring in the context of a hidden curriculum.

8.2.2. Addressing the devaluation and under-prioritization of communication skills and the hidden curriculum. Both health care communications in general and in HF-EOL planning and care in particular are seen to be complex and unique. Yet, communication skills are often devalued and underemphasized in relation to other professional education topics.
LeBlanc (2015) wrote about communication in medical education and explained:

When I give lectures on communication, there are always skeptics. Some complain about how simulated communication exercises take valuable time away from ‘real’ medical education. Others criticize the examples, possibly to deflect the focus from the discomfort the subject matter causes them. Some others say this content cannot be taught and should be learned slowly, through experience...[yet] the evidence is clear; communication techniques make a difference, and they can be taught and learned (p. 139).

LeBlanc’s excerpt reveals how the need-to-know schemas structure emphasis on the development of particular clinical knowledge over others—that is, the “real” education which emphasizes biomedically-based knowledge and skills focused on diagnosing, treating, and...

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91 The devaluation of communication in relation to other health care education topics has been described by other authors as well. For example, Kenison, Madu, Krupat, Ticona and Vargas (2017) examined experiences learning communication for thirteen undergraduate health care students (n=7 medical students and n=6 nursing students). These authors noted that “students described a learning environment that emphasized an implicit hierarchy of values in the clinical setting. This hierarchy places much higher value on efficient completion of defined clinical tasks than on ensuring either effective communication or excellent care” (p. 96). Such hierarchical ordering illuminates the focus on developing physiological practices and competencies (e.g. focusing on the presenting, acute illness) above communication.
curing, instead of the optional content such as communication. LeBlanc's argument is relevant to my findings because it points to how need-to-know is taught and learned within acute care and structures the way HCPs perceive their competencies and practice expectations.

8.2.2.1. The lessons taught and learned in a hidden curriculum. Lempp and Seale (2004) used the term “hidden curriculum” to describe implicit and explicit influences that exist at cultural- and structural-levels of organizations such as health care institutions. These implicit and explicit influences guide agents’ navigation and survival of institutional customs, rituals, and other taken-for-granted aspects of the environment. A raised voice, eye-roll, or expression of frustration in response to a request from a colleague to review goals of care or resuscitation directions, conveys an implicit lesson that the recipient quickly learns about norms and values. These tacit lessons become understood, shared, and accepted as immutable conditions of the environment (Hafferty, Gaufbery, & O'Donnell, 2015).

Two key axioms underpin the premise of the hidden curriculum: that teaching and learning are dissimilar (i.e. what is taught is not necessarily what is learnt); and, what is taught

92 Hafferty, Gaufbery, and O'Donnell (2015) similarly defined the hidden curriculum as the “attitudes and values conveyed, most often in an implicit and tacit fashion, sometimes unintentionally, via the educational structures, practices, and culture of an educational institution” (p. 131).
and said to be done, often differs from what is taught and learnt about what is actually done (Hafferty, Gaufberg, & O'Donnell, 2015; Kenison, Madu, Krupat, & Ticona, 2017; Lempp & Seale, 2004). Moreover, what is taught and learnt can come from “informal” and/or “null” lessons. “Informal lessons” refers to the unscripted and often impromptu teaching and learning occurring outside formal lessons\(^9^3\) (Hafferty, Gaufberg, & O'Donnell, 2015; Lempp & Seale, 2004). In education and health care institutions, a substantial amount of informal learning occurs during activities such as clinical practicums and residency experiences. Beyond undergraduate education, nurses and other HCPs also continually build professional practices and frequently engage in a range of formal and informal learning experiences (British Columbia College of Nursing Professionals, 2019; College of Physicians and Surgeons of British Columbia, 2019).

Many of the participants who joined this study described practice experiences where both formal and informal learning took place. For example, participant AC006 described having recently attended formal knowledge sessions aimed at integration of a palliative approach to

\(^9^3\) MacMillan (2016) provided an example of “null” and “informal” lessons: “if lecture content is biased towards medical evidence over nursing evidence and we emphasize the importance of technical skill mastery over other cognitive abilities and competencies, we are conveying important messages without being fully aware of them. Students may receive the hidden message that a good nurse is someone who can skillfully and efficiently get all the tasks done in a set time and that relational skills are less valued” (p. 39).
care, which had a transformative impact on their understanding of HF as a life-limiting illness. In contrast, participant BM017 described their learnings from informal lessons around who and when HCPs can engage patients and their families in EOL planning and care work (e.g. when the physician has already written a “terminal care” order).

The power of the need-to-know schema is that it is recursive (i.e. reinforced by itself), taken-for-granted, hierarchically ordered, and is a hidden curriculum. This important idea about need-to-know as a hidden curriculum is important in relation to my study findings because it indicates that HCPs’ willingness to engage and actually doing EOL planning and care, takes place within a context where lessons are taught and learned outside of a formal curriculum—these implicit lessons and teachings will need to be addressed if meaningful improvements are sought. The hidden curriculum is certainly at play when it comes to HF in acute care, where HCPs “know” EOL planning and care is beyond what they need-to-know and learn to work within that boundary.

It is my contention on the basis of my research that to improve the EOL planning and care for patients with HF (and their family members), we will need to reconsider structural issues such as problematic access to patient information (e.g. difficulty locating paper-based charts) and equipment (e.g. scales). We will also need to address practices by considering issues including awareness, knowledge and skill, and the influence of hidden curriculum for all HCPs. In doing so, particular attention will need to be directed towards emphasizing and
restoring value in non-technical aspects of care such as communication. As MacMillan (2016) cautioned in relation to nursing:

> There may still be active faculty who believe that nursing is really about clinical skills; a technical occupation rather than a cognate profession. I would argue that this view of nursing is still dominant in many institutional practice settings where students may be supervised by preceptors who emphasize the technical performance of skills in their instruction, particularly if these are complex skills that were formally the province of the physician (p. 40).

In summary, teaching and learning HF-EOL planning and care for nurses and all HCPs will necessarily need to address what is currently an undervaluing of many of the competencies associated with endeavor. “Hidden curricula” is an important idea in this discussion because it illuminates practical implications from “need-to-know” that I will return to in Chapter Nine. As I will explain, practical implications of “need-to-know” will need to address two main aspects of HF-EOL planning and care: first, how nurses and HCPs come to understand their role and scope of work in acute settings and who is allowed to do this work; secondly, what knowledge content is learned and actually valued.

**8.3. Achieving Mutual Understandings when Narratives are Implicit and Shifting**

In Chapter Six, I presented findings about *What HCPs said and heard*. I began by discussing what I called my own “narrative” of EOL planning and care and I described my reflections in coming to appreciate how my own knowledge had impacted my understandings of
EOL-related words (e.g. “palliative”). Throughout my analysis, I showed how particular EOL-related words (e.g. palliative and also phrases related to “code status”) were used beyond their definitions and instead, within interprofessional communications, these words conveyed much more nuanced information such as goals of care and other patient preferences.

The way nuanced information was conveyed through particular EOL-related words reflected narratives, which I described as being underpinned by various schemas and characterized as implicit and shifting. Shifts in narratives reflected HCPs’ changing knowledge and schemas, thus highlighting interrelatedness between the first area of findings What HCPs saw and knew and the second area of findings What HCPs said and understood. The nature of narratives as implicit and shifting also underscored what I found as variation and difference—meaning, that these EOL-related words were understood and acted upon differently, depending on the agent. The word “narrative” is common in health care and research literature and, as I have argued, is relevant for interpreting my findings. How other authors have explicated the concept of narratives points to particular implications, including how we may move towards mutual understandings.

8.3.1. Differences in how clinicians understand EOL-related words. Differences in how nurses and other HCPs use and understand particular EOL-related words have been described by other authors (Abu-Ghori et al., 2016; Chen, Sosnov, Lessard, & Goldberg, 2008; Jonson, Siegler, Winslade, 2015; Kavalieratos, Mitchell, Carey et al., 2014; LaPuma, Silverstein, Stocking, Roland, & Siegler, 1998; Yuen, Reid, & Fetters, 2011). For example, in their
qualitative study with 18 multi-disciplinary HCPs, Kavalieratos, Mitchell, Carey et al. noted confusion and misunderstandings about the term “palliative care”:

One barrier is confusion about the terms ‘palliative care’ itself. All cardiology and primary care providers reported familiarity with nonhospice palliative care; however, phrases such as ‘comfort care’ or ‘just the basics’ implied their equating nonhospice and hospice palliative care (p. 8).

Likewise, Abu-Ghori et al. (2016) explicated differences in understandings about the phrase “DNR.” Abu-Ghori noted that HCPs used “DNR” to indicate that curative options have been exhausted; “DNR” also conveyed imminent death: “The ‘do not attempt cardiopulmonary resuscitation’ decision is initiated at a point when the curative treatment has been exhausted. A range of EOL care options is therefore provided on [medical units] to such patients when death is imminent” (p. 22). Indeed, my findings and analyses above similarly reflected confusion about the term “palliative” and different meanings about code status directives.

As I discussed in Chapter Six, when these EOL-related terms were unexplained, which they almost always were, participants made assumptions about others’ intended meanings. That is, HCPs interpreted the meanings about terms and phrases such as “palliative” and “DNR” from their own implicit assumptions and understandings. In some situations, participants described conflicted and contested practices. In their paper on resuscitation directions, Yuen, Reid, and Fetters (2011) similarly described challenges related to HCPs differing
understandings about the meanings of code status terms\textsuperscript{94}. For example, the authors reported that HCPs inappropriately extrapolated resuscitation orders to inform other treatment preferences:

- A DNR order only applies to the decision to withhold CPR in the event of a cardiopulmonary arrest and should not impact other aspects of care. However, many providers inappropriately alter treatment plans for patients with a DNR order without discussion with the patient or surrogate...They make assumptions to avoid a discussion with patients about EOL preferences because of the lack of time or discomfort with having the conversation (p. 792).

The inappropriate extrapolation of preferences for resuscitation to other aspects of health care decision-making and preferences supports my findings about conflicts and/or contested practices. Indeed, as I captured in my data, inappropriate alterations of treatment plans (e.g.

\textsuperscript{94} Yuen, Reid, and Fetters (2011) explicated three other issues that were seen to be problematic related to resuscitation directions. First, the authors noted that discussions about resuscitation preferences occur \textit{infrequently} and options are inadequately considered. Secondly, the authors reported that discussions about resuscitation are delayed until it is too late for meaningful participation with patients and their families. And lastly, Yuen, Reid, and Fetters argued that inadequate information is provided for patients to make fully informed decisions. Indeed, the findings presented in from my study in Chapter Six and Seven illuminate all three of these issues. Participants clearly emphasized how conversations about resuscitation status were often avoided and/or truncated, and were also said to take place too late in the illness trajectory.
removing oxygen for someone who is “palliative”) stemmed from clinicians’ own understandings of what particular words conveyed. Yuen, Reid, and Fetters’ observations that HCPs extrapolate meanings from code status directives reflect and support my findings about the narratives of EOL-related words. Such observations also point to an important implication about improving communication to promote care decisions based on what a patient actually wants, rather than on a HCP’s assumptions.

While I used the term “narrative” to convey implicit meanings and nuance within participants’ own understandings and explanations of particular EOL-related words and phrases (including “DNR”), I recognize my use is distinct from other uses in current nursing and medical literature, particularly in relation to the ideas of narrative medicine and narrative nursing. I also recognize the term “narrative” fits within broader and well-conceptualized bodies of philosophy and social science literature that is beyond the scope and intent of this discussion. Thus, in the section forthcoming, I compare and contrast how I have used the term “narrative” in relation to other authors.

