

**Engaging Personhood at End of Life:
A Qualitative Study of Nurses' Practice in Acute Care**

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Abstract

The acute care setting is designed to provide short-term care for people who require treatment for a severe episode of acute illness and exacerbations of chronic conditions. Yet, more than half of Canadians die in acute hospitals every year. Evidence shows that nurses in acute care units feel limited in their ability to provide quality end-of-life care due to a variety of factors. As a result, the needs of patients that are dying are often overlooked, which can cause them to experience a loss of identity and control, as well as suffering at the end-of-life; a unique time in one's life trajectory marked by significant changes in personhood. Personhood is the philosophical underpinning of the frequently used concept 'person-centered care' – one of the fundamental ideologies of nursing and a central concept in palliative care. An interpretive description design was used to explore the following research question: What do nurses' stories reveal about the ways in which they engage, or fail to engage, with personhood in end-of-life care in acute care units? To appreciate the culture in which participant stories were situated, a literature review of acute care culture, end-of-life care in acute care units, and the concept of personhood was conducted. Eight nurses from an acute medical-surgical ward of a tertiary care hospital in Eastern Ontario were interviewed for this study. Thematic analysis was used to analyze the data, which elucidated tensions between participants' ability to enact ethical end-of-life care reflective of their values and the contextual constraints of working in a culture of biomedicine. Exploring these tensions provided insight on the nuances and complexities of navigating ethical end-of-life care in an acute care setting as well as implications for nursing practice, education, and research with particular attention to promoting moral communities in acute care that value personhood and biomedicine equally.

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Chapter 1: Introduction

According to the Canadian Nurses Association (CNA) (2015), nearly three-quarters of Canadians die in hospitals, with hospital-based palliative care provided only to a minority of these patients (Fowler et al., 2013). And yet, two-thirds of healthcare professionals working in hospitals do not feel that they are able to provide adequate end-of-life care to patients (Ingleton et al., 2013). Evidence shows that nurses in acute care units feel particularly limited in their ability to provide quality end-of-life care due to a perceived lack of time, staff shortages, lack of privacy to have sensitive conversation – and fear of what may be uncovered when they do, lack of skills and ability to engage in sensitive conversations, and differences in personal beliefs about death and dying (Keall et al., 2014). As a result, the needs of dying patients are often overlooked, which can contribute to suffering at the end of life; a unique time in one's life trajectory marked by significant changes in personhood. Personhood is broadly defined as *that* which makes us human and consists of a person's past, family, culture, role, relationships, body, secrets, hopes for the future, and spirituality (Cassell, 1991). Personhood is the philosophical underpinning of the concept 'person-centered care' – one of the fundamental ideologies of nursing as well as a central concept in palliative care. At the end of life, peoples' personal sense of identity and control are at stake, yet there is a lack of inquiry on acute care nurses' engagement with personhood in end-of-life care.

The idea for this thesis stems from my personal clinical experience. Over the last six years working as an acute care nurse on a medical-surgical unit, I have had the opportunity to care for many people, with varying diseases and complex diagnoses, at different stages of their lives. Although acute care units are designed to provide short-term care for people who require treatment for a severe episode of acute illness, many people end up living out their final days on these busy units. The following personal narrative recounts a pivotal moment in

my nursing career that led me to pursue my Master's degree, with the intention of gaining insight on other nurses' experiences caring for dying patients in acute care settings.

I was working as a nurse on an acute medical-surgical unit in a large city tertiary hospital. The ward was an eight-bed, open-concept, step-down unit with merely curtains separating patient beds. At any given time, more than half of the patients had tracheostomies, one or more intravenous lines, multiple drains and dressings, and were attached to cardiac monitors. There was the constant sound of patient bells, machine alarms, high humidity oxygen bottles, and staff and visitor conversations.

One shift, I was caring for a patient, Richard (pseudonym), who had undergone surgery on his face and mouth preventing him from being able to speak. He also had difficulty writing because of arthritis, therefore communicating was extremely challenging and frustrating for him. Richard had been on our unit for several weeks and yet I knew almost nothing about him as a person. He didn't have any visitors, and his only contact was a neighbor who was looking after his apartment while he was in the hospital. As nurses, we would often try to guess what Richard was trying to say, or worse, not engage in conversation at all out of fear that it would only add to his distress. Looking back, maybe it wasn't just Richard's distress we were worried about but our own. I felt uncomfortable starting conversations with Richard out of fear of not knowing what to say to him or how to 'fix' how he was feeling. Regrettably, I also felt rushed by the busyness of our unit and knew that communicating with Richard would take time I did not feel I had.

The wound on Richard's face had to be kept clean, moist, and covered. Despite doing mouth care every 15 minutes – which on our busy unit became a quick and task-oriented interaction – his oral cavity was always dry and cracked. Although Richard shook his head “no” when asked

if he had any pain, he would often be found crying alone in his room. We could tell that his distress was not confined to his physical symptoms. His tears would cause him to cough and choke on his secretions and we would take turns rushing in to suction and apply oxygen. We would wipe his tears and hold his hand. We would reassure him that we were doing everything to help him, although I wasn't sure if that was true. Was there a better way that we could be caring for Richard? Why wasn't palliative care involved? Why was this surgery done in the first place?

Although Richard was informed that he would be dying soon, he preferred remaining a full level of intervention, which meant we were still administering antibiotics, running intravenous fluids, suctioning his secretions every 15 minutes, and doing blood work up until the moment that he died. In spite of our care, which focused mostly on his body and its physiological needs, I felt that Richard was suffering when he died. Reflecting back, I wonder why I was unable to acknowledge his suffering, and whether doing so might have made a difference. Would taking the time to sit and be present with him have helped? Ultimately, I struggle with a troubling awareness that the nursing tasks that I performed in his final moments did little to affirm that he was a person who was worthy of compassion and care.

The scenario presented above describes my own struggle in caring for a patient who was dying on an acute medical-surgical ward. Unfortunately, encountering scenarios like this one are not uncommon amongst nurses in these care settings. Acute care units are busy and demanding, with patients who have difficult and complex diagnoses (WHO, 2012) where nurses prioritize their care of patients based on acuity, time, and available resources (Mazzotta et al., 2015). Nurses often feel torn between the type of care they feel they ought to be providing and the biomedical culture of care that dominates these units today. Biomedicine is a model of care that prioritizes treating the physiological ailments of patients over their emotional, psychological, and existential needs. Contemporary biomedicine is itself situated within a larger systems culture of

neoliberalism (Sharp et al., 2018) that values “auditable, measurable activities” (p.16) and prioritizes efficient and fiscally responsible care. When nursing care is organized according to such priority, nurses can feel paralyzed in their ability to respond to the needs of dying patients, causing them to question their role at the bedside. This failure to recognize and respond to the needs of patients who are dying within acute care nursing represents a contemporary moral crisis; high numbers of terminally-ill people receive end-of-life care on highly technical and predominantly cure-oriented units that risk overshadowing the person behind the disease. Therefore, insight into nurses’ engagement with personhood in end-of-life care is needed. Although the term person-centered care is used frequently in healthcare literature, little is known about the ways in which nurses care for patients-as-persons at the end of life in acute care units. Specifically, no studies to date have explored the ways in which acute care nurses engage, or fail to engage, with their patients’ personhood at the end of life.