8.3.2. The concepts of narrative nursing and narrative medicine: Practices of hearing, understanding, and responding to others’ illness stories. Tropea (2012) traced the early uses of the term “narrative” in nursing scholarship back to research that was being carried out in the 1960s. In these early instances, scholars were examining narratives in qualitative studies aimed at understanding both patients’ and nurses’ experiences. Contemporary uses continue and discussions about “narratives” are now widespread in the
current nursing and health care literature. While I referred to both “narrative” and “story” in Chapter Six, my use and presentation of the term “narrative” treated these two terms as distinct; that is, I explicated schemas underlying narrative processes, through which meanings were constructed into implicit stories, which were made explicit through expression.\footnote{As I introduced in Chapter Six, definitional differences for the term “narrative” exist (Laranjeira, 2013). For example, Rejnö, Berg, and Danielson (2014) argued that in nursing research in particular, the use of “narrative” and “story” are commonly presented and interchanged as synonymous. However, Rejnö, Berg, and Danielson endorsed using these terms as distinct and explained narrative as the process through which a story comes to be: the “narrative can be seen as the process of making a story, the cognitive scheme or the result of the process” (Rejnö, Berg, and Danielson, p. 619). Laranjeira (2013) explicated these definitional differences similarly and concluded: “‘narrative’ is involved in the way in which humans make sense of things, how they make connections and how they interpret based on these connections” (p. 470). In this dissertation, I focused on the process of narratives—that is, on the stories that HCPs develop from their own narratives.}

The current volume of publications about “narrative” is related in part to the increasingly discussed concepts of “therapeutic emplotment”, “narrative medicine”, and “narrative nursing.” While these three concepts are connected, in the literature, they are currently theorized as distinct. In my findings, I illuminated multiplicity of schemas underlying narratives, thus my purpose in explaining and exploring these three concepts about narratives is to provide some theoretical foundation that informs clinical practice implications aimed towards mutual understanding of these multiple schemas, which I explore in Chapter Nine.
As I noted in the introduction of Chapter Six, narratives are temporally organized as an effort to form linkages between associated series of events and show connections and relationships between locations of past, present, and future (Charon, 2006; Roberts, 2012; Rejnö, Berg, and Danielson, 2014; Sharf et al., 2011; Small, 2017). Mattingly (1994) proposed the term “therapeutic emplotment” to capture the way narratives and stories are organized into plots, which become enacted in practice. From her ethnographic study of practicing occupational therapists, Mattingly explicated the way clinicians connect with patients in a narrative process to co-create stories: clinicians “actively struggle to shape therapeutic events into a coherent form, organized by a plot” (p. 811).96

The organization of events into plots, points to how narratives help HCPs anticipate what is to come. Plotlines point to an anticipatory characteristic of narratives because when narratives are familiar, connections and relationships between locations of past, present, and future may be extrapolated and applied in other circumstances (Mattingly, 1994; Sewell, 1992; Small, 2017; Sharf et al. 2011). The use of familiar narratives to make meaning in other

96 Sharf et al. (2011) similarly explained this tendency for humans to understand events by placing them within a plot: “providers and patients alike read physical symptoms narratively and contextually, urged by the impulse to emplot events befalling a character, search for causality, and develop actionable interventions” (p. 43).
circumstances means narratives are characteristically anticipatory and thus inherently predictive (Sharf et al.). For example, a clinician who encounters the phrase “he’s palliative” may be drawing from schemas, meanings, and an implicit narrative formed in another circumstance to interpret and anticipate future events in this new situation. Considering another example, participants also emphasized implicit meanings about what it means to have “cancer” and the assumptions about what the future holds. Indeed, the anticipatory nature of narratives was evident in findings about how EOL-related words became symbols which represented rich narratives with implicit assumptions that shaped HCPs’ thinking about what is to come and about what patients want. Conceptually, therapeutic emplotment thus also supports my findings about how participants described narratives and stories as enacted into clinical practice decisions and actions (for example, participant NC022 who described uses of the word “palliative” with unintended removal of oxygen).

The concepts of narrative medicine and narrative nursing align with therapeutic emplotment in that they also recognize clinicians’ narratives tendencies—that is, agents’ inclinations to frame experiences within plots and make decisions and actions from those plots. Narrative medicine and narrative nursing, however, provide additional direction for how to proceed and achieve greater understanding of one another, which point to an implication from my findings I explore in the next chapter. For example, Charon (2001, 2004, 2006) proposed “narrative medicine” to recognize a foundational idea that health care encounters are interpersonal interactions, dialogic and intersubjective in nature. Likewise, the term “narrative
nursing” similarly captures health care experiences as interpersonal in nature and emphasizes reflection as essential towards mutual understanding in communication exchanges (Fitzpatrick, 2017). In Charon’s (2001) view, empathy and human connection are at the core of narrative medicine. In contrast, in Fitzpatrick’s (2017) view, reflection, and the actions that follow (e.g. increased awareness of beliefs, values; enhanced connections with patients/families), are at the core of narrative nursing. Both practices seek to interact with others’ stories and acknowledge and understand meanings from others, which is important in relation to my findings because I illuminated problematic differences in the ways that commonly used EOL-related words and phrases (e.g. “palliative”) were understood among clinicians.

According to Sharf et al. (2011), multiple narratives should be expected in any particular social context97. Such multiplicity explains my findings that clinicians in acute care practice settings (e.g. medicine units, cardiac units) are currently navigating multiple, and sometimes divergent schemas and narratives. This multiplicity also suggests the best approach towards

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97 The applications of narratives to other contexts can be supported by the theoretical framework. Sewell (1992) described five axioms of structures, one of which is “transposability” of schemas. The axiom of transposability refers to agents’ abilities to apply schemas to a range of different circumstances: “to say that schemas are transposable...is to say that they can be applied to a wide and not fully predictable range of cases outside the context in which they are initially learned” (p. 17). Furthermore, Sewell argued that by very nature, agency is underscored by the capacity to transpose and apply a multiplicity of schemas to new and unfamiliar contexts and then effect human action.
navigating these differences is not to seek conformity, but instead to seek recognition of differences and mutual understanding. Thus, navigating these differences points to the need to strengthen HCPs capacity to understand narratives—meaning, the capacity to understand their own and others’ narratives. Narrative knowledge and narrative competencies undergird paths to mutual understandings.

8.3.2.1. Narrative knowledge and narrative competencies. Recognizing the multiplicity of schema and narratives, narrative knowledge and narrative competencies point to an approach that might promote greater understanding about what others’ actually mean—that is, mutual understandings. In Charon’s view (2001, 2004), doing narrative medicine and narrative nursing means using a different kind of knowledge: narrative knowledge. Charon (2001, 2004, 2006) framed narrative knowledge as a way through which HCPs use cognitive, symbolic, and affective means to understand the meanings of others’ stories. Charon (2004) described this approach using a practical example; in the excerpt below, she details different aspects of a patient’s narrative and writes about how she considers these aspects in a health care interaction (i.e. enacts narrative knowledge):

I listen not only for the content of [a patient’s] narrative, but for its form—its temporal course, its images, its associated subplots, its silences, where [the patient] chooses to begin in telling of himself (sic), how he (sic) sequences symptoms with other life events. I pay attention to the narrative’s performance—the patient’s gestures, expressions, body positions, tones of voice (p. 862).
Charon also described the development of narrative knowledge in relation to the goal of narrative competence. Narrative competence is the development and mastery of a variety of narrative skills that enable HCPs to recognize, absorb, interpret, and respond to others’ stories. To achieve these aims, Charon (2004) argued clinicians should draw from particular skills including: “textual skills (identifying a story’s structure, adopting its multiple perspectives, recognizing metaphors and allusions), creative skills (imagining many interpretations, building curiosity, inventing multiple endings), and affective skills (tolerating uncertainty as a story unfolds, entering the story’s mood)” (p. 862). Overall, the goal of narrative medicine is to hear, understand, and act in response to patients’ illness stories (Charon, 2004). The notion to narrative also points to the need to hear other HCPs’ stories as well.

The concept of narratives and recognition of their existence and impacts in health care communication is important because, as I also learned, HCPs can control words and narratives and do so in situations that are emotionally difficult, including those where value tensions exist. In the next section, I discuss my third area of findings in relation to the literature and what is currently known about emotion in work and how such emotion relates to my findings about HCPs efforts to control narratives and emotions by using careful words.

**8.4. Considerations for the Emotional and Values-Based Dimensions of EOL Planning and Care**

In Chapter Seven, I presented my third major area of findings about *How HCPs felt and acted*. I examined the emotional- and value-based dimensions of EOL planning and care, where
clinicians’ emotions were interrelated with value-based dimensions. As I described in Chapter Seven, my findings indicated clinicians used strategies to manage and mitigate emotion in EOL planning and care encounters (e.g. careful words such as “function” versus “failure” as described by AC021). That is, my findings illuminated how strategies such as carefully selected words were used to control narratives within communication exchanges and mitigate emotion, thus illuminating relationships between What HCPs said and heard and How HCPs felt and acted.

Other authors similarly have recognized the emotional nature of health care work and have described the implications of such. There is also related literature in which authors have touched on the relationships between values and emotions and have described instances where HCPs use similar strategies to control narratives and regulate emotion in order to maintain a particular outward demeanor in the context of professional work. In the discussion forthcoming, I begin by exploring related writing about emotion in health care work and I explain concepts related to my findings including “emotional labor” and “moral distress.”

8.4.1. “Bad news” and the nature of situations that evoke difficult emotions. In Chapter Seven I presented data where participants had described EOL planning and care work as “difficult” and “awkward.” In my analysis, I showed how difficulty and awkwardness were related, in part, to clinicians’ assumptions that EOL planning and care was “bad news”, which
implicitly meant patients and their families did not want it. This belief about “upsetting” patients was reflected from participants in my study (AC021 who described not wanting to “shock” patients).

From my findings, participants also described how HCPs use strategies such as careful words and/or avoidance in relation to EOL planning and care. Avoidance of EOL planning and care conversations have been reported by other authors as well. Nouvet, Strachan, Kryworuchko, Downar, and You (2016) noted: “a culture of death avoidance pervaded across study contexts, and goals of care discussion and decisions about the use of life-sustaining technology were delayed until days or hours prior to death” (p. 27). As became clear to me over the course of this dissertation, assumptions that others do not want to talk about death, or that talking about death and death-related issues is “bad news” and as such is difficult, underpinned what I observed and heard as strong emotion in EOL planning and care work. My findings about emotion in work was important because I also uncovered strategies clinicians used to control

98 Other authors have written about this assumption that people do not want to talk about death. For example, the phrase “death-denial” has been used to reflect broader societal-level assumptions considering death is unpleasant and thus talking about it is avoided or delayed (Nouvet, Strachan, Kryworuchko, Downar, & You, 2016). As Storch, Starzomski, and Rodney (2013) have argued, “we are a death-denying society, or, at least, we are in denial that a situation requiring [EOL planning] will ever happen to us. Our societal mind-set is about living with an assumption that we can leave death decisions until later...” (p. 341).
emotion—for example, in effect, the use of careful words (e.g. “heart is weak”) controlled the narrative and thus also controlled emotion.

8.4.2. The nature of health care work as emotional and the strategies to control it.

The emotional nature of health care in general and of EOL care specifically is well explicated in the literature (Badolamenti, Silli, Caruso, & Fida, 2017; Gray, 2008; James, 1986; Zapf & Holz, 2006). Strategies used by HCPs to control and mitigate emotion in health care work have also been described. For example, Sudnow (1967) used the term “detached practices” to describe the way HCPs unconsciously impersonalize patient care to protect themselves from anxiety and other emotions evoked from EOL-related work. In a guest editorial for the Journal of Palliative Medicine, Tucker (2009) explicated ways HCPs use strategies such as medical jargon to distance themselves from difficult emotions, which is similar to how I found HCPs were using careful words and thus also controlling the narratives:

Because of the hegemonic positioning of the doctor over the patient, the doctor can often dictate the course of these conversations. Shifting from lay-language to medical

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99 In Watson’s (2005) view for example, at the very core of nursing is caring for others—and at the core of caring (and of being caring) is an emotional dimension. In their writing about physicians, Blair and Wasson (2015) similarly articulated medical work as emotional work; when physicians support patients and their families’ through suffering for instance, Blair and Wasson explained that physicians can experience their own intense emotions.
jargon, a physician can devise a buffer zone to retreat behind inequality and language. Behind the smoke and mirrors, the doctor protects himself (sic) from the risk of engaging emotionally (Tucker, p. 1106).

Tucker attributed physicians' shifts from lay-language to medical jargon as a strategy to protect themselves from engaging emotionally (and in particular, engaging in difficult emotions). The findings in Chapter Seven about “careful words” add another layer of understanding to this notion of protecting oneself from emotion—while Tucker is pointing to an intensification of language (e.g. medical jargon), my findings illuminate that uses of careful or softer language can be also used by HCPs with similar aims (e.g. “weak” heart aimed at lessening the “shock” of “bad news”).

Tucker (2009) described other strategies HCPs use to distance themselves from emotion including avoiding patients’ rooms, visiting when family is not present, and evading conversations that elicit HCPs’ anxiety. In Tucker’s view, these strategies can be problematic because they lead to issues including vague, contested, and misleading communication. Beyond communication issues, Tucker also noted patients’ and families’ experiences within therapeutic relationships may also be diminished when HCPs employ strategies to distance themselves from emotion—a state Tucker (2009) referred to as “emotional detachment.” Overall, Tucker emphasized that these strategies jeopardize patients’/families’ opportunities to engage HCPs in meaningful and informative communication and threaten to erode trust inherent in therapeutic clinician-patient relationships. Implications are potentially serious; communication
and trust for example, are often vitally important in patients’/families’ own decision-making processes and undergird elements of HF-EOL planning and care. For example, participant AC021 described how controlling emotion and controlling the narratives with careful words was an important aspect of trust within the health care relationship (“you have to slowly feed them like a baby”). Thus, trust can be nurtured from some emotional- and narrative-control strategies. Conversely, however, strategies such as avoiding according can erode trust and interfere with EOL planning and care.

According to Tucker (2009), HCPs who use emotional-avoidance strategies do so as a result of their inadequate capacity to process and respond to their own emotional responses. This important point illuminates an implication from my findings to which I will return in Chapter Nine—that is, clinicians need to recognize how their own values and emotions influence their decision-making; and, clinicians also need support to address the emotional aspects of EOL planning and care work. Without a way to process and respond to these emotions, Tucker argued that avoidance are “flight” response strategies used as coping mechanisms:

Broaching the bad news of impending death with a patient and family, running the risk of being in a room when the patient actually dies, and confronting their own powerlessness may culminate in an urge for flight as a coping strategy. Avoiding the patient and family can be accomplished as visits to the room may become shorter and less frequent and conversations steer away from the uncomfortable (p. 1106).
Tucker’s work highlights an implication area that ought to be more purposefully foregrounded in thinking about HCPs’ competencies: coping skills for emotional responses.

Other authors have described ways emotion influences behaviors and the ways individuals manage emotion with strategies. Hochschild (1983, 2003), for example, proposed the idea of “emotional labor” as a term to describe disconnects between internal emotions in relation to outward actions (i.e. behavior and outward expressions of emotion) in professional contexts. This concept is important because it supports my findings about how clinicians use strategies to control emotion, and because it indicates the need to recognize these strategies and better support clinicians who are doing EOL planning and care work.

8.4.3. Emotional labor: Managing emotions in professional contexts. Several clinicians who participated in this study told me about their practice experiences where both the engineering and management of their emotions can be imagined. Participant AC002 for example, described their experience nursing a patient who was dying; during a night shift, the patient was expressing fear, worry, and anxiety so the participant explained how they invited the patient to “talk about it.” The participant reflected on their own feelings of self-doubt and worry about not being qualified to meet patients’ needs in this situation—internally, feelings of fear and worry were described, which were engineered and managed in order to produce a particular outward impression and support the patient in that moment.
Hochschild (2003) studied and wrote about how people manage and engineer emotions at work. Hochschild’s findings were primarily gathered from flight attendants' experiences.

Hochschild defined “emotional labor” as an experience in which an agent in their work role, may “induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others” (p. 7). In Hochschild’s view, emotional labor is an act where individuals encounter a psychological disconnect between the coordination of their thinking, their feelings, and their outward display of particular feelings and thinking. In practice, Hochschild explained, this means the smiles on people are not the smiles inside of people and proposed the term “emotional engineering” to achieve this coordination.

100 As Hochschild (2003) described, flight attendants were chosen because of the nature of service work—and in particular, the value and importance of their outward demeanors in work settings where “the emotional style of offering the service is part of the service itself” (p. 5). In Hochschild’s view, flight attendants are expected to create artificial elation because their emotions positively relate to customer’s experiences and company’s reputations (bill collectors, in contrast, employed a starkly opposite emotional style in their work). Combined with the physical responsibilities that make-up physical labor (e.g. pushing carts, serving beverages), and the mental responsibilities (e.g. organizing emergency procedures), the outward emotional appearance constituted what Hochschild termed “emotional labor” (p. 7).

101 James (1986) used the term “emotional labor” to describe a different phenomenon. According to James, emotional labor refers to emotional skills that are used to provide psychological support, enhance a dying person’s well-being, and deliver emotional care. This definition contrasts with Hochschild (2003), who is describing a disconnect between an internal self and external self.
The concept of emotional labor is applicable in health care and indeed, Hochschild (2003) recognized this relatedness in her writing; she also recommended that scholars explore emotional labor in nurses, as has Gray (2008) and others (Smith, 1992). Health care encounters and exchanges between patients, patients’ families, and HCPs constitute emotional labor and necessitate a degree of emotional engineering (i.e. coordination and control of HCPs’ thoughts, feelings, and outward feelings). The findings from my study illuminate the existence of both disconnect (i.e. stemming from incongruence where an individual HCP experiences tension between what is thought and felt and yet must continue to display a controlled outward expression) and engineering (i.e. that act of controlling that outward appearance or actions). As was clear from my findings, there is a relationship between emotions in EOL planning and care and HCPs’ values.

Participants described many aspects of EOL planning and care that make the work emotionally difficult—for example, fear of giving the wrong information to a patient/family, worry about overstepping professional boundaries, evoking strong emotions (e.g. anger, sadness) in others by talking about EOL issues. A values-dimension of EOL planning and care work also underscored why EOL planning and care was difficult and particularly so when tensions arose from discrepancies between HCPs’ own values. This finding, and the related literature, indicates clinicians themselves need to more clearly understand this aspect of their work and its influence on decision-making; as well, clinicians need to be supported in coping with value conflicts and with their emotions.
8.4.4. Value-based dimensions of health care work: Relationship between values and emotions and related concepts. In Chapter Seven, I illuminated various aspects of HF-EOL planning and care that evoked strong emotions and expressions of values. For example, expressions of HCPs’ values were evident in how HCPs articulated preferences for and about patients’ wishes. Tensions arose when HCPs’ values and preferences differed from their perceptions about the patients’ (and/or families’) actual wishes and directions (for example, participant BC019 described HCPs “pre-set ideas” about what patients should do and the influence of such). Health care professionals having their own values and resulting preferences for patients’ care has been described by other authors. Jiwani (2017) noted: “our emotions—the visceral experiences we have—are connected to our beliefs about reality and to our values. Each of us has values—things that matter to us significantly. The extent to which we believe we have or will get that which is important to us, determines our feelings. Our feelings are helpful indicators of our beliefs” (p. 11).

Hopkinson, Hallett, and Luker’s (2003) also described HCPs’ values in relation to experiences working with dying patients. In their qualitative study of nurses working with dying patients in medical units, Hopkinson, Hallett, and Luker explicated what they named “the personal ideal” which they said underpinned nurses’ experiences working with dying patients. The personal ideal was expressed by nurses in descriptions such as “a good death”, “the right thing to do” or “the way it should be.” That is, these authors described the “personal ideal” as a nurse’s personal view about how dying people ought to be cared for. When this “personal ideal”
was not met, the consequence was what the authors called “tension.” According to Hopkinson, Hallett, and Luker, “tension was the phenomenon experienced when nurses’ personal ideals of what death and dying could be or should be failure to match the personal reality of their experiences” (p. 529).

In his early writings from a neuroscience perspective, Greene (2003) proposed the term “moral judgment” to explain the intuitive “gut reactions” about what is right and wrong in particular situations. Greene called this intuitive component “moral intuition.” In Greene’s view, moral judgments can be thought of as being along a spectrum. In many instances these judgments are accomplished effortlessly and at times, they are instinctive emotional responses. Greene described these instinctive responses as perceptually-based and reactive and thus moral judgment is “more a matter of emotion and affective intuition than deliberate reasoning” (Greene & Haidt, 2002, p. 517). Greene’s and Hopkinson, Hallett, and Luker's (2003) explications align with what I called incongruence, which I used to articulate misalignments between a HCP’s values and preferences about patients and the HCP’s own perceptions about patients’ actual wishes and choices. This phenomenon illuminates moral judgments.

My findings about incongruence points to a tension between what HCPs think ought to happen, and their beliefs about what is actually happening. This conflict reflects similar thinking around the concept of moral distress (Corley, Minick, Elswick, Jacobs, 2005; Jameton, 2013;
And indeed, I think congruence is a related idea. Moral distress is an important concept in this discussion because instances of moral distress are recognized for having deleterious effects on HCPs who experience it and can deteriorate the quality of patients’/families’ care experiences (Henrick, Dodek, Gladstone at al., 2017; Musto, Rodney, & Vanderheide; Rodney, Kadyschuck, Liaschenko, et al., 2013).

According to Jameton (2013), moral distress is a challenge that arises “when one has an ethical or moral judgment about care that differs from that of others in charge” (p. 299). The concept has evolved and continues to evolve; Musto, Rodney, and Vanderheide (2015) summarized how thinking around moral distress has shifted: “Jameton’s initial conceptualization of moral distress pointed to a disjuncture between moral choice and moral action as a consequence of external constraints with the moral agent experiencing anger, frustration, guilt, and powerlessness as a result” (p. 92). In current thinking, moral distress is now recognized more broadly as an issue of constrained moral agency:

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\[ ^{102} \text{I recognize that moral distress is a well-developed concept that has been discussed widely in the literature. My purpose in discussing it in this chapter is to show relationships between what I have called congruence and between the concept of moral distress. I have not entered into a full explication of the concept of moral distress as that is beyond my aim.} \]
Moral distress is now recognized as a phenomenon that affects nurses and other health care providers in diverse arenas of practice, and as a phenomenon that reflects providers’ difficulties enacting the moral agency (fulfilling their moral responsibility) for a diverse range of reasons (p. 92).

According to Musto, Rodney, and Vanderheide, reasons included excessive workloads and complexities and challenges in EOL-related decision making. Indeed, the participants in this study illuminated both of these reasons, as I showed in Chapter Five.

Health care professionals’ experiences of moral distress can be problematic because moral distress is recognized as being related to moral detachment and diminished quality of care. Henrick, Dodek, Gladstone at al. (2017) described this relationship in their qualitative study about moral distress in 13 Intensive Care Units in British Columbia. Using surveys and focus groups, n=56 multidisciplinary health care professionals joined the study. The authors reported that participants described difficult feelings such as guilt, stress, frustration, embarrassment, worthlessness, helplessness, disillusionment, and discouragement. The authors described how these difficult emotions result in HCPs disconnecting and distancing themselves:

Some participants said to cope with moral distress, they have become less invested in their work and attempt to distance themselves from causes of moral distress. At the tertiary hospitals, some nurses and other HCPs felt that there was a culture within their ICUs that staff should hide or repress their emotions to avoid appearing weak (p. e51).
Of note, the authors also described strategies participants said were helpful in navigating moral distress. For example, opportunities to debrief situations that were morally distressing were important.

The concept of moral distress clearly highlights how tensions and misalignments between HCPs’ own values and preferences, and their perceptions about what they think the patient actually wants, can lead to serious issues such as detachment, attrition, and burnout. Collectively, this concept strongly undergirds why clinicians who engage in HF-EOL planning and care thus ought to be offered emotional support (e.g. debriefing), including coping skills and resources to manage value conflicts, should they arise.

8.5. Chapter Summary

In this eighth chapter, I discussed my three major areas of findings in relation to the current literature. Throughout this chapter, I introduced several implications that I will explore in Chapter Nine. For example, in the first section of discussion, I looked at the topic of knowledge, skills, and competencies in acute care in relation to my first area of findings What HCPs saw and knew. I pointed to how need-to-know schemas act as tacitly understood ways of thinking and align within a hidden curriculum. This discussion provides a foundation for implications that I explore in the next chapter where I highlight the need to more explicitly consider issues of the hidden curriculum in current initiatives aimed at improving EOL planning and care experiences for patients with HF (and for other patient groups).
In the second section of this chapter, I discussed literature in relation to my second major area of findings: *What HCPs said and heard*. I looked at how other authors have written about the way HCPs use and understand meanings in particular words in practice. I also explicated my use of the term “narrative” in relation to other authors’ conceptualizations of the term—in particular I explicated the concepts of *emplotment*, *narrative medicine*, and *narrative nursing*. These three concepts are important because they point at implications including recognizing the diverse and different understandings of the way HCPs use words in clinical practice. Instead of seeking standardization, *narrative medicine* and *narrative nursing* outline a framework for mutual understanding.

In the third section of this chapter, I discussed literature about my area of findings *How HCPs felt and acted* and the *emotional and values-based* dimensions of EOL planning and care. I also examined how others have described and identified the *strategies* HCPs use to control emotions and control the narratives. I discussed the related of *emotional labor*, *emotional management*, and *moral distress* which are of significant importance to my findings because they illuminate implications including the need to more clearly support HCPs to develop communication strategies to better manage and respond to in EOL planning and care work. In the chapter forthcoming, I will synthesize my findings and discussion and present what I see as salient implications for clinical practices, including implications and recommendations for practices that seek to enhance and strengthen the success of these existing EOL quality initiatives.
Chapter 9
Clinical Practice Implications, Study Limitations, and Future Research

In Chapter Eight, I discussed literature related to the three major areas of my findings. In this final chapter, I emphasize the implications from my findings. As such, I present and discuss a number of nursing and interprofessional practice implications, recommendations, and areas for further research and discovery. The findings and their related implications are relevant to nurses and all HCPs because they may improve HF-EOL planning and care experiences for patients and their family members. Nurses in particular spend the greatest amount time providing direct care to patients in hospitals and make-up the largest proportion of HCPs on interdisciplinary clinical teams. Nurses thus have an important role and share in the responsibility all HCPs have to engage patients and their families in opportunities for meaningful EOL planning and care activities (Adams, Bailey Jr, Anderson et al., 2011; Canadian Nurses Association, Canadian Hospice Palliative Care Association, & Canadian Hospice Palliative Care Nurses, 2015; Pesut et al., 2014; Strachan, Kryworuchko, Nouvet et al., 2018).

9.1. Overview of Chapter Nine

I begin this final chapter with a brief overview and summary of my study. I re-visit my three research questions and three thematic areas of findings: *What HCPs saw and knew* (Chapter Five), *What HCPs said and heard* (Chapter Six), and *How HCPs felt and acted* (Chapter Seven). As explained previously, these three areas of findings illuminate several important implications for clinical practice, which may improve EOL planning and care for the HF
patient/family population. Thus, I discuss existing provincial and national-level EOL improvement initiatives that are underway and present implications. I explicate limitations of my study and describe areas where future research and inquiry could be considered. I close this dissertation with some reflective insights and concluding remarks.

9.2. A Brief Overview and Summary of the HF-EOL Study

This study examined the problem of reportedly poor quality EOL experiences for patients with HF in hospitals. Patients with HF often die in hospitals, where prolonged dying, inadequately managed symptoms, and worsened suffering for patients and their family members are reported. Hospital environments have also been described as having significant influence on HCPs’ approaches to HF-EOL planning and care. Thus, the study purpose was to examine HCPs’ experiences in hospital contexts and acute care settings and to understand how HF-EOL planning and care are structured in relation to these contexts.

The concept of structure was defined within a theoretical framework which also informed the study design. I sought to answer three research questions: 1) What are the relationships between agents, schemas, and resources within acute care practice contexts where patients with HF experience care and how can such relationships be said to structure clinical practices specifically concerning EOL planning and care? 2) How is power operating within these health care practice contexts to preserve (or sustain) some structural configurations, and limit (or constrain) others? And, 3) What are the implications for nursing and interprofessional practice, research, and policy? A qualitative approach with ethnographic methods and an overall
interpretive description methodology guided data collection and analysis. A sample of twenty-two HCPs from various disciplines experienced in acute care and HF-EOL participated from two study sites; data were collected over 250 observation hours and eighteen semi-structured interviews.