Background

Nursing care that focuses on personhood places the person at the center of its delivery and recognizes the person as an individual with a unique personality, values and needs (McCormack, 2010). This approach to care is often described as holistic – that is, caring for the whole person through attention to body, mind, emotion, spirit and environment – and is foundational to nursing ideology (Selanders et al., 2012). Personhood is the philosophical concept that underpins the frequently used term ‘person-centered care’ and is also foundational to the palliative approach to care. The palliative approach honours people’s values and healthcare wishes by promoting autonomy, dignity and control as well as shared decision-making (as appropriate) with healthcare teams (CNA, 2014). Although the ethical relevance of such an approach should seem evident, the biomedical culture of acute care units is not set up for this type of care. Nurses who work on acute care units juggle multiple patient care responsibilities and, therefore, feel pressured to prioritize where to expend their limited time and energy (Thompson et al., 2006). As a result,

nurses are forced to be task-based in order to stay on top of their work resulting in care that resembles a checklist of actions that emphasizes curative and task-based treatments over the needs of the individual.

Centering the construct of personhood in this study is important for two reasons: 1. It is a helpful frame to learn about what is actually happening in the lives of people as they die, and to appreciate the significance of these happenings for their moral experiences of end-of-life care; and 2. Notions of ‘person-centered care’ are popular in organizational discourse (e.g. hospital mission statements, policies, and initiatives), despite evidence of limited enactment of these values at the level of direct nursing care, which will be explored in detail in chapter 2. In chapters 2 and 3, I draw on examples from published nursing research from acute care settings about the end-of-life experience of nurses, patients, and families to illustrate the ways in which personhood is at stake in these settings, and how the neglect of personhood by nurses in this context can aggravate suffering. I also argue that caring for patients in a way that recognizes and promotes their personhood cannot be the sole responsibility of individual nurses. Rather, care that is focused on the person – or ‘person-centered care’ – is only possible when the culture of the nursing work environment reflects an authentic commitment to this value. In this way, individual nurses and nursing leaders need to work together to bring about a cultural shift in which the needs of dying patients and their families are taken seriously.

Problem Statement

Despite the abundance of literature on ‘person-centered care’ and quality end-of-life care in nursing research, it is discouraging to know that the needs of dying patients are often not met (Clissett et al., 2013). Specifically, there is a paucity of research exploring how nurses care for patients-as-persons at the end of life in acute care. This is especially important to consider in acute care settings where the highly technical and biomedical environment place patients’

identities at risk of being lost. Furthermore, the frequent use of the term ‘person-centered care’ in healthcare has put it at risk of becoming an empty discourse, meaning those using it do not have a real sense of what the term should actually mean. Thus, the values of person-centered care are not being enacted in practice.

Research Purpose and Objectives

This is a qualitative interview study of registered nurses working in acute care, set within an interpretive description design. Interpretive description is a qualitative research methodology that aligns with constructivist inquiry. The aim of interpretive description is to generate qualitative research relevant for clinical practice for the purpose of developing nursing knowledge (Thorne, 2016). According to Thorne et al. (1997), in following the general principles of this study design, nurses can create sound interpretive description that contributes directly to our understanding of how people experience health and healthcare. In this study, interviews with nurses were initially designed to elicit their descriptions of caring for people at the end of life, with a specific focus on the concept of suffering – a deeply personal emotion that is inherent to being human. My analysis of these interviews then led me to interpret the ways in which nurses engage, or fail to engage, personhood at the end of life. The research question therefore became: “What do nurses’ stories reveal about the ways in which they engage, or fail to engage, with personhood in end-of-life care in acute care units?” The objective of this study is to better understand how acute care nurses recognize, engage with, and promote patients’ personhood in a way that responds to, and sometimes alleviates, peoples’ suffering at the end of life with the greater intention of bringing about a cultural shift in which the needs of dying patients are taken seriously in acute care units.

Overview of the Chapters

In the chapters to come, I will provide an overview of the steps taken to conduct this research. The second chapter consists of a comprehensive literature review on the topics of acute care as a care environment, acute care culture and its influence on nursing practice, end-of-life

care in acute care units, and, lastly, person-centered care and the concept of personhood. My analysis of the literature reviewed reveals that personhood is particularly important to consider in acute care as these settings are often described as highly technical, impersonal, and capable of stripping away patients' identities (Chan et al., 2017; Mazzotta, 2015). This chapter also identifies gaps in the literature that this study seeks to address. In chapter 3, I describe the theoretical and methodological approaches underpinning this study. The relevance and appropriateness of situating the research in interpretive description and constructivism are discussed. I also draw on theoretical notions within the field of nursing ethics to advocate for a renewed ethic in acute care that recognizes the moral experiences of nurses and addresses the needs of dying patients and their families. Chapter 3 also provides an overview of the research design used to guide the participant interviews and generate data, as well as considerations for ethical research and rigour. In chapter 4, I provide a description of the six themes that make up the study findings. The overall findings reveal that participants have the knowledge, willingness and capacity to engage personhood but are unable to do so fully due to the task- and efficiency-based priorities of their acute care unit. This tension is evident throughout participant narrations which I interpret through the following themes: *Engaging personhood through "little things"*, *nursing "with blinders on"*, *being "less distracted by nursing while nursing"*, *suffering as a "dark, emotional, twisty thing"*, *"I don't think I'm ever going to get it right"*, and *"the things we do to patients here are not nice"*. Chapter 5 provides a general discussion of the study findings, drawing on previous studies of end-of-life care practice in acute care. It concludes with implications for practice, education, and research, study limitations and a personal reflection on the impact this research has had on my own identity as an acute care nurse.

Chapter 2: Literature Review

This chapter presents a review of the literature that allowed me to come to know and draw conclusions about existing research in relation to the research problem, as well as identify any gaps in research relevant to this study. In this review, I will present the literature related to the phenomenon of interest (nurses' engagement with personhood at the end of life), focusing first on the acute care setting as a care environment, followed by a review on the culture of acute care and its influence on nursing care. Then, pertinent literature about end-of-life care in acute care will be reviewed. Finally, the last section of the review will present literature on person-centered care and the concept of personhood. The primary goal of this literature review is to identify the current state of knowledge surrounding nurses' experiences of end-of-life care in acute care units as well as provide conceptual clarity on person-centered care and personhood.

Search Strategy

Based on the research topic and phenomenon of interest, the following databases were used: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Embase, PsychINFO, and Google Scholar. My engagement with the literature was iterative and on-going throughout the duration of the study, including the write-up. No limitations were placed on dates to ensure that a rich comprehensive literature review was achieved. Search terms for the setting of interest included MeSH terms acute care*, medical unit, surgical unit, acute hospital, biomedicine, culture of care, and biomedical culture. Articles that took place outside of acute care (e.g. palliative care units, hospice, and long-term care settings) were also included in the literature review as they provided valuable insights into the topics of end-of-life care and personhood. Search terms for the population of interest included nurses, nursing, patients, families, and experiences. The following MeSH terms were used for the phenomena of interest: End-of-life*, death, death and dying, suffering, palliative*, personhood, and person-centered

care. Published books, reference lists, organizational reports, and positions statements were also used to broaden my understanding of my topic.

The Acute Care Setting

The acute care setting is designed to provide short-term care for people who require treatment for a severe episode of acute illness and exacerbations of chronic conditions; acute care settings include both medical units and combined medical-surgical units. The World Health Organization (WHO) (2012) defines acute care as a healthcare setting that “includes the health system components, or care delivery platforms, used to treat sudden, often unexpected, urgent or emergent episodes of injury and illness that can lead to death or disability without rapid intervention” (WHO, 2012, para. 3). In other words, the purpose of acute care units is to respond to immediately life- or limb-threatening health conditions (WHO, 2012). Yet, due to limited healthcare resources (i.e. bed shortages and over-burdened emergency departments) and increasingly complex diseases, patients are now being admitted to acute care to manage chronic, life-limiting illnesses. As a result, lengths-of-stay are longer and many patients receive end-of-life care on these units. New technology and advancements in medication and treatments allow patients who would previously have been treated in the Intensive Care Unit (ICU) to now be admitted to acute care units. Furthermore, multi-morbidity and an aging population are also adding to the complexity of care. As a result, meeting the health care needs of these patients is more complex and challenging than ever before.

According to the Canadian Institute for Health Information (CIHI) (2006), the largest proportion of nurses (17.5% or 42, 936 nurses) identify their area of practice as acute medical-surgical nursing. Acute medical-surgical care nurses provide care in environments that are in a constant state of fluctuation including (CIHI, 2015): 1. Client populations with variability in age, diagnosis, acuity, level of dependency, hospital length of stay and expected outcomes; 2. Unpredictable and dynamic patient to nurse assignments with variation in types of conditions,

number of clients, and changes within the shift; 3. Unpredictable and variable resource availability (e.g. varying number of nursing care providers, staff mix, supplies, equipment, information, education, technology and leadership support); and 4. Expansive and changing use of clinical and non-clinical technology to care for a diverse population. Adding to the complexity of the patient care environment, acute care units are often used for clinical placements requiring nurses to mentor and support a high volume of learners such as nursing students, new graduates, medical students, and medical residents (CAMSN, 2008).

According to the CIHI (2015), nurse to patient ratios in acute care average 1:4, with ratios going up as high as 1:6 on night shifts. Nurse to patient ratios may also vary depending on staffing numbers and patient admissions and discharges. Some acute care wards have step-down units, also known as observation units or intermediate care units. These sub-units provide an intermediate level of care between the ICU and the general medical-surgical ward. These units often have cardiac and respiratory monitoring systems in place. The nurse to patient ratio in a step-down unit averages 1:3 (CIHI, 2015).

Acute care nurses must be prepared to care for patients with a variety of diagnoses including chronic lung disease, heart failure, cancer and kidney disease, who vary in both age and acuity (CAMSN, 2008). Moreover, every patient comes in with their own unique combination of comorbidities, disabilities, degree of functional capacity as well as their own unique personality, psychosocial history and needs. Take the following quote from a nurse working on an acute medical ward (Oliveira, 2014):

“We can have elderly patients...And they are coming in, not with one illness, not with a broken hip and not with...an acute kidney injury related to dehydration. They’re coming in with congestive heart failure with COPD, with chronic renal failure that’s in an acute phase. They may have an underlying long term, slow growing cancer along with all of

that. They may have some mild dementia...And all of these things are, are in a basket, and it can be one or two of those things that exacerbate and they're very very sick" (p.43).

In addition to caring for patients post-operatively and those with acute and chronic diseases, acute nurses are also looking after patients who are dying. According to Thompson et al. (2006), the vast majority of patients who are terminally-ill in Canada die in acute hospitals, with little access to formalized palliative care services. Thus, acute care nurses are not only juggling different care responsibilities but they are also shifting back and forth between delivering curative care – which prioritizes life-prolonging treatment – and end-of-life care – which ideally focuses on maintaining comfort, quality of life, dignity and personhood.

In a recent article reporting ethnographic findings about end-of-life nursing care on a medical unit, Chan et al. (2017) demonstrate how a cultural ethos of 'busyness' causes the needs of dying patients to be systematically devalued and unrecognized. Participants, including nurses, physicians, physiotherapists and support staff, agreed that the medical ward was busy and demanding, primarily due to the variety of patients and diagnoses and the high level of acuity. The staff often referred to limited resources and frequently described not having enough time to accomplish all that they would like during their shift. Nurses reported feeling like they were forced to be task-oriented in order to stay on top of things which meant certain aspects of care (e.g. emotional engagement) were neglected. Such a task-oriented approach to nursing care was evident in my opening narrative (chapter 1), when I failed to address why Richard was crying even though I knew he was not experiencing any (somatic) pain.

In Malone's (2003) work on the spatial dynamics of nurse-patient relationships within hospitals, she argues that hospital nursing is increasingly constrained by spatial- structural

practices that disrupt relationships and reduce or eliminate nurses' proximity to patients.

Structural–spatial changes affecting proximities include but are not limited to: shifts toward treatment of patients in outpatient and home settings, reduced length of stay for hospitalized patients; work redesign strategies aimed at reducing costs; use of so-called “flexible” staffing, which involves using more part-time and temporary staff; certain efficiency measures, including changes in charting and reporting practices; and an emphasis on abstract classification systems and “standardization” of care (Malone, 2003). A major problem associated with these institutional changes includes nurses not having enough time to spend with their patients.