Data analysis produced three main areas of findings. In Chapter Five, I presented and discussed practice knowledge and notions of expertise within findings about *What HCPs saw and knew*. I explored participants’ common framing of HF-EOL planning and care as the work of clinical experts and discussed what I learned about HCPs’ understandings of expertise in relation perceptions about the knowledge required to practice in acute care hospitals settings. In Chapter Six, I examined findings about *What HCPs said and heard* where I explored HCPs’ differing uses and interpretations of the meanings of EOL-related words and phrases. I showed how particular EOL-related words were used within interprofessional communications; I also presented and discussed the existence of differing interpretations of EOL-related words and phrases, and explored the effects of such. As I explained in Chapter Six, findings about differing interpretations of EOL-related words was important because varied understandings shaped and structured actual clinical practices. In Chapter Seven, I explored emotional and value-based dimensions of HF-EOL planning and care with findings about *How HCPs felt and acted*. Emotions and values related to HCPs’ uses of strategies, such as avoiding particular words, in order to manage emotion in EOL-related situations.
In Chapter Eight, I discussed my three areas of findings in relation to concepts in the existing literature including the hidden curriculum, narrative nursing and narrative medicine, emotional labor, and moral distress. The implications and recommendations discussed in this chapter may strengthen the success of these current provincial and national-level EOL planning and care improvement initiatives.

9.3. Provincial and National-Level End-of-Life Care Quality Improvement Initiatives that are Currently Underway

As I explored in Chapters One and Two, the palliative approach to care has been recommended as framework from which patients (and their family members) with HF could be proactively engaged in EOL planning and care, early on in the illness trajectory and then repeatedly throughout as the illness experience progresses and as patients’ needs change (Canadian Council of Cardiovascular Nurses, 2015; Canadian Hospice Palliative Care Association, 2015; Canadian Nurses Association, Canadian Hospice Palliative Care Association & Canadian Hospice Palliative Care Nurses, 2015; Jaarsma et al., 2009; McKelvie et al., 2011). This recommendation is rooted in the idea that the needs of patients with HF include strategies such as support for chronic illness and self-management, integration of palliative care principles (e.g. symptom management, holistic approach), effective and ongoing communication about illness issues and EOL planning, and inclusion of specialist palliative care clinicians and services when appropriate. Together, these needs are addressed within the palliative approach to care framework.
Recognizing this call to improve EOL care for all, including patients with HF, several provincial and national-level EOL care initiatives are currently underway. For example, *The Way Forward* is a national-level initiative from the Quality End-of-Life Care Coalition of Canada (QELCCC) aimed at improving EOL planning and care through greater integration a palliative approach to care and via expanded access to hospice and palliative care specialists (Quality End-of-Life Care Coalition of Canada, 2019). Similarly, the Pallium Foundation of Canada (2018) is another national-level organization which is leading initiatives towards improving access to palliative care via the integration of the palliative approach.

Related provincial-level initiatives are also underway. In 2016, the BC Center for Palliative Care launched a provincial initiative to “embed the Serious Illness Conversation Guide (SICG) in care for all persons with serious illness in the last year of life” (Barwich, Beddard-Huber, Hassan, Fyles, & Tayler, 2018, p. 1). As communication is an integral aspect of the palliative approach and is foundational for HCPs to understand patients’ wishes and care
preferences, the SICG is currently used as a tool\textsuperscript{103} to support clinicians in EOL planning and care communications. Bernacki et al. (2015) called this communication “EOL conversations” and noted that clinicians in general, tend to avoid them, which aligns with my findings about how clinicians commonly refrain from doing this work. The SICG is a multicomponent communication tool that clinicians can use to identify patients who are at risk of high death and to engage them in EOL planning and care related conversations (Bernacki et al., 2015). Within a palliative approach philosophy, such engagement would occur early on in any life-limiting illness trajectory including HF, be repeated throughout the trajectory, and fall within the responsibilities of all involved HCPs.

Recognizing the large patient population who is likely to benefit from this type of conversation, Bernacki et al.’s (2015) suggested use of the “surprise” question. The “surprise”

\textsuperscript{103} The SICG breaks down EOL-related conversations into simple steps. Open-ended questions are also used. For example, the SICG has clinicians first thinking through a “set up”; in this set-up, clinicians think in advance about issues such as benefits for patients/families and decision goals. The next step points clinicians to consider the communication guide itself. The guide contains suggestions for open-ended questions that are simplified into eight subject areas: understanding, information preferences, prognosis, goals, fears/worries, function, trade-offs, and family (Bernacki et al., 2015). Within each subject area, the authors have suggested open-ended questions (e.g. “what is your understanding now of where you are with your illness?”, “How much information about what is likely to be ahead with your illness would you like from me?”, “What are your biggest fears and worries about the future with your health?”). After the conversation has taken place, the clinician is director to complete two last steps: summarize and confirm, and then act (e.g. affirm commitment, make recommendations, document).
question is a simple, single-item screening tool proposed for clinicians to identify risk of death and thus also identify patients who are likely to benefit from EOL planning. The clinician asks themselves, “would you be surprised if this patient died in the next 12 months?” (Downar, Goldman, Pinto, Englesakis, Adhikari, 2017; Lakin et al., 2016; Moss et al., 2008). Patients who, in the clinician’s view, would not cause the clinician to be surprised if they died in the next year, may gain benefit from engaging in illness and EOL planning conversations.

The upstream communication and planning and activities inherent within the palliative approach to care emphasize identification of patients’/families’ individual preferences, wishes, and goals and thus promote the delivery of EOL care that is aligned with patients’/families’ actual wishes. As is clear from my findings, these upstream communication opportunities are overlooked in acute care hospital settings, which underscores why a central focus of the implications I identify and discuss next are related to optimizing uptake and integration of a

104 Of note, Downar, Goldman, Pinto et al. (2017) conducted a meta-analysis looking at how well the “surprise” question predicts death in seriously ill patients. The authors reported that the “surprise question” as a single-item screening test performed poorly in actually predicting death. However, it may still be useful in helping clinicians identify patients (and families) who might benefit from integration of a palliative approach. As Reimer-Kirkham et al. (2015) noted, “the upstream orientation relies on early identification of those who may be on a dying trajectory and seeks to ascertain the care goals of the patient to guide the plan of care” (p. 188). Thus, the “surprise” question will likely remain useful as a screening tool for clinicians to identify the need to consider upstream planning, rather than actually function in a prognostic capacity to predict death.
palliative approach and related EOL care initiatives. Indeed, successful integration of the palliative approach may achieve several important goals: first, it may improve EOL planning and care experiences overall via enhanced interprofessional collaboration. Second, it may begin to address the widespread issue of limited access to palliative care specialty services and thus bring into focus issues and care needs related to advanced illness and death (e.g. symptoms, grief, bereavement). And lastly, and perhaps most importantly, integration of the palliative approach seeks to ensure that the EOL care provided aligns with patients’ actual preferences by improving interprofessional collaboration and communication.

9.4. Clinical Practice Implications and Recommendations: Strengthening the Success of EOL Care Initiatives by Addressing Influential Aspects of Acute Care Contexts and Structured Practices

I have identified several clinical practice implications from my study findings. I frame the implications in relation to issues of HF awareness and invisibility and HCPs’ knowledge about HF and EOL; discrepant uses and interpretations of EOL-related words and the various narratives that inform how these words are used and understood; and, issues of emotion and value-based dimensions of EOL planning and care and strategies used by HCPs to control emotions in EOL planning and care communications. As I noted in Chapter Eight, while I discussed these three areas of findings within separate chapters, they are interrelated and align within an overarching theme about HCPs’ willingness and actually doing EOL planning and care
work. This interrelatedness between my three areas of findings becomes clearer as the forthcoming implications reflect different aspects of my findings and subsequently overlap.

9.4.1. Awareness in HF and EOL planning and care: Addressing environmental issues that relate to HF invisibility and improving how HCPs see and know HF in acute care. In Chapter Five, I examined findings about issues of awareness of HF in acute care settings and illuminated how the organization and design of resources within these practice settings can make seeing and knowing HF difficult—that is, I identified layers of HF invisibility. I showed how acute care contexts related to difficulties seeing HF in acute care. One aspect of these layers of invisibility included resource aspects of acute care contexts such as staffing make-up, layouts of the physical clinical environments, and the organization of nurses’ time within a clinical shift. For example, patient information was located within a single paper-based chart, which was oftentimes challenging to find. Challenges locating patients’ charts contributed to nurses and other HCPs’ overall difficulties accessing and ascertaining patients’ illness histories and other information.

Nurses’ workflows and high workloads also related to challenges accessing patient information. For example, as patient care was required almost immediately after nurses began their clinical shifts, little time was actually allotted or available for nurses and others to seek out and/or acquire patients’ histories. In response to these issues, nurses used truncated handover tools. These tools contributed to the invisibility of HF and the difficulties seeing HF because they emphasized the acute ED admission cause and focused on the prioritization of associated
tasks. Consequently HF, as a chronic illness process with high morbidity and mortality and with related EOL planning and care needs, was commonly overshadowed and missed. Overall, issues of awareness and invisibility in acute practice contexts point to three important implications: consider large-scale structural changes towards the goal of addressing problems such as workload, workflow, and staffing and related impacts on care; improve how nurses and other clinicians access and assimilate patient information; and, re-visit how the ED admission cause is foregrounded in interprofessional communications.

9.4.1.1. Addressing issues such as workload, workflow, staffing, and other large-scale structural changes. In Chapter Five, I explained study findings about issues such as workload, workflow, and staffing and showed how various aspects of these areas related to difficulties both knowing and seeing HF and EOL. For example, study findings highlighted the impact of high proportions of newly graduated nurses, irregular work schedules and casualization of the workforce, and high staff turnover and attrition. Participants described these features of acute care context in relation to diminished collective clinical knowledge and practice experience and in terms of having fewer opportunities to consolidate knowledge and clinical practice. Combined with the clinical complexities in supporting all-organ patient populations, participants described the clinical knowledge, skills, and competencies required on medical units as especially complex and challenging.

Issues such as casualization of the nursing workforce, rotations and schedules where nurses worked across multiple units and on different teams, and frequent staff turnover as staff
relocated from areas such as medical units to practice in other settings represent large-scale structural issues which have an effect on both knowing and seeing HF-EOL in acute settings. As participant BM007 explained to me, newly graduated nurses may only have access to causal work, which can make it difficult to consolidate their practice (“[newly graduated RNs are only offered] casual [episodic work]. And so every day is their Monday. And that to me is just poor. Like, they need to come [more consistently]. They need to really consolidate [their practice]”). Indeed, the Canadian Nurses Association (2004) has also explained issues of casualization of the nursing workforce including diminished continuity of care, diminished ability to know the patients and their individual needs, fewer opportunities to attend in-service education and continuing education, and less mentorship experiences. While Becker, McCutcheon and Hegney (2010) have noted positive aspects of casualization, including increased scheduling flexibility and thus increased ability for nurses to balance work with other personal commitments such as parenting and caregiving, these authors also discussed casualization in relation to limitations including potentially negative effects on patient safety.

My study findings about issues with staffing and workload, illuminate the need to find creative strategies to support newly graduated nurses access regular work opportunities with the goals of promoting consolidated learning experiences and practices, and establishing new clinicians onto clinical teams where mentoring and knowledge sharing are promoted. Such strategies may include initiatives such as supernumerary clinical learning and consolidation positions; decreased nurse-to-patient ratios, particularly when clinical leaders and/or managers
identify high numbers of newer nurses scheduled on shifts; and, greater opportunities for mentored clinical practices through enhanced clinical leader support and/or increased presence of nursing educators and other clinical leaders (Canadian Nurses Association, 2004). Creative approaches such as these may also address what were described as high instances of turnover and attrition as interprofessional relationships can be strengthened by these kinds of initiatives. While strategies to address staffing and workload are necessary, workflow issues—such as access to patient information—are also important and will need to be considered.

9.4.1.2 Improving HCPs’ access to patient information. Nurses and other HCPs cannot be expected to enact and engage patients and their family members in HF-EOL planning and care without first recognizing the relevance for the individual patient/family. As my findings indicated, HF was not always recognized nor was the relevance of HF-EOL planning or care. These issues about awareness stemmed, in part, from challenges accessing patient information, including complete health histories. The physical layouts of the clinical environments contributed to difficulties accessing information because relevant patients’ health histories were kept in paper-based patient charts, which were also located away from where nurses actually worked. At times, accessing the single patient record was also challenging for other HCPs. Large interdisciplinary care teams were commonly also seeking access to the single paper-based patient record and thus the issue difficulties accessing patient information were widespread.
At a macro- and system-level, difficulties accessing patient information due to layout and limitations of a single, paper-based chart, point to the need for mechanisms where all involved HCPs can simultaneously access patients’ records. For example, the use of health information technologies (HIT) such as electronic patient health records may help clinicians to more easily access patients’ information and may mitigate some of the current challenges accessing a single paper-based record. These types of information systems could also potentially address workflow issues because they may be designed with different data organization strategies such as compiled admission histories, trend functions (e.g. laboratory and/or diagnostic values), and previous admission documentation, which could improve clinicians' reviews of patients' histories (Hoover, 2017; King, Patel, Jamoom, & Furukawa, 2014; Laramee, Bosek, Kasprisin, & Power-Phaneuf, 2011). Recognizing the multidisciplinary nature of health care teams, HIT such as electronic records thus should be designed so that individual HCPs can simultaneously access patients’ records. Navigation and effective search functions should also be considered in the designs so that all HCPs can effectively locate the information they need (Payne, 2013).

While digital systems such as electronic health records may address some aspects of existing patient information access issues, as Borycki (2013) and Sittig and Singh (2011) have cautioned, HIT such as electronic health records can present new patient safety issues and hazards. Technology-related errors can arise in HIT at various stages including the design and development, implementation and customization, and during ongoing maintenance (Borycki; Sittig & Singh). These errors can also stem from newly created workflows that result from the
HIT such as physician order entry, changes in pharmacy or laboratory processes, and clinician charting templates (Sittig & Singh). Technology-related errors usually arise after HIT has been implemented and clinical users are interacting with the system, thus efforts to pro-actively identify potential issues and/or to correct known issues is a necessary component of HIT uses in clinical practice. For example, several authors have recommended health care organizations develop reporting and surveillance systems and creation of processes to review and alter HIT when necessary (Borycki; Sittig & Singh; Singh & Sittig, 2016).

In Chapter Six, I discussed study findings where I identified a narrative process underpinning different EOL-related words. I also illuminated diversity in HCPs’ understandings and assumptions about the meanings of these words. This finding highlights an important implication where electronic patient information or other related HITs might be impacted. For example, the design of these systems should consider providing patient information such as a particular resuscitation preference (e.g. DNR) in conjunction with related contextual documentation (e.g. ACP documents, goals-of-care conversations). This strategy aims to address potential misunderstandings that may be derived from individual HCPs’ own assumptions about what these EOL-related terms mean.

At an organizational-level, there should be clear support for implementation and integration of these electronic, multi-user patient information systems. Organizations should also actively engage end-users (e.g. HCPs) in consultation for design and implementation decisions (e.g. location of workstations), and commit to ongoing assessment, detection, and correction of
technology-related errors that result from these HIT (Borycki, 2013; Sittig & Singh, 2011). At an individual HCP-level (micro), clinicians should understand and be able to articulate the need and rationale for these systems. Individual HCPs should also contribute to organizational requests for consultation in the function and design of these patient information systems (e.g. placement of workstations in proximity to relevant and meaningful work areas, instead of at an arbitrary centralized location), and be proactively engaged in ongoing quality evaluations where technology-related errors are addressed (Borycki; Laramee, Bosek, Kasprisin, & Power-Phaneuf, 2011). While these systems may improve the ways HCPs access patient health information, the existing prioritization of particular patient information (e.g. ED admission cause), will also need to be considered.

9.4.1.3. Re-visiting the prioritization of patient information in relation to the ED admission. As I described in Chapter Five, in response to challenges accessing patient information, nurses created communication tools (e.g. "cheat sheets"). These communication tools focused predominantly on patients’ admission causes as reported in the ED (e.g. hyperglycemia) and related tasks were emphasized (e.g. check blood glucose levels). While the focus on the acute admission cause has inherent relevance to the care planning of any hospital admission, as I presented and discussed in Chapters Two and Eight, caring for hospitalized patients with chronic illnesses such as HF, requires a more comprehensive approach. This comprehensive approach should include recognizing and considering concurrent chronic illnesses, which can be missed when clinical teams focus solely on the acute issue. For
example, in Chapter Five I showed how important patient self-management activities such as daily weights can be missed when HF is overshadowed or obscured by the admission cause as reported in the ED. Thus, a key implication from my study findings is that HCPs need to consider how best to balance the necessary emphasis on patients’ ED admission causes with the proportionately necessary emphasis on concurrent chronic illness(es) and related care needs.

The work of considering how best to balance acute care causes with chronic illness needs points to implications most relevant at the individual and organizational levels. For example, individual HCPs should reflect and evaluate how patient information work-arounds (e.g. “cheat sheets”) are used in their practices and reflect on how these work-arounds might be emphasizing one aspect of the hospitalization (e.g. ED admission cause) and overlooking another (e.g. HF and daily weights). At an organizational-level, HCPs should be supported to undertake this reflection and examine the impact of work-arounds such as “cheat sheets.” For example, clinical and organizational leaders could explicitly ask individual HCPs to undertake this self-reflection. Leaders should also be prepared and equipped to provide clear rationale for this exercise. Organization-level HCPs such as educators and managers should also consider how to include such self-assessments in ongoing orientation activities, continuing clinical education, and quality reviews. Patients and their family members are also key partners in care and should be invited to provide inputs into their care planning such that any ongoing self-
management and/or chronic illness need is clearly considered and incorporated (e.g. sodium and fluid restrictions, self-monitored weights).

The two key implications discussed above address the complexities of organizing information for all-organ admissions and patient populations with many comorbidities, particularly in general medical units where clinical care needs for the patient populations are especially diverse. The organization of all-cause admissions was complex because it involved considerable memory work and broad knowledge and was identified as one aspect within the layers of HF invisibility—that is, it was an aspect of how HF was difficult to both see and know in acute care contexts. Complexity deepened when these layers of invisibility came up against clinicians’ *knowledge* and skills about HF generally, and other aspects of EOL planning and care more specifically. For example, participants repeatedly emphasized how they were *not* experts in HF or EOL. Their perceptions of the expectations and prioritization of knowledge in acute care points at additional implications.

**9.4.2. Knowledge, skills, and competencies and perceptions and positioning of EOL planning and care experts: Addressing clinicians’ perceptions about the prioritization and value of knowledge domains related to EOL planning and care.** In Chapter Five, I examined findings about issues of HF *knowledge* in acute settings, including what HCPs knew, what they *thought* they should know, and what they preferred to know. I explored HCPs’ common self-reported knowledge deficits related to HF and EOL planning and care. Indeed, knowledge deficits were described about both HF and EOL concepts. For
example, self-described knowledge deficits were evident in many domains including HF and self-management education, HF as a terminal illness and prognostic estimates, palliative care principles and care needs for dying and death, and EOL planning and care communications.

Linked to these knowledge deficits, I also explained what I learned about structured practices in relation to the prioritization of acquiring some types of knowledge, skills, and competencies over others; the valuation of some knowledge domains and de-valuation others; and how implicit beliefs about scope, role, disciplinary authorities and power interfaced to shape both knowledge development and enacted practices. For example, HF-EOL planning and care were commonly framed as outside of basic and standard acute care practice and thus were seen as the work of experts or those with disciplinary authority or particular specialty expertise. At the same time, HCPs in acute care practice emphasized how proficiencies in skills such as interpreting vital signs and rapid assessment were necessary and thus were prioritized. Such prioritization of these biomedically-based knowledge areas and skills (e.g. vital signs, rapid assessments) also meant these areas became the focus of professional development activities. That is, what was seen to be needed for acute care practice was also seen as more necessary knowledge and had a higher development priority than EOL-related and communication knowledge. As I interpreted from my analyses, participants also conveyed HF-EOL planning and care were not likely to occur without HCPs believing they had the necessary knowledge, skills, and competencies to do so.
Such beliefs about the prioritization of knowledge illuminated structured practices in relation to a schema I called need-to-know. Need-to-know was a way of thinking about what needed to be known in order to provide an acceptable standard of care in acute practice settings from a biomedical perspective. Need-to-know however, also highlighted what I appreciated as gradients and hierarchies of knowledge. Some domains of knowledge and skill were seen as the work of experts, best carried out in another setting; that is, somewhere that was not acute care, such as palliative care. In other words, aspects of HF-EOL planning and care commonly were seen as falling outside of “needed” knowledge and instead were seen to be more appropriately situated within an “expert” or “specialty” role. Collectively, my findings about knowledge and structured showed how HCPs prioritized knowledge development in their practices in relation to acute care priorities such as assessing, diagnosing, and curing. My findings also indicated implicit and explicit devaluing of other practices and knowledge development, including communication about difficult topics such as serious illness and HF-EOL. These findings about knowledge point to three implications for clinical practice and policy: the need to re-frame knowledge expectations for HCPs in acute care; to understand ways the hidden curriculum is at play in relation to EOL quality initiatives and EOL-related knowledge; and to consider stakeholders and change management.

9.4.2.1. Reframing HF-EOL knowledge, skills, and competencies within acute care practices and addressing the “need-to-know.” Patients with HF who become hospitalized have a range of illness and EOL-related needs that my research shows are inadequately
addressed by the knowledge, skills, and competencies that are aligned with the basic and standard practices that followed from the need-to-know framing—that is, what was seen to be necessary for acute care practice. In Chapter Five, I illustrated how I came to understand what knowledge and skills were included within this basic and standard practice (see Figure 5.2). In relation to HF-EOL planning and care, many domains of knowledge, skills, and competencies (e.g. conversations about EOL) were positioned as the work of experts and thus were not necessarily seen as within the scope or role of most HCPs. As Bernacki et al. (2015) have explained, there are not sufficient numbers of palliative-specialty clinicians to assume complete responsibility for this work; and thus, there is a need for non-specialist HCPs to develop proficiencies in EOL planning and care activities such as goals-of-care and serious illness conversations. And in the case of HF, there is also a need to develop communication skills aimed at supporting patients with self-management and illness education.

My findings bring into focus an important implication for nursing and interprofessional practice: prior to implementation of initiatives aimed at expanding and improving integration of a palliative approach and related methods (e.g. the “surprise” question), it may be necessary to frame new knowledge and related skills within the “need to know” thinking and positioning. For example, clear statements such as “this is your work in acute care” may augment successful uptake. Purposeful situating of specific information or skills in relation to current practice expectations will promote clarity in how HCPs approach their own professional development in terms of understanding their disciplinary roles and developing their proficiencies and
competencies (e.g. “this is your work now” or “this will be your work after...”). This purposeful situating may also create ways for clinical and operational leaders to incorporate supportive frameworks, progress measures, and continuing competency programs in education programs.

At a macro-level, this implication—that is, explicit framing of HF-EOL planning and care as within the work of HCPs in acute care—means that within improvement initiatives such as ones I described above, statements about the role that all HCPs have in EOL planning and care activities should be foregrounded. Likewise, organizations that represent macro-level interests, including professional regulatory groups (e.g. Canadian Nurses’ Association, Canadian Medical Association), should ensure they equivalently reflect and endorse this message.

Endorsements should also originate from organizational leadership. For example, in their mixed-methods study of a project which evaluated integration of a palliative approach in acute care, Hilliard, Stajduhar, Sawatsky, Reimer-Kirkham, Doane et al. (2017) recommended that a successful integration “requires executive leadership to make it an organizational policy” (p. 1). This at the meso-level, leaders in clinical and operational roles should also determine how best to align these new knowledge, skills, and competencies in relation to basic and standard requirements for practice in acute care. For example, leaders should consider how to influence professional development opportunities such that content seen as a lower priority is framed and embedded within expected continuing education and workflows (Hilliard, Stajduhar, Sawatsky, et al.).
At the micro-level, individual HCPs who practice with strong foundational clinical skills (i.e. who are knowledgeable, skilled, and competent in the required and necessary foundation for acute care practice) may consider championing the value of EOL planning and care and lead the way in acquiring the related knowledge, skills, and competencies. In each of these recommendations, the explicit recognition and reframing of the value of EOL planning and care and the related knowledge, skills, and competencies is important because it addresses what I learned about the hidden curriculum and its influence in acute care contexts.

**9.4.2.2. Understanding the hidden curriculum and addressing the devaluation of communication skills and other knowledge and competencies related to EOL planning and care.** Building from the findings I presented in Chapter Five, in Chapter Eight I discussed my findings about the need-to-know schemas in relation to what authors have called a “hidden curriculum.” As I explored in the previous chapter, the hidden curriculum refers to lessons that are taught and learned outside of a formal curriculum—it is also reflective of what HCPs know, that is, it makes up an aspect of the *culture* of acute care.

As I understood from my findings, perceptions about what knowledge was needed were tacitly understood and unquestioned. These characteristics thus point to how the “need-to-know” schema and related perceptions and prioritization of what needs to be known, may be taught and learned as hidden curricula. Hidden curriculum can be problematic because covert teachings and lessons can undermine the formal content, including content associated with
current HF and EOL care initiatives. Tucker (2009) explains this potentially complex hidden curriculum as it relates to EOL specifically:

In [the medical profession] in which one may feel a steady barrage of emotional encounters, some enormously satisfying, some utterly draining, the lecture hall is not the forum to address affective responses to the experience of clinical learning in palliative and EOL care...We must capitalize on all coping strategies, and facilitated learners’ discovery of others, all the while cognizant of the ‘hidden curriculum’ of death as a failure that attempts to undermine our efforts. We must expose the hidden curriculum to diminish it’s impact; unvoiced is unchallenged” (p. 1107).

In other words, Tucker is illuminating how “affective” responses can shape EOL planning and care, which reflects what I described as the emotional dimensions of HF-EOL work. The “affective” and emotional aspects of HF-EOL may require a more fulsome consideration of how to support HCPs involved, which I explain in section 9.3.4 below.

At the macro-level, recommendations for how the hidden curriculum should be considered include providing clear and explicit statements about what is taught and learned outside of the formal content. For example, explicit recognition that HF-EOL-related knowledge, skills, and competencies may currently be undervalued may also strengthen learners’ abilities to respond to lessons in clinical practice where devaluation is experienced. Likewise, learners may benefit from recognition from more direct explanations of how other lessons could appear (e.g. disciplinary roles and implicit ideas about necessary permissions).
At the meso-level, organizations might consider proactive approaches to countermand lessons that undermine the formal curriculum. For instance, where there may be implicit lessons outside the formal curriculum about disciplinary permissions, policy infrastructure such as position statements might be used to promote a clear endorsement of what is taught in the formal curriculum. Clinical and operational leaders within organizations should also engage HCPs at the micro-level in order to get a sense of the informal curriculum that may need to be specifically addressed. For example, Hilliard, Stajduhar, Sawatsky, et al., (2017) note the need for culture shifts: “education and tools alone will not create culture shifts. Engagement, and ongoing mentorship and coaching of unit staff is needed” (p. 1). Collectively, these implications point to practices that may change as a result of these recommendations, thus, there are relevant implications for stakeholder engagement and change management considerations.