Furthermore, increased reliance on “flexible” staffing means that a patient may have a different nurse each day which minimizes the possibility of building a strong nurse-patient relationship. These changes also reduce proximity among nurses themselves, as fewer nurses are spread more thinly causing them to interact less with their nursing colleagues. It is clear in the literature that culture of care, time constraints, and increased workload on acute care units do not afford nurses the opportunity to care beyond the expectations of a dominant biomedical influence (Chan et al., 2017; Malone, 2003; Mazzotta et al., 2015; Thompson et al., 2006).

The Culture of Acute Care & its Influence on Nursing Care

As previously mentioned, nurses in Chan et al.'s (2017) study “reported feeling like they were forced to be ‘task-oriented’ in order to stay on top of things and that, consequently, certain aspects of care were overlooked (p. 7)”. The highest priorities on this acute medical unit included managing acute medical crises and biomedical tasks – tasks that focus on the patient's physiological needs and often consist of curative treatments. In a literature review by Robinson et al. (2014) on the patient and family experience of palliative care in an acute hospital setting, the perception of busyness within the hospital resulted in patients and families feeling as if they were “lost in the numbers” (p. 22), causing them to feel unvalued and uncared for. In contrast,

when families felt cared for, it was often because of staff who were attentive to their needs, appeared approachable and friendly, and checked in frequently to make sure they had what they needed. Research shows that nurses working in acute care face the challenge of blurring the boundaries of competing paradigms: biomedicine and nursing (Mazzotta, 2015). As well as working within a constraining neoliberalist healthcare system that prioritizes efficiency and cost-saving measures (Sharp et al., 2018).

According to Mazzotta (2015), the biomedical model has influenced healthcare practice for centuries. Historically, this model was used to guide physicians' assessment, diagnosis, treatment, critical thinking, and decision making to ensure best patient outcomes (Mazzotta, 2015). The curative focus of biomedicine was integrated into nursing education up until the 1980's and continues to influence nursing practice today. Despite current nursing education being tailored towards more holistic approaches to care, nurses grapple with integrating theoretical knowledge learned in academic institutions with the realities of clinical practice due to contextual factors such as time constraints, patient acuity, and increased workloads (Mazzotta, 2015; Sharp et al., 2018; Thompson et al., 2006). As a result, nurses struggle to provide whole person care to their patients.

In a scoping review by Mazzotta (2015) examining how the dominance of biomedical approaches to care influence point of care nurses' presence in high acuity areas, many of the nurses expressed that the biomedical and technological paradigms had "control over them" (p. 96) in their area of practice. Nurses in the review acknowledged that factors such as diminished funding, increased workload, demands on nurses, policy changes, shorter hospital stays and increased technology influenced their care and presence at the bedside. As a result, their care focused predominantly on treating physiological ailments and neglected the emotional, psychological, and existential needs of their patients. Similarly, a recent critical ethnography on the tension between person-centered and task-focused care in an acute surgical setting (Sharp et

al., 2018), described the prevailing culture of neoliberalism – which values “auditable, measurable activities” (p. 16) – in acute care as causing nurses to feel constrained in their ability to enact person-centered care. Furthermore, despite an espoused commitment to person-centered care, this group of nurse participants were observed practicing in a way that suggests a task-based approach, despite being explicitly critical of this type of care. According to Sharp et al. (2018), nurses in this study were unable to see that their work culture could function in any other way and felt a deep sense of powerlessness and resignation that the task-oriented culture of their workplace “controlled their practice” (p. 16) (Sharp et al., 2018).

In the abovementioned study by Chan et al. (2017), two types of ‘tasks’ were considered top-priority: 1. Managing acute medical crises; and 2. Tangible, biomedical tasks. Tangible, biomedical tasks were those that most impacted the patient’s current state of biomedical health and were often related to prolonging life. Furthermore, staff prioritized biomedical tasks (e.g. medication administration, intravenous therapy, tracheostomy care and dressing changes) over basic care (e.g. washing and feeding patients) and emotional support. Not only was basic care considered low-priority, the healthcare team perceived this type of care as less important than other care practices. Thus, it was not uncommon at the end of a nurse’s shift for care practices such as bathing, feeding, and emotional support to be neglected due to ward busyness (Chan et al., 2017). As Chan et al. (2017) observe, this finding is important to consider when caring for terminally ill patients, where basic care needs often grow in importance as the person’s ability to manage them alone decreases.

On the medical ward in Chan et al.’s (2017) study, a ‘logic of care’ driven by discourses of limited resources and the demanding medical unit created a context of busyness. The nurses experienced an overwhelming workload and felt forced to create priorities, which reflected values regarding the importance of curative/life-prolonging care over end-of-life care. These values were observed by the authors through the way in which staff prioritized life-prolonging

practices and rationalized inconsistent and less attentive care for dying patients. Take the following quote in which the nurse expresses distress about not paying more attention to dying patients while also rationalizing that there is ‘nothing to do’ task-wise for these patients:

“Unfortunately, they’re usually left at the end of my priority list [...] Even if I’m trying to be more attentive to them [...] It’s just, task-wise, there’s nothing to do. So, I always go towards the other patients – dressing changes, IVs to be put in. [...] And then leave these (patients) towards the end, and I get really frustrated at the end of the day, when I haven’t done more for them within the whole day, for a dying patient” (Chan et al., 2017, p.7).

These values can influence the care of dying patients by delaying the delivery of palliative and end-of-life care, limiting palliative care services to patients with cancer, and providing highly invasive treatments at the end of life (Chan et al., 2017). Palliative and end-of-life care will be described in detail in a later section of this chapter. According to Thompson (2006) a significant barrier to providing end-of-life care in acute care units lies in the fact that nurses are “being pulled in all directions” (p. 169) while trying to provide care for the dying. System factors involve the lack of a palliative care philosophy on acute care units (or an overshadowing of palliative care by a dominant biomedical culture) and difficulties encountered by nurses when working within an environment strongly influenced by a biomedical model of intervention.

According to Mazzotta (2015), dominant discourse in biomedicine and technology has the potential to overshadow holistic nursing care, causing patients to feel like a disease rather than a person living with an illness. Returning to the opening narrative presented in the previous chapter, I wonder how Richard must have felt lying in his bed, unable to communicate verbally, being cared for by nurses who were either too busy or too uncomfortable to talk to him. By default, I tended to focus on the numbers on his monitor instead of the person in the bed. This notion of focusing on the monitor instead of the person is further supported by Almerud et al.