9.4.2.3. Addressing issues of HF-EOL awareness and changing practices:

Implications for stakeholder engagement and change management. For many HCPs, explicitly situating EOL planning and care into acute care could be a significant practice change. As would be the case with any practice change, stakeholder engagement and a thoughtful change management strategy should be considered (Erlingsdottir, Ersson, Borell, & Rydenfält, 2018; Olson, Tooman, & Alvarado, 2010; Stirk & Sanderson, 2012). Stakeholder engagement may also need to include the endorsement of both operational and clinical leadership as the practice development and changes I described above likely necessitate a financial investment as well as reconfiguration of clinicians’ current workloads and training requirements.
At a meso-level, both clinical and operational leaders should have a central role in supporting HCPs through practice changes associated with all HCPs having a role in HF-EOL planning and care. Operational leaders, for example, are responsible for organization of aspects of clinical work such as schedules, staffing, and workload reviews; purchasing equipment; approving educational pay; and authorizing schedule changes such as those that might be needed for HCPs to attend education events. Thus, operational leaders are key stakeholders with important decision-making roles who are also central figures in finding creative solutions for workflow issues such as the limited amounts of time to acquire patients’ health histories. In contrast, clinical leaders often include HCPs who deliver education and model practice changes; these leaders commonly also have particular expertise and thus provide support for other HCPs to build capacity. Clinical leaders are key stakeholders because they usually design practice resources and educational events and thus should be engaged in change management strategies.

In this section, I presented several implications from the area of my findings about What HCPs saw and knew. I recommended a more explicit situating of EOL planning of care as within nursing and other HCPs’ work in acute settings. Without this explicit situating and explanation of how responsibilities are likely to shift, problematic assumptions about this work belonging outside of acute care and within the domain of particular experts or specialists will persist. This expansion of EOL planning and care to involving all HCPs has been endorsed by others researchers who have examined EOL planning and care in hospitals. For example, Strachan,
Kryworuchko, Nouvet et al. (2018) have argued “nurses’ roles in these formal and informal embedded-in-care serious illness conversations should be developed and supported as a practice expectation within the unpredictable and spontaneous conditions of everyday practice and not in isolation of those realities” (p. 31). Effective EOL planning and care will also require related narratives of EOL-care be addressed.

9.4.3. Addressing the narrative dimensions of EOL-related words and phrases:

Clarifying and understanding what we saying in clinical practice and recognizing the narratives underpinnings. In Chapter Six, I explored an area of findings about uses and meanings of particular EOL-related words and phrases (e.g. “palliative”, “DNR”, “comfort care”, “full code”). Implications related to my findings about What HCPs said and heard focus around a central point: in acute care practice contexts, commonly used EOL-related words were used often beyond their definitions and instead, the meanings users (i.e. agents) derived reflected implicit narrative underpinnings. And because schemas underscored narratives (and schemas belonged to agents), and narratives underscored meanings, these words affected assumptions, interpretations, and actions differently depending on the agents involved. For example, to some HCPs the word “palliative” signified nearness to death and indicated implementation of and focus on non-curative care. In contrast, other HCPs understood “palliative” as an approach aimed at improving patients’ QOL and as compatible and complementary to cure-focused treatments. Problematically, the information shared between HCPs too often reflected assumptions about patients’ care, rather than actual information.
As I have indicated in my analyses above, narrative underpinnings had inherent complexity because narratives and their related schemas, were taken-for-granted and implicit and rarely explicated or defined. That is, the meanings of EOL-related words were largely assumed and unquestioned. As I showed in Chapter Seven, schemas and narratives also shifted. For example, participants told me about their experiences learning about the palliative approach to care, which introduced new schemas about what it meant to be palliative and thus also created new narratives for what the HCPs anticipated from a patient being palliative. In the absence of mutual understandings about the meanings of words used in clinical practice settings to discuss a range of EOL issues, contested practice decisions resulted. For example, a participant described a clinical scenario where the use of supplemental oxygen was unclear because the patient was thought to be palliative. Importantly, contested practice decisions and actions may be misaligned with what other HCPs intended; and most importantly, contested practices may misalign with what patients actually want. Thus, the clinical practice implications and recommendations from this area of my study findings focus on two essential points which are collectively aimed at promoting clear communication and mutual understandings: recognizing narratives and coming to know our own narratives; and, coming to know others’ narratives.

9.4.3.1. Developing awareness of how narratives shape practice. The results of my research make it clear that there is a critical need for all HCPs in acute care contexts to develop
awareness of how narratives shape their practices. This is an important implication with recommendations at all levels: individual, organizational, and larger health care systems.

At the individual HCP level, HCPs should be encouraged to recognize, acknowledge, and think about how EOL-related words/phrases (such as the ones I brought to light in Chapter Six) may be impacting their own decisions and enacted practices. For example, individual HCPs should self-reflect on questions such as, “if a patient is a called a ‘DNR’, what assumptions are made about their care preferences outside of resuscitation?”, or “how does being ‘full code’ change meanings and assumptions about what that individuals’ treatment preferences are?” Fitzpatrick (2017) has called this introspective reflexivity “reflective practice” and situated it within the notion of “narrative nursing”:

Narrative nursing is focused on the use of reflective practice, a systematic approach to thinking about one’s actions as a professional nurse in the context of caregiving. The reflective practice guides nurses to improve future interventions through an understanding of the actions and processes inherent in the narrative stories. This reflection enables change as the reflection incorporates attention to one’s knowledge, beliefs, and values within the context of a nurse-patient encounter. As a component of reflective practice, nurses can be encouraged to engage in storytelling about their personal experiences with patients and families (p. 1).

At the micro-level, such self-reflections may be helpful in making the findings I presented and discussed in Chapter Six about words such as “DNR” more relevant to individual HCPs.
Through the process of recognizing, acknowledging, and thinking about words and phrases where narratives inform and inflate meanings, HCPs should also seek to recognize, reflect, and explicate other words and phrases that may also exchange highly nuanced clinical information. Identifying these other words and phrases for various patient groups in different practice contexts will also be important.

At an organizational level, individual HCPs should be supported and facilitated to engage in these self-reflection exercises. For example, self-reflection exercises such as my example above could be encouraged in quality initiatives or at continuing education events. Leaders in clinical and operational roles should also recognize the influence of narratives and similarly seek to identify and understand words and phrases where narratives are inflating meanings and consider policy implications—for example, by including explicit statements within policy and/or practice guidelines that define words were meanings are known to vary among HCPs.

At a systems level, the micro and meso-level initiatives described above should be supported and encouraged. Macro-level initiatives such as The Way Forward and other national- and provincial-level initiatives should consider including content for knowledge users about how narratives inform our understandings of commonly used EOL-related words (e.g. “palliative”). This recommendation will help HCPs grow awareness of their own assumptions and also promote recognition of the variability in their own understandings. Of note, the ways patients/families and HCPs understand EOL-related words is evident in several current
campaigns. For example, Care Dimensions (2019), which is an organization leading several initiatives aimed at promoting clearer understandings of hospice and palliative care for the public, recently published a short video called “Palliative Care PSA we’re the fire department not the fire” which uses humor to explore challenges navigating assumptions about what it means when the word “palliative” is used. Likewise, iPanel (2017) also recently released a short video called “Shift your care to a palliative approach” which also explores assumptions about what “palliative” means. A second important implication from the area of my findings about What HCPs said and heard is around improving our mutual understandings of EOL-related words.

9.4.3.2. Supporting clinicians towards mutual understandings: Communication skills and narrative competency. The clinical practice implications and recommendations from this area of my study findings about What HCPs said and heard also indicate the need for HCPs to come to know others’ narratives—that is, not only to know that words and phrases in clinical practice may have varied meanings with narrative underpinnings, but also to develop strategies to purposefully seek mutual understandings. A central goal may be achieved through clearer communication in clinical practice: communication skills and narrative competency promotes the goal of mutual understandings.

Though there may be value in seeking to standardize how EOL-related words are used (e.g. “palliative”), the practicality of this effort is limited. Such limits relate to the large number of HCPs who practice in acute care contexts, varying levels of clinical practice experience and education, and variability in ongoing professional development engagement activities. Thus, a
stronger implication from this finding is to seek greater understandings of others towards the goals of clearer communication. It is my conclusion that a focus on narrative can promote such understanding. Montello (2014) described how the notion of narrative relates to practical applications as a process of inquiry and a mode of engagement. Within this process of inquiry and mode of engagement, Montello stated that the “narrativist” seeks out others’ (colleagues, patients, families) stories, including the way others arrive at particular decisions. That is, the how is emphasized:

A narrativist would try to capture the stories [families] tell about the way they arrived at this particular decision as well as the how of their moral decision-making at other important moments of their lives prior to this decision. To do that, a narrativist needs a method for discerning what matters to them. What we need is what novelist Rebecca Goldstein has called the ‘mattering map’ (p. S3).

Newberger Goldstein (n.d.) proposed the mattering map as a way of listening to others with a clear goal of hearing and discerning “what matters and what matters overwhelmingly” to the speaker. To carry out a mattering map, the listener uses narrative competencies including attending to voice, character, plot, and resolution (Montello, 2014). That is, attending to these elements in communication works towards actually understanding what the other person is saying.

Narrative competencies may also provide a therapeutic benefit for patients and their family members. For example, according to Casey, Proudfoot, and Corbally (2016): “In health
care contexts internationally, stories about illness and caring are shared at shift handovers, at bedsides, in corridors, offices, cars, and staff rooms...in the sharing, narratives of illness and caring have communicative, sense-making and transformative potential” (Casey, Proudfoot, & Corbally, 2016, p. 1204). That is, the therapeutic capacity of narratives, and in particular, inviting others’ narratives and sharing an individual’s own narratives, creates two opportunities. First, clinician-patient/family interpersonal relationships are likely strengthened as HCPs strive to better understand patients’ illness experiences and act upon understandings in the interpersonal family context. Secondly, clinicians themselves may benefit, which follows from greater understandings of another’s perspective.

In summary, the goal of excellent communication and greater understanding of each other involves more explicit support for the development of communication skills and narrative competencies, which ties in with the implications I identified from the area of findings about What HCPs saw and knew. Greater incorporation of communication and narrative competencies might also serve clinicians as a tool towards understanding each other. I turn now to explore the implications of the third and last thematic area of my findings, How HCPs felt and acted, by returning to the idea reflexive practice.

9.4.4. Supporting HCPs to manage the emotional and value-based dimensions of EOL planning and care. In Chapter Seven, I explored an area of findings related to what I recognized as the emotional and value-base dimensions of HF-EOL planning and care. In particular, I explained how in some instances, EOL planning and care work can be emotionally
difficult for HCPs, particularly values are misaligned. For example, emotions can be elicited by different aspects of EOL planning and care, including navigating assumptions about others’ desires to avoid illness and EOL discussions, managing uneasiness or discomfort, enduring personal emotional impacts related to delivering “bad news” while witnessing the responses of patients and their families, and being worried about giving inaccurate or mistaken information. Difficult emotions can also be evoked when HCPs’ own values are misaligned with what that HCP perceives are the patients’ actual wishes and choices—this point illuminates the value-based dimension of EOL planning and care.

The value-based dimension of EOL planning and care relates to how HCPs form and interpret perceptions and preferences about others’ care, where perceptions refers to what HCPs think is happening and preferences refers to what HCPs think should happen. Both experiences are internal and individual processes and both relate to an idea I called congruence. Congruence can be thought of as the degree of similarity between what HCPs think ought to happen compared to what they think is happening. Congruence is important because it illuminates the interrelatedness between the emotional- and value-based dimensions. Such relatedness underscores how incongruence can evoke emotionally difficult situations. The subjective nature of this experience also indicates that HCPs may possibly have perceptions about patients’/families’ wishes that might have been misunderstood or may be incorrect.
Importantly, difficult emotional experiences generate HCPs' uses of particular strategies such as careful words or avoidance, which can deteriorate the clarity of communication. Thus, the implications of this area of my findings points to two areas: first, the emotional nature of EOL planning and care should be foregrounded and HCPs emotional needs should be considered. Such support may include emotional support and ethics and valued-based support (e.g. understanding an individual HCPs' own values and relationships to others, clinical ethics consultations), which should be endorsed at the meso-level. Secondly, in recognition of the interrelatedness of emotion and values, and the strategies that function to control emotions, values and assumptions need to be uncovered and discussed. Uncovering values assumptions also points to the need for reflexivity in practice, which I raised in the previous section as well. As I indicated above where I previously explicated implications for supporting HCPs in reflexive exercises, these initiatives should be supported at the executive level and should be foregrounded as an important organizational priority (Hilliard, Stajduhar, Sawatsky et al., 2017).