(2008) who describe that when nurses focus solely on equipment and measurable outcomes, the nurse “becomes an extension of the machine” (p. 59). As a result, patients’ emotional, psychological, spiritual, and cultural needs are often unmet causing them to feel invisible and uncared for. Both Mazotta’s (2015) literature review and Oliveira et al.’s (2016) work on the lived experience of nurses providing end-of-life care to patients on an acute medical unit revealed that acute care nurses often find themselves stuck between two models of care – curative and palliative – especially when a curative, lifesaving approach is the focus despite medically futile situations. Mazzotta (2015) does not, however, advocate for an alternative approach to care but rather a collaborative approach in which biomedicine, technology, and holistic nursing care can be achieved simultaneously. Although this approach may sound ideal, this integration would require a significant shift to take place at both the individual and organizational level. Healthcare leaders, in nursing and across disciplines, in academic and organizational institutions, would need to integrate diverse paradigms into curriculum, and clinical practice, in order to shift the current worldview of acute care towards one that values biomedicine, technology, and holistic care equally.

End-of-Life Care in the Acute Care Setting

End-of-life care on acute care units is often described in terms of the aforementioned competing philosophies of care – curative versus palliative – in which curative and life-prolonging approaches take precedence (Chan et al., 2017; Thompson et al., 2006). Nurses on these units often struggle to provide quality end-of-life care due to the constraints of an environment that prioritizes active treatment over palliative care. According to Kaufman (2005), within hospital culture, death is still considered to be a ‘problem’ and the heroic rescue of biomedicine is considered more important than the opportunity to provide a ‘good death’.

There are important differences between palliative and curative approaches to care. In the early days of the palliative care movement, palliative care was viewed as synonymous with dying and dichotomous to life-prolonging care. In contrast to these earlier conceptualizations, palliative care has evolved into both a philosophy and approach to care that is now being used alongside curative treatments (Ferris et al., 2013). In a joint position statement by the Canadian Nurses Association, the Canadian Hospice Palliative Care Association and the Canadian Hospice Palliative Care Nurses Group (2015), palliative care is described as seeking to improve the quality of life of persons facing chronic, life-limiting conditions at all stages, not just at the end of life. Enacting a palliative approach reinforces personal autonomy, the right for persons to be actively involved in their own care and a greater sense of control for individuals and families. It also facilitates conversation with people about their end-of-life needs and wishes. Care that focuses on personhood is the foundation of the palliative approach; this is care that honours people's values and healthcare wishes by treating the whole person, promoting autonomy, dignity and control as well as capacity for shared decision-making (CNA, 2015).

The term 'end-of-life' addresses the period of time when a person has entered the final stage of their illness and is approaching death (CHPCA, 2014; CNA, 2015). End-of-life care is described by the Registered Nurses Association of Ontario (2011) as an *aspect* of palliative care that focuses specifically on the final days and hours of life. End-of-life care continues after death to include family bereavement and care of the body (CNA, 2015). It is meant to be provided across all care settings to relieve suffering and improve quality of life until death. Thus, end-of-life care shares the principles of palliative care that include maintaining quality of life, reducing and alleviating suffering whenever possible, and caring for patients and their families in a holistic way (physical, psychological, emotional, social, cultural, and spiritual) (CNA, 2015; CHPCA, 2014). Yet, while the definitions of palliative and end-of-life care have evolved over the last decade, the idea of palliative *versus* curative care persists in acute care settings today.

According to the CNA (2015) nearly three-quarters of Canadians die in hospitals, with palliative care provided only to a minority of these patients (Fowler et al., 2013). In a recent comparison of hospital deaths across 45 countries, it was found that for half of these countries, more than 54% of deaths occurred in the hospital and that at any one time 13%–36% of hospital inpatients met the criteria for receiving palliative care (Robinson et al., 2014). In a study by Ingleton et al. (2016) on the perceptions of healthcare professionals regarding their training and educational needs for palliative care, nurses and physicians reported differing understandings of what constitutes a “palliative care patient” and reported difficulty recognizing when a patient should transition from active treatment to palliative care. The uncertainty around knowing when a patient is or is not considered palliative is important to consider since, in most developed countries, acute hospitals play a significant role in determining the provision of palliative care. Despite the fact that more than half of Canadians will die in acute hospitals, two-thirds of healthcare professionals working in these settings do not feel that they are able to provide adequate end-of-life care to patients (Ingleton et al., 2014). It is not implausible to assume that the healthcare professionals’ insecurities in delivering end-of-life care will have a negative impact on the end-of-life experiences of patients and their families.

A literature review on patient and family experiences of palliative care in hospital (Robinson et al., 2014) found that patients and families frequently reported dissatisfaction with pain and symptom control at the end of life. For instance, in a study by Lynne et al. (1997), almost 40% of terminally ill patients on an acute medical ward reported having severe pain and dyspnea in the last three days of life. Moreover, the family members of these patients expressed feelings of distress in witnessing their loved ones in discomfort. In Robinson et al.’s (2014) review, the overriding view from both patients and families was that the standard of communication with healthcare professionals – nurses and physicians – in acute care settings

was poor. More specifically, patients and families felt the staff lacked the skills required to have difficult, sensitive conversations about the end of life. Studies reported that patients and families also perceived nurses on medical units as being unavailable due to the busyness of the ward and felt that the nurses were unable to spend time with patients to find out what was important to them (Robinson et al., 2014). It was also reported that staff rarely approached patients or family to ask them what they needed, which left patients and families feeling forgotten, unimportant, and uncared for (Robinson et al., 2014).

In the articles reviewed by Robinson et al. (2014), the hospital environment was criticized by patients, families, *and* nurses as being noisy and busy and not conducive to end-of-life care. The study findings revealed that while a majority of participating nurses (70%) viewed end-of-life care as an important aspect of hospital care, only 8% of them felt that the hospital was a suitable environment to care for the dying. In a study by Oliveira (2014) on the lived experiences of nurses providing end-of-life care to patients on an acute medical ward the environment was described as follows:

“Lights were described as “always on” and interruptions frequently occurred during the night as participants woke patients for either scheduled care or assessments. Even the physical layout of the unit, the size of the rooms, the congestion of equipment in the rooms and hallways, created a sense of chaotic clutter, a physical barrier that required moving or dodging in order for the participants to reach the patient” (p. 69).

Other barriers to providing end-of-life care in acute care include a perceived lack of time, demanding workloads and balancing the pressure of competing priorities (e.g. patient acuity, unit demands, and patient needs). Nurses in Oliveira et al.’s (2016) study also described the limits of physical and human resources as barriers to providing end-of-life care. High nurse-patient ratios

and limited staff impacted the nurse's time and ability to tend to the needs of patients who were dying (Oliveira et al., 2016). The participants spoke of trying to shield dying patients and their families from the chaotic environment by: 1. Consciously 'slowing down' when providing end-of-life care (e.g. decreasing the speed of their movements and lowering the tone of their voice); and 2. by manipulating the physical environment in an effort to maintain privacy (e.g. pulling curtain, closing the door, moving the patient to a private room whenever possible). According to the nurses in this study, it took a conscious effort and presence of mind to be able to switch from providing active cure-oriented care to one patient and then providing end-of-life care to another. Take the following quote from an acute care nurse (Oliveira, 2014):

“We can be zipping up and down that hallway and then stop, pull yourself together, and then go into the room very quietly. That's part of your nursing...being able to switch from your high-powered energy of saving lives, to helping this one (patient) have a nice exit” (p. 71).