9.5. Study Limitations

In Chapter Four, I presented the strengths in my study design and in my methodological considerations. For example, I described strengths including issues of quality in the design and pointed to particular decisions that strengthened the quality overall (e.g. using multiple data collection methods, multiple study sites). However, limitations are also inherent within any research study. In this section, I will explain limitations of my study.
While data for this study was collected from two study sites, and a range of clinical specialists with diverse years of clinical expertise are captured in the study sample, the findings may not be fully transferable or generalizable. Experiences of HCPs with differencing views is possible and practices may differ in other practice locations. These differences may result in different structural implications than what are described in this dissertation. For example, both study sites were associated with a major academic site and were both designated as teaching hospitals for medical students, nursing students, and allied professional students. As the sites were both teaching hospitals, there was an obvious and continuous presence of students (e.g. clinical groups, preceptor students, medical student interns, residents, and fellow physicians). Both study sites were also geographically located in proximity to populated urban centers; structured practices may differ in more rurally-located regions.

Also of note, the nature of both study sites as academic-affiliated teaching hospitals meant that concurrent research and related knowledge translation activities were underway throughout my fieldwork. For instance, at Site B research specifically aimed at integration of a palliative approach to care in some hospital units was underway. Participants who were familiar with these other research projects underway may have benefited from research-related initiatives such as education sessions about the palliative approach. Thus, the influence of these initiatives may have actively shaped the way I recognized narratives as shifting.

Not all views or experiences may have been elicited or shared. Participants who joined this study did so voluntarily, which may have emphasized participation from those with a
particular interest in this topic. Conversely, HCPs with less involvement or interest may not have been inclined to join and thus their perspectives and experiences may be under-described or absent entirely. Participants also controlled what they shared and how they joined the study (e.g. observation or interview). Thus, participants only shared what they chose to, which means some views or experiences may also be absent.

Nonetheless, overall, the sample of participants who joined this study was diverse. Collectively, the study participants also had a great deal of experience and knowledge about the care of patients with HF in acute hospital environments. I think the diverse sample in this study is a strength. Of note however, I was not able to successfully recruit a generalist physician (i.e. a non-specialist), which means perspectives from this view are missing. In future research, it would also be valuable to engage community-based clinicians for their views, particularly as participants in this study commonly expressed their assumptions about the role of community-based providers and their responsibilities for HF-EOL planning and care.

9.6. Opportunities for Future Study

Several opportunities for future research are brought to light by my study findings. As I explained in Chapter Four, the two study sites where I collected data for this study were both located with proximity to large, densely-populated, urban centers. This proximity ensured patients and their families who sought care at both study sites had access to many services including specialist cardiac clinics and specialist HCPs, including palliative care clinicians. Thus, the experiences of HCPs and patients who access HF-EOL planning and care in rural hospitals
settings may be dissimilar. As the access to resources in rural settings differs from access in urban centers, the structural relationships may differ. Therefore, one opportunity for future study is to better understand structured practices in rural and community settings.

As is also explained in Chapter Four, the sampling strategy used in this study recruited HCPs only. How patients and their family members experience HF-EOL planning and care hospitalizations and structured practices would thus be an area well worth understanding more fully. In particular, there is a clear opportunity to better understand patients’ and family members’ experiences with “code status” conversations and what is understood by patients (or substitute decision-makers) in terms of their experience with HCPs’ implicit assumptions related to their code status preferences. For example, findings from this study indicate that code status directives (e.g. “DNR”, “full code”) inform HCPs’ assumptions about patients care preferences outside of resuscitation events. This points to potential issues in the process of informed consent and resuscitation preferences and is an opportunity for further study.

The focus of Chapter Six was about how HCPs understood particular EOL-related words. I explicated how some words, including code status directives, functioned with underlying narratives. These narratives were *implicit* because they were unspoken, and they were also *shifting* because narratives different between agents and were changing. This finding about narratives was significant because it illuminated how particular words functioned past their intended definitions. For example, “DNR” shaped HCPs assumptions and actions about care provided outside of resuscitation. Thus, this finding points to the need to seek and identify
other words used with similar effects and an opportunity for future study. For example, in patient self-management teaching patients and their family members are offered a range of patient health education materials about topics such as diet, fluid intake, warning signs, and others. These materials and their related instructions may convey implicit messages about what it means to “restrict” fluids or other possible messages that could reveal assumptions in the same way my research findings have shown assumptions about EOL-related words. Though I am unaware of another group of words where narratives inform meanings, I nonetheless encourage future researchers to consider this type of study.

9.7. Reflections and Conclusions

At the time of this writing, I have been practicing as a Registered Nurse for over fifteen years. Over these years, I have served in different nursing roles including direct bedside care in general surgery/medicine, acute cardiology, critical care; clinical leadership and nursing education; and operations/management of a variety of settings including critical care, specialty outpatient clinics, and diagnostic services. Throughout my time in each of these roles, I have been involved in a number of HF-EOL planning and care experiences with patients in acute care. Patients with HF in particular, have stood out to me as a vulnerable group, in part due to the readmission patterns commonly experienced by these patients and their family members. As I have explained throughout this dissertation, the nature of the HF illness trajectory, characterized as life-limiting and terminal, has also stood out. In my own clinical experiences, despite multiple acute care encounters and this known life-limiting trajectory, HF-EOL planning
and care considerations were rarely foregrounded and dying and death seemed unexpected for patients and their family members, as well as for myself as a supporting HCP. I felt patients’ acute care experiences as unexpected and have been involved in many situations where little was known about patients’/families’ understanding of their illness, or their values, care preferences, or wishes. It was in these lived experiences that I personally recognized the underutilization of EOL planning for this patient/family population and saw how this upstream gap impacted the EOL care that was provided. The literature I reviewed in Chapter Two empirically supports many of my own experiences.

As I showed in Chapters Four to Seven, this study created opportunities for me to enter different clinical practice settings and connect directly with diverse HCPs providing EOL planning and care for patients with HF. Throughout this entire research experience, I have been truly grateful for the countless warm welcomes I received at study sites and by the many study participants who hosted me during their work and spoke with me both informally and in semi-structured interviews. As is evident in my data, the HCPs who joined as participants generously gave me their time and shared candid and personal experiences, which were critically important for me as I moved through the research process. I encountered innumerable HCPs who eagerly expressed interest in these findings and stated their desire to better understand HF and EOL care.

I was continually impressed by HCPs’ expertise, dedication, and desire to provide excellent HF-EOL planning and care for these patients and their families. Simultaneously, I was
also regularly reminded about how EOL planning and care in HF is a “big problem” and was frequently commended by research participants for my interest in this area. The combination of participants’ clinical excellence along with their widespread regard for EOL planning and care in HF being a “big problem,” led me to feel optimism that the knowledge and messages I derived from carrying out this study comes at a time when nurses and all HCPs are seeking insights and directions towards improving patients’ (and their family members’) EOL planning and care experiences in hospitals. For patients with HF specifically, I think the learning from this dissertation could help to improve the HF-EOL planning and care experiences for patients and their family members, as well as HCPs.

As I explored in my findings chapters (Five, Six, and Seven) and discussed in Chapters Eight and Nine, at the heart of this dissertation, my findings explicate that there are many structures in acute care that impact HCPs’ approaches and practices around EOL. As such, the discussion and findings I presented in the preceding chapters may have applications beyond HF—indeed, my findings may be relevant to other patient groups who have chronic, life-limiting illnesses and who similarly access EOL planning and care in acute care hospital settings such as general medical units. The “HF-EOL Study” adds new knowledge in an emerging body of literature about EOL planning and care for patients with HF.

In summary, in carrying out my research and writing this dissertation, I explored EOL planning and care in hospitals towards the goal of understanding how the context of acute care settings in hospitals, structured HCPs’ related beliefs and values, decisions, and actions. I
focused on the HF patient population because HF is characteristically life-limiting illness and because this population has been identified as having difficult EOL experiences. Patients with HF also experience frequent re-hospitalizations in their illness trajectory. Together, these characteristics illuminated the need to examine current practices and seek opportunities to improve care for patients and families in hospitals in particular. The findings in this study explicated complex and dynamic relationships between agents, schemas, and resources in acute care settings where patients with HF access care and indicated that they interface as structural conditions that shape HCPs’ practices related to EOL planning and care. The findings in this dissertation bring into focus a number of nursing and interprofessional practice implications, recommendations, and areas for further research and discovery.
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Appendix A: Study Poster

Understanding the clinical contexts where patients and families with Heart Failure access End-Of-Life care: The HF-EOL Study

Principal Investigator (PhD supervisor): Patricia A. Rodney, Professor, School of Nursing, University of British Columbia,

Graduate Student Researcher (PhD student): Jennifer A. Gibson, Doctoral Candidate, School of Nursing, University of British Columbia,

The HF-EOL Study is a research study designed to investigate and understand how clinical practice environments influence the end-of-life care for patients and families who have heart failure. These clinical practice areas primarily include general medical units and may also include cardiac specialty areas, and critical care settings.

You are being invited to participate in this study because you are a healthcare provider currently working in a clinical practice area where patients and their families access end-of-life care. As a healthcare provider working in these settings, you interact firsthand with the features that make up these complex clinical practice environments and you have experiences with people who are facing the end of life and who die from heart failure.

If you are a healthcare provider who works in a clinical practice environment where patients and families with heart failure access end-of-life care, we are interested in your perspectives.

Participation in the HF-EOL Study is voluntary and can occur in different ways. You may contribute by taking part in 45 to 90 min long interviews, on one or more occasion, with a researcher. You may also join this study by allowing a researcher to observe you in your practice setting during your regularly scheduled workday.

We are grateful for your interest in the HF-EOL Study. If you would like to join as a participant, or have questions about this study, or, please email or call:

Jennifer Gibson
Appendix B: Information for HCPs

Understanding the clinical contexts where patients and families with Heart Failure access End-Of-Life care: The HF-EOL Study

Principal Investigator (PhD supervisor): Patricia A. Rodney, Professor, School of Nursing, University of British Columbia

Graduate Student Researcher (PhD student): Jennifer A. Gibson, Doctoral Candidate, School of Nursing, University of British Columbia

If you are a healthcare provider who has experiences working with patients and families with heart failure, we invite you to consider joining as a study participant in the HF-EOL Study

General information about the HF-EOL Study for healthcare providers

Why are we conducting this study?

Heart failure is a chronic and life-limiting illness that follows a progressive and deteriorating trajectory towards the end of life. Patients and families who have heart failure have been reported to experience a particularly difficult end-of-life period. As a result, this patient and family group have been said to endure a poor quality of dying.

Researchers who have looked the problem of poor quality of dying and heart failure have illuminated relationships between current clinical practices and features within clinical practice contexts. The HF-EOL Study is a PhD dissertation that is being conducted to explicitly examine and highlight these contextual, environmental features and better understand their relationships and implications on practice.

The goal of the HF-EOL Study is to produce knowledge that explains the ways in which clinical environments shape our end-of-life care practices for patients and families with heart failure. This knowledge can improve practice by supporting strategies and policies that address the environmental features that may be functioning to erode or diminish the quality of end-of-life care with this patient/family group.
Why should you take part in this study?

The HF-EOL Study is designed to investigate and understand how clinical practice contexts influence the end-of-life care for patients and families who have heart failure. These clinical practice areas primarily include general medical units and may also include cardiac specialty areas, and critical care settings. You are being invited to participate in this study because you are a healthcare provider currently working in a clinical practice area where patients and their families access end-of-life care. As a healthcare provider working in these settings, you interact firsthand with the features that make up these complex clinical practice environments and you have experiences with people who are facing the end of life and who die from heart failure.

We invite you to help us understand more about the ways in which your clinical practice context shapes end-of-life care by sharing your knowledge and insights as a participant in the HF-EOL Study.

What will happen if I participate in this study?

Participation in the HF-EOL Study is entirely voluntary and can occur in different ways. You may contribute by taking part in interviews. You may also elect to partake as a host and buddy to the researcher in your practice setting.

Interviews

If you volunteer to take part in interviews, you will be asked to meet with Jennifer Gibson (Graduate Student Researcher) for 45 to 90 minutes, on one or more occasion. Jennifer will ask you questions about your clinical practice experiences with patients and families with heart failure, and about your experiences with clinical practice environments. You may also be asked about your clinical practice more generally. Interviews are digitally recorded with an audio device.

Examples of questions that you may be asked during an interview include:

- Tell me about your general experiences working with patients and families who have heart failure
- Describe a situation where you were involved with a patient and family who had heart failure and was at the end-of-life
- Describe the ways that your clinical practice environment influences your care?

Interviews are located and scheduled as you choose, with your convenience in mind. Provided the space is available for the 45 to 90 minute interview, the surroundings ensure confidentiality, and the space is sufficiently quiet enough for audio recording, you may choose the location for your interview. Such locations may include a private residence, a private space (e.g. a meeting room) at a public place (e.g.
library), or a private area (e.g. office) at your workplace.

Jennifer may ask you for a follow-up interview(s) to clarify statements from your initial interviews. Follow-up interviews are similarly scheduled based on your convenience and may take 15 to 30 minutes.

Buddy shifts

If you who join the HF-EOL Study as a researcher-buddy, you will be asked to partner with Jennifer Gibson for one or more of your regular work shifts, or for a part of your regular work shift, so that we may better learn and understand your clinical practice environment. Being a researcher-buddy does not require any additional time from you because buddy-shifts will be scheduled with your regular work rotation.

If you give permission to be a researcher-buddy, you will be observed in your work environment. Jennifer will watch you and may also ask you questions in order to learn about and better understand different situations. Jennifer will take notes during observations and may document information about interactions such as verbal and non-verbal exchanges as well as actions and activities that occur. Observational notes will not contain any identifying information about anyone involved in any interaction.

All observations and notes made for the HF-EOL Study will be done with consent from those being observed. Jennifer will ask for verbal consent to observe interactions that you have with other healthcare providers or patients and families. No observations or notes will be made about any person who does not consent.