This nurse describes having to force herself to slow down both physically and mentally, in order to exude a quiet, calming presence in caring for patients at the end-of-life. Similar depictions were found in a paper by Thompson et al. (2006) describing the facilitators and barriers encountered by acute care nurses caring for patients who are transitioning from curative to palliative care. In this paper, the transition from curative to palliative care was described as “a difficult process for individuals, fraught with uncertainty and mixed emotions” (p.91). The authors also describe this transition period as not having clear boundaries, resulting in a blurring of curative and palliative care. Nurses in Thompson et al.'s (2006) study indicated that facilitating and maintaining a 'lane change' – the transition from curative care to end-of-life care – is critical in being able to deliver quality end-of-life care. However, this 'lane change' requires a significant shift in thinking from curative treatment to one that is focused on palliation of symptoms and the preparation of death and bereavement. Despite the presence of several

barriers, nurses in Thompson et al.'s (2006) study described being able to facilitate this transition by advocating for patients and families to the medical team, facilitating clear and open communication between the patient and family and the entire healthcare team, and, if the patient is unable to communicate, engaging in conversations with the family about what their loved one would want.

In a study by Borbasi et al. (2005) that addressed situations in which palliative care service referrals were made, the authors noted that referrals were frequently made too late on acute care units. Consequently, once palliative care was involved there was not enough time to improve the quality of life of the dying patient. This delay in consulting palliative care was attributed to difficulties in determining when patients with progressive illnesses were at the end of life (Thompson et al., 2006), and to the 'fix it' mentality of biomedicine wherein death is viewed as a failure (Thompson et al., 2006; Oliveira et al., 2016). Nurses spoke of the tendency of physicians to want to pursue active treatments on patients who are dying; noting that it happened more often when inexperienced residents and medical students were involved. Nurses described advocating for palliative care as "an uphill struggle in trying to break through disciplinary boundaries in order to offer their professional input" (Oliveira, 2014, p. 60). When describing their relationship with physicians, some nurses felt a lack of respect, a dismissal in their professional opinion, a lack of inclusion in decision-making or being uninformed of the plan of care. Furthermore, participants in Oliveira et al.'s (2016) study felt that decision-making and reporting structures on their unit were grounded in a "traditional" system in which the physicians were the drivers of care. As previously mentioned, acute care units often have several clinical placements taking place at one time, including both nursing and medical students. In Thompson et al.'s (2006) study, nurses noted that once patients were palliative, they were removed from teaching services. Although the intention behind this may have been to provide

privacy and minimize disruptions, it also reinforces the notion that there is ‘nothing to do’ for these patients that is worth learning about.

Several studies on acute hospital settings have identified that end-of-life care could be improved (Chan et al., 2017; Mazzotta, 2015; Oliveira et al., 2016; Robinson et al., 2014). In Oliveira et al.’s (2016) study, end-of-life care was described as “stressful” not only because the ward was often lacking in material and human resources but because the nurses found it to be emotionally difficult. Nurses in Mazotta’s (2015) scoping review justified maintaining emotional distance to honour patients’ dignity and privacy at the end of life, despite patients expressing a strong desire to have their emotional needs addressed. Other nurses were said to distance themselves out of fear of becoming emotionally fatigued or burnt-out. Nurses also reported having a lack of confidence in communicating with patients about death and dying and in providing psychosocial care for families. Feeling unsupported by physicians, managers, and the healthcare organization further hinders nurses’ abilities to deliver quality end-of-life care. Lastly, another common barrier encountered by nurses in providing end-of-life care was when families did not accept the patient’s worsening condition. Nurses in Oliveira et al.’s (2016) study, for example, found it difficult to provide quality end-of-life care to patients whose family members had not accepted that the patient was dying. This hesitancy to accept death makes me think about how Richard (chapter 1) insisted on remaining a full level of care despite us having told him that he was dying. Was this because he wanted to live, or at least fight against his impending death? Alternatively, could it be that our failure to engage his emotional needs caused him to mistrust us? Perhaps we caused him to doubt that we had his best interest in mind, making it impossible for him to engage with us in a transition from curative to palliative care.

As previously mentioned, the biomedical model, which is nested in the larger systems culture of neoliberalism, fosters a culture of care that values life-prolonging treatments (Chan et al.,

2017) and risks overlooking the needs of dying patients. Unmet needs at the end of life include uncontrolled symptoms (e.g. pain, breathlessness), inadequate emotional support and poor communication and can cause patients to feel unimportant, dehumanized, and a loss of control, all of which are antecedents to suffering (Rodgers et al., 2008). In reviewing the literature, it was found that few studies have explored the ways in which nurses in acute care challenge the constraints of biomedicine and neoliberalism when delivering end-of-life care to patients.

Suffering in acute care. The concept of suffering is important to consider when addressing end-of-life care on acute care units; overlooking the needs of dying patients in this context can lead to and intensify suffering. Due to both the physical and cultural environment of acute care, suffering can manifest in at least two different ways: Suffering caused by acute care interventions and suffering caused by acute care neglect. I will elaborate on each of these below. Although minimizing suffering is believed to be at the core of nurses' work, ironically the role of the acute care nurse also "carries with it substantial responsibility for the infliction or perpetuation of human suffering" (Rodgers et al., 2008, p.1048). Suffering caused by acute care interventions include the infliction of physical and emotional pain as a result of procedures that include, but are not limited to, intravenous insertions, blood tests, and nasogastric tube and urinary catheter insertions. Participants in Chan et al.'s (2017) study described interactions where patients and families perceived acute interventions as causing suffering. In the following quote, a nurse describes a situation in which the medical team performed invasive treatments on a patient who was dying despite these interventions going against the wishes of the patient's family:

"So the patient's daughter [...] has voiced her concerns, has said what she wants for her father, which is comfort care, [saying] 'This is not how my father would have wanted to be *tortured* on long term' and all that. And then [...] the blood pressure is off, they bolus him, he gets a fever, they give him active treatments of antibiotics, chest X-rays, urinary catheter

insertion and so forth, when we know and we have spoken to his daughter who said ‘Why aren’t we just making him comfortable?’” (Chan et al., 2017, p. 10).

In the above quote, the word ‘tortured’ and the notion of challenging the healthcare team on why they weren’t providing comfort care suggest that these invasive treatments are perceived as harmful and distressing by patients and their families.

When I refer to suffering as caused by acute care neglect, I am referring to the distress that patients and families experience when nurses overlook the needs of people at the end of life. Suffering caused by neglect also refers to patients that are suffering for reasons *outside* of the acute care context but, in which, their suffering is not acknowledged or addressed. Returning to the opening narrative presented in chapter 1; if Richard’s insistence on remaining a full level of care was due to our failing to engage with him emotionally about what *he* felt he truly needed as he approached his own death, then this might be an example of suffering caused by acute care neglect. Evidence shows that acute care nurses struggle to address the needs of patients who are dying, specifically, due to a perceived lack of time, staff shortages, fear of what may be uncovered, lack of privacy to have sensitive conversation, lack of skills and ability to engage in sensitive conversations, and differences in personal beliefs about death and dying (Keall et al., 2014). Take the following quote by a palliative care nurse who, while recognizing the importance of tending to her patients’ end-of-life needs, felt limited in her ability to properly care for them out of fear of not knowing what to say (Leung, 2010):

“We need to be treating the whole person [at the end of life] ... although I don’t know that I’m the greatest at doing that because I don’t feel confident enough...because I am afraid if they come up with something and I don’t how to answer” (p. 3201).

I can relate to this nurse as I, too, recognize the importance of providing emotional support at the end of life but did not address this with Richard (chapter 1) out of fear of not knowing what to say or how to make him feel better. In a video by Canadian Virtual Hospice (n.d.) entitled ‘The Story About Care’, a man living with end stage lymphoma reflects on the power of the caring relationship that can exist when people working in healthcare see the “person and not the pathology” (6:30). Take the following quote where Jim describes the loneliness and despair that he would often experience in hospital in the middle of the night:

“Often time it’s late at night when you’re alone that that nurse comes in. And you often – or I did anyway – share the depths of your soul and of your depression and despair and anxiety with [that nurse]. More so than your family because you don’t want to tell your family anymore because you don’t want to add to their grief. So, you tell that [nurse] that” (Canadian Virtual Hospice, n.d., 10:52).

Jim acknowledges that the nurse may not “solve” the way he is feeling but the nurse can approach it, be present and listen to him:

“Now, can’t you (the nurse) just stay here and listen to me? You can’t solve it, I know you can’t solve it. But it’s the middle of the night and I’ve been up all night [...] I’ve been up all-night thinking ‘What’s going to happen to my children?’, ‘What’s going to happen to my wife if I die?’ [...] This is your chance of experiencing that nobility and [...] sacredness of being a caregiver” (Canadian Virtual Hospice, n.d., 11:19).

According to Ferrell et al. (2008), nurses’ sense of needing to “fix” their patients’ problems stems from a biomedical perspective that implies that the only true relief of suffering comes from curing the disease. In a review of empirical research by Leung et al. (2010) on clinicians’ experiences with terminally-ill cancer patients, many nurses felt unprepared to face the challenge

of becoming emotionally involved with suffering patients when they felt there was little support to do so from their working environment (Leung et al., 2010); as the dominant biomedical model does not provide guidance on how to respond to the needs of these patients. This review described nurses feeling distressed when they were required to bear witness to patient suffering without being able to alleviate it. These situations occurred when the patient's condition was progressively deteriorating towards death, yet the plan of care continued to focus on curative goals.

Coker et al. (1998) argued that personhood revealed one's vulnerability, and reflected the values, spirituality, history, and strengths one acquired throughout their life span. The authors stated that when personhood is honored, one feels comfortable, and when it is neglected, one feels depersonalized. According to Sofronas et al. (2018), this description implies a relationship between personhood and suffering: "Through illness or injury, one's personhood becomes threatened, which causes suffering. In a healthcare setting where one traditionally seeks care and treatment for an illness or injury, ignoring someone's personhood would further contribute to their suffering" (p. 5).

Person-Centered Care: Recognizing & Maintaining Personhood

Person-centered care. Person-centered care is the foundation of palliative care and recognizes people's unique values and healthcare goals as being central to the nursing process (CNA, 2015). The history of person-centered care in nursing can be traced back to the work of Florence Nightingale who distinguished nursing from medicine by its focus on the patient rather than the disease (Lauver et al., 2002). The term 'person-centered care' is used frequently in healthcare and represents an approach to care that puts the person at the center of its delivery (Morgan et al., 2012; McCance et al., 2011). In person-centered care, 'person' encompasses all the attributes that represent our humanness and the ways in which we construct our life

(McCance et al., 2011). According to McCance et al. (2011), such constructions include how we think about our moral values and beliefs, how we engage in our relationships, and the kind of life we want to live. The term ‘person’ also refers to the patients’ relationships and includes their family, friends, and caregivers. Despite the frequent use of the term, however, person-centered care has been described in the literature as vague and varying (Morgan et al., 2012; Slater, 2006; Morgan et al., 2012). According to Slater (2006), the term person-centeredness is used repeatedly in nursing literature with few studies providing an actual definition of the concept. Furthermore, the frequent use of surrogate terms (e.g. patient-centered, client-centered, and family-centered) has led to unclear understandings of the concept.

In an article by McCance et al. (2011) exploring the concept of person-centeredness and how it relates to the practice of nursing, the authors argue that person-centered care has been used as ‘tokenism’, meaning those using it do not have a real sense of what the term actually means. In a study by Clissett et al. (2013) on the challenges of achieving person-centered care for people with dementia in acute hospitals, the authors explain that healthcare professionals may not understand the true meaning of person-centered care as a result of an “ambiguous policy climate” (p.1502) wherein the term person-centered care is used in terms of service organisation rather than individual or team approaches to care. Additionally, numerous studies indicate that nurses *falsely* believe that the task-based approaches to care that they are enacting are person-centered (McCarthy, 2006; Skaalvik et al., 2010). Bolster et al. (2010) conducted a qualitative study using naturalistic observation and semi-structured interviews to examine how nurses and patients interact with each other during medication activities in an acute care setting, where the underlying philosophy claimed to be about ‘person-centered care’. This study took place in an acute care ward at a teaching hospital where both nurses and patients were interviewed. The overall finding of the study was that, while some nurse–patient interactions during medication

activities were consistent with the principles of person-centered care (e.g. providing an individualised approach to care and opportunities for patient participation), discrepancies were also found between what nurses say they do and what they actually do in practice. The authors spoke of how many nurse-patient interactions centered on task-oriented routines and that nurses appeared to use a standardized ‘check-list’ rather than tailor the medication activities to the patients’ specific needs and preferences:

“Some nurses were observed to provide a flexible approach to meet the requirements of individual patients, such as the timing of medications or the crushing of tablets [...]