For further information

We are grateful for your interest in the HF-EOL Study. If you would like to join as a participant, or if you would like more information, please email or call:

Jennifer Gibson

Thank you for your consideration.

Dr. Patricia Rodney, Associate Professor,
University of British Columbia,
School of Nursing

Jennifer A. Gibson, Doctoral Candidate,
University of British Columbia,
School of Nursing
Understanding the clinical contexts where patients and families with Heart Failure access End-Of-Life care: The HF-EOL Study

**Principal Investigator (PhD supervisor):** Patricia A. Rodney, Professor, School of Nursing, University of British Columbia

**Graduate Student Researcher (PhD student):** Jennifer A. Gibson, Doctoral Candidate, School of Nursing, University of British Columbia

Information about the HF-EOL Study for patients and families

The HF-EOL Study is a research study being done by Jennifer Gibson. Jennifer is a PhD student at the University of British Columbia. This study is being done to look at how our clinical areas affect how healthcare is given to patients and families with heart failure. The study is being done to find ways to make healthcare better.

Watching people like nurses and doctors is one part of this study. Watching nurses and doctors helps the researchers to see first-hand how health care wards work. Seeing clinical activities on the hospital wards is one way to help the researcher’s understand how clinical areas affect patient care.

If your nurse or doctor is taking part in this study, and they talk and work with you or your family member, Jennifer will ask for your permission to watch. Jennifer will only watch your doctor or nurse work with you if you say yes. If you or a family member cannot say yes or no, Jennifer will not watch your doctor or nurse work with you.

Jennifer may take notes while watching your doctor or nurse. Notes may be about what is being said or done. The notes for this study are only about people like doctor and nurses. Notes are not about patients or families.

You can say no at any time. The care of you or your family member will not be affected if you say no.

If you have any questions or worries about the HF-EOL Study, please email or call:

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Dr. Patricia Rodney, Associate Professor, University of British Columbia, School of Nursing

Jennifer A. Gibson, Doctoral Candidate, University of British Columbia, School of Nursing
Appendix D: Study Consent

Understanding the clinical contexts where patients and families with Heart Failure access End-Of-Life care: The HF-EOL Study

Consent to be interviewed and observed as a study participant in the HF-EOL Study

Who is conducting this study?

Principal Investigator (PhD supervisor)
Patricia A. Rodney, Professor, School of Nursing, University of British Columbia

Graduate Student Researcher (PhD student)
Jennifer A. Gibson, Doctoral Candidate, School of Nursing, University of British Columbia

Co-investigators
Colleen Varcoe, Professor, School of Nursing, University of British Columbia
Kelli Stajduhar, Professor, School of Nursing, University of Victoria
Bashir Jiwani, Director of Ethics Services, Fraser Health Authority

Why are we conducting this study?

Heart failure is a chronic and life-limiting illness that follows a progressive and deteriorating trajectory towards the end of life. Patients and families who have heart failure have been reported to experience a particularly difficult end-of-life period. As a result, this patient and family group have been said to endure a poor quality of dying.

Researchers who have looked the problem of poor quality of dying and heart failure have illuminated relationships between current clinical practices and features within clinical practice contexts. The HF-EOL Study is a PhD dissertation that is being conducted to explicitly examine and highlight these contextual, environmental features and better understand their relationships and implications on practice.

The goal of the HF-EOL Study is to produce knowledge that explains the ways in which clinical environments shape our end-of-life care practices for patients and families with heart failure. This knowledge can improve practice by supporting strategies and policies that address the environmental features that may be functioning to erode or diminish the quality of end-of-life care with this patient/family group.
Why should you take part in this study?

The HF-EOL Study is designed to investigate and understand how clinical practice contexts influence the end-of-life care for patients and families who have heart failure. These clinical practice areas primarily include general medical units and may also include cardiac specialty areas, and critical care settings.

You are being invited to participate in this study because you are a healthcare provider currently working in a clinical practice area where patients and their families access end-of-life care. As a healthcare provider working in these settings, you interact firsthand with the features that make up these complex clinical practice environments and you have experiences with people who are facing the end of life and who die from heart failure.

We invite you to help us understand more about the ways in which your clinical practice context shapes end-of-life care by sharing your knowledge and insights as a participant in the HF-EOL Study.

What will happen if I participate in this study?

Participation in the HF-EOL Study is voluntary and can occur in different ways. You may contribute by taking part in interviews. You may also elect to partake as a host and buddy to the researcher in your practice setting.

Interviews
If you volunteer to take part in interviews, you will be asked to meet with Jennifer Gibson (Graduate Student Researcher) for 45 to 90 minutes, on one or more occasion. Jennifer will ask you questions about your clinical practice experiences with patients and families with heart failure, and about your experiences with clinical practice environments. You may also be asked about your clinical practice more generally. Interviews are digitally recorded with an audio device.

Examples of questions that you may be asked during an interview include:
- Tell me about your general experiences working with patients and families who have heart failure
- Describe a situation where you were involved with a patient and family who had heart failure and was at the end-of-life
- Describe the ways that your clinical practice environment influences your care

Interviews are located and scheduled as you choose, with your convenience in mind. Provided the space is available for the 45 to 90 minute interview, the surroundings ensure confidentiality, and the space is sufficiently quiet enough for audio recording, you may choose the location for your interview. Such locations may include a private residence, a private space (e.g. a meeting room) at a public place (e.g. library), or a private area (e.g. office) at your work place.
Jennifer may ask you for a follow-up interview(s) to clarify statements from your initial interviews. Follow-up interviews are similarly scheduled based on your convenience and may take 15 to 30 minutes.

**Buddy shifts**

If you who join the **HF-EOL Study** as a researcher-buddy, you will be asked to partner with Jennifer Gibson for one or more of your regular work shifts, or for a part of your regular work shift, so that we may better learn and understand your clinical practice environment. Being a researcher-buddy does not require any additional time from you because buddy-shifts will be scheduled with your regular work rotation.

If you give permission to be a researcher-buddy, you will be observed in your work environment. Jennifer will watch you and may also ask you questions in order to learn about and better understand different situations. Jennifer will take notes during observations and may document information about interactions such as verbal and non-verbal exchanges as well as actions and activities that occur. Observational notes will not contain any identifying information about anyone involved in any interaction.

All observations and notes made for the **HF-EOL Study** will be done with consent from those being observed. Jennifer will ask for verbal consent to observe interactions that you have with other healthcare providers or patients and families. No observations or notes will be made about any person who does not consent.

**How will the study results be used?**

Results from this study will be published as a doctoral dissertation and may also be published in articles or books. Knowledge gained from the **HF-EOL Study** may also be presented in various formats including talks given at the local study sites and at conferences.

**Are there any risks or benefits to participating in this study?**

We do not think there is anything in the **HF-EOL Study** that could harm you or be bad for you. If a question or discussion point upsets you, you can choose to decline a comment. Please let Jennifer or another study contact know if you have any concerns. If you require emotional support after you participate in this study, Jennifer can assist you to access your employer’s assistance program for follow-up.

You may not derive any direct benefit from your participation in the **HF-EOL Study**. However your contributions may improve our understanding of how clinical practice environments influence the end-of-life care for patients and families with heart failure. Such insights may improve future clinical practices and clinical practice environments by supporting policies and practice changes which relate to environmental features that contribute to poor quality of end-of-life care.
How will your privacy be maintained?

Your privacy will be respected. No information that discloses your identity will be released or published without your specific consent unless required by law. You will not be identified in any reports or publications of this research.

Your name and any identifying characteristics will be disguised by a pseudonym or will be altered to maintain your privacy. Your work site will be referred to as an “urban Canadian hospital” and will be masked with either code “A” or “B”. Your clinical practice area will be assigned a number and will be reported with a coded name such as “area 1”, “area 2”, “area 3.”

All printed documents that contain your identity by name or initials (e.g. signed consent forms) will be kept separately from any research data and will be stored in a locked cabinet, in a locked office, at a UBC-affiliated hospital. Documents that contain information about your identity will remain with the Principal Investigator (or designate) only. The list that matches your name to your unique study identifier will not be removed or released without your consent unless required by law.

All printed documents associated with this study will be converted into an electronic and non-modifiable protected document format (PDF) and will be stored in a password protected, secured online repository called UBC TeamShare (more information about the UBC TeamShare workspace is available online at: https://it.ubc.ca/projects/ubc-workspace-service/ubc-workspace-project-faqs). Prior to electronic conversion, all printed documents will be stored in a locked cabinet, in a locked office, at a UBC-affiliated hospital. Once hardcopy documents are stored electronically, paper-copies will be destroyed in confidential shredding.

All electronic files (e.g. interview audio files) associated with the HF-EOL Study will be stored on an encrypted, password protected, external hard drive until they can be similarly uploaded to a UBC TeamShare workspace. Once files are securely uploaded to the UBC TeamShare workspace, they will be permanently deleted from the external hard drive.

All documents generated from this study will be digitized and stored securely on the UBC TeamShare workspace for at least five years as required by UBC. After five years, all digital files (including audio recordings of interviews) will be permanently deleted.

Representatives of the Fraser Health Research Ethics Board may inspect the HF-EOL Study research records in the presence of the Investigator or designate for the purpose of monitoring the research.
Will you be paid for participating in this study?

We will not pay you for the time you take to be in this study.

Who can you contact if you have questions about this study?

We are grateful for your interest in the HF-EOL Study. If you have questions about this study, or you would like to join as a participant, please email or call:

Jennifer Gibson  
Paddy Rodney

For emergencies related to this study, please call

Dr. Patricia Rodney, Associate Professor,  
University of British Columbia,  
School of Nursing

Jennifer A. Gibson, Doctoral Candidate,  
University of British Columbia,  
School of Nursing

Who can you contact if you have concerns about this study?

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 Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.
Participant Consent to be Interviewed and Signature Page

Taking part in the **HF-EOL Study** is entirely up to you. You have the right to refuse to participate in this study. Deciding not to participate in this study will not impact your current or future employment at Fraser Health Authority.

You may withdraw from this study at any time without giving reasons. If you choose to enter the **HF-EOL Study** and then decide to withdraw at a later time, you have the right to request the withdrawal of your information collected during the study. This request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your identity) or where the data has been merged with other data. If you would like to request the withdrawal of your data, please let Jennifer Gibson know. If you withdraw from the **HF-EOL Study** there will be no negative impact on your employment at Fraser Health Authority or education (if you are enrolled in any educational program).

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to participate in interviews for this study.
- You are not waiving any legal rights by signing this form.

________________________  ______________
Participant Signature Date Printed Name of the Participant

Dr. Patricia Rodney, **Associate Professor,**
University of British Columbia,
School of Nursing

Jennifer A. Gibson, **Doctoral Candidate,**
University of British Columbia,
School of Nursing

This document contains confidential information. If printed, this document must be stored separately from any research data, in a locked office, at all times. If used electronically, this document must be stored securely on a password protected, encrypted external hard drive or on a secure, remote workspace (e.g. UBC TeamShare Workspace).
Participant Consent to be Observed and Signature Page

Taking part in the HF-EOL Study is entirely up to you. You have the right to refuse to participate in this study. If you decide to take part, you may choose to pull out of the study at any time without giving a reason and without any negative impact on your employment or education (if you are enrolled in any educational program).

- Your signature below indicates that you have received a copy of this consent form for your own records.
- Your signature indicates that you consent to be observed as a study participant
- You are not waiving any legal rights by signing this form

_____________________________  ___________________________  ___________________________
Participant Signature                  Date                           Printed Name of the Participant

Dr. Patricia Rodney, Associate Professor,  Jennifer A. Gibson, Doctoral Candidate,
University of British Columbia,          University of British Columbia,
School of Nursing                        School of Nursing

This document contains confidential information. If printed, this document must be stored separately from any research data, in a locked office, at all times. If used electronically, this document must be stored securely on a password protected, encrypted external hard drive or on a secure, remote workspace (e.g. UBC TeamShare Workspace)
Appendix E: Interview Guide

Understanding the clinical contexts where patients and families with Heart Failure access End-Of-Life care: The HF-EOL Study

Interview Guide

Principal Investigator (PhD supervisor)
Patricia A. Rodney, Professor, School of Nursing, University of British Columbia

Graduate Student Researcher (PhD student)
Jennifer A. Gibson, Doctoral Candidate, School of Nursing, University of British Columbia

Examples of trigger questions
The interviewer will use trigger questions to start the interviews and direct conversations. Examples of trigger questions that may be asked include:

- Describe your current clinical practice position. How did you come to work in this role and in this area?

- Tell me about your general experiences working with patients and families who have heart failure.

- What does the term “end-of-life care” mean to you? How do you understand “end-of-life care” in relation to your clinical practice generally? What are your perceptions about how your professional role, and your clinical practice area fits with end-of-life care?

- Describe a situation where you were involved with a patient and family who had heart failure and was at the end-of-life.
  - Was this a typical or atypical case? What made this case typical/atypical?

- Describe your clinical team and reflect on how that team organizes care for patients with heart failure.

- How do you enact your clinical decisions for patients and families with heart failure?
Examples of probing or follow-up questions
Probing or follow-up questions will be asked based on what the study participant says during their interview. Probing and follow-up questions will be used to clarify content, delve deeper into what was said, and propel conversations. Example of probing questions that may be asked include:

- Tell me more about...
- Can you explain what you meant by...?
- What were you thinking when you described [situation]...?
- What were you feeling when you told me about...?
- Can you give me an example of what you meant when you talked about...?
- I think I’ve heard you say.... Have I understood that correctly? Can you add...?