However, medication administration was *largely* determined by the routine medication times and processes [...] it was not common practice for nurses to assess patients’ knowledge of the medications they were administering to them” (Bolster et al., 2010, p. 161).

According to Bolster et al. (2010), communication challenges with the healthcare team and time constraints were described by nurses and patients as contextual barriers to providing person-centered care. Communication challenges included nurses being unable to contact the medical team to verify medication prescriptions for individual patients. Another issue with communication on this unit was that nurses and pharmacists did not appear to communicate with one another. This lack of communication led to uncoordinated and disjointed delivery of medication information. A lack of time was identified by every participating nurse as a factor that potentially inhibits a person-centered approach. Nurses stated that a lack of time restricted their ability to establish relationships with patients and limited their interaction with patients during medication administration. Although findings from this study suggest that nurses do not always enact the person-centered philosophy that they claim to value, it is important to be mindful that the authors in this study observed nurse participants during a single nursing task instead of a series of tasks over the duration of their shift. Therefore, the authors’ conclusions of this study are somewhat limited in speaking to how nurses enact, or fail to enact, person-centered

care in their practice. This study does suggest, however, that at least some nursing interventions are centered on routine, despite a claimed philosophy of person-centered care. Moreover, this is not the only study to reach this conclusion. Similar studies have been conducted in this area and demonstrate that interactions between nurses and patients in acute care are rarely consistent with the principles of person-centered care (Martens, 1998; Haglund et al., 2004; Manias et al., 2005; Sharp et al., 2018).

Several analyses have been conducted over the last decade in an attempt to clarify the concept of person-centered care (McCormack et al., 2006, McCance et al., 2011; Morgan et al., 2012; Slater, 2006). According to Slater (2006), ideas associated with person-centered care include empowerment, treating the person behind the patient, valuing the person, and recognizing the person's identity. McCormack (2003) defines person-centered care as "the formation of a therapeutic narrative between professional and patient that is built on mutual trust, understanding and a sharing of collective knowledge" (p. 203). Bolster et al. (2010) describe person-centered care as having the following attributes: "existence of a therapeutic relationship between nurses and patients, the provision of individualized care, and evidence of patient participation" (p. 155). In a concept analysis by Morgan et al. (2012), the authors found that person-centered care is a complex concept with variable definitions. The authors offer their own "more complete" conceptualization of person-centered care as follows:

"It is a holistic (bio-psychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving care" (p.8).

Despite the variety of definitions of person-centered care, none of them explicitly address the concept of personhood – the philosophical idea at the root of patient-centered care.

Many models related to person-centered care exist, with several of these models focusing on care of persons with dementia. The social psychologist Tom Kitwood was a major influence in the field of dementia care; his work emphasizes that preservation of personhood is the central issue in care of people with dementia (Kitwood, 1993, 1995, 1997). Kitwood's model of Positive Person Work formed the basis of several other person-centered frameworks including the Person-Centered Nursing Framework (McCormack et al., 2006), the VIPS (Values people, Individual needs, Perspective of service user, Supportive social psychology) Framework (Brooker, 2007), and the Person-Centered Dementia Care Framework (Love et al., 2013). Although three of the above-mentioned frameworks were created specifically for the care of persons with dementia, the ethos of person-centered care can be applied to all people in receipt of any form of healthcare.

The Positive Person Work framework was first theorized by Kitwood (1997), then further built upon by Packer in 2003. The framework calls for the 'voice' of the person with dementia to be heard alongside those of professional and family caregivers. The aim of the Positive Person Work model is to fulfil the needs of people living with dementia in order to retain or enhance their personhood and well-being (Agnelli, 2015). The remaining three frameworks share similar approaches in that they all value patients as persons regardless of age or cognitive ability. They highlight the need for individualized care practices that support and honor the person's unique interests, preferences, and needs. The frameworks also emphasize the importance of self-awareness amongst clinicians, encouraging nurses and physicians to reflect on how their personal values and beliefs influence patient care. Two out of the three frameworks (Person-Centered Nursing Framework & the VIPS Framework) address the impact of the care environment and the culture of an organization in limiting or enhancing person-centered care. According to the VIPS Framework, person-centered care requires involvement from all levels of

the healthcare system, from management and policy makers, to nurses and the entire interdisciplinary staff (Rosvik et al., 2011).

According to Binnie et al. (1999), adopting a person-centered approach to nursing provides more holistic nursing care. Furthermore, it can increase patient satisfaction with care, reduce anxiety among nurses in the long term, and promote team work among staff. According to McCormack (2013) the three primary ‘results’ of person-centered nursing identified for patients were improved quality of care, increased satisfaction with health care, and improved health outcomes. Care that is person-centered improves quality of care because its focus is on the interpersonal relationship between those providing care and those receiving care rather than simply task completion (Morgan et al., 2012; McCormack, 2003). Studies have shown that nursing care is the strongest predictor of patient satisfaction with the overall health care experience (Morgan et al., 2012), thus person-centered care improves satisfaction because interactions are tailored to the unique needs of each person. Nurses who provide person-centered care contribute to increasing the patient’s feelings of well-being – the subjective understanding of how a person feels about his or her life (Morgan et al., 2012) – which in turn can improve the patient’s functional abilities. While these suggested positive consequences of person-centered care are encouraging, I am cautious about appealing to results-driven language, as this fits more within a biomedical model than that of a holistic nursing model of care. I see person-centered care as less about achieving measurable outcomes (e.g. patient satisfaction), and more about authentically understanding and engaging with the experience of people involved in the care.

Although person-centered care and notions of person-centeredness are popular in both healthcare literature and organizational discourse (e.g., hospital mission statements, policies, and initiatives), research shows that there is a limited enactment of these values at the level of direct nursing care. For example, in the aforementioned critical ethnography by Sharp et al. (2018) on

the tension between person-centered and task-focused care in an acute surgical setting, the findings revealed a disconnect between the holistic, person-centered care nurses wanted to provide, and the actual task-focused care that was provided. The authors of this study took a critical approach to research and acknowledged that the hierarchies of power in healthcare may constrain nurses' ability to plan and deliver nursing care according to their personal values, professional mandate, and patient expectations (Sharp et al., 2018). In this study, participant observation was the primary method of data collection which was then supplemented with interviews to highlight the information gained through observation. According to Sharp et al. (2018), nurses in this study prioritized efficiency and the swift completion of tasks despite voicing a philosophical commitment to person-centered care. According to the participants, a range of factors contributed to this lack of enactment of person-centered care including busy workloads with competing priorities and a focus on paperwork. It is important to note, however, that Sharp et al. (2018) did not offer a description of what 'person-centered care' actually entails, nor did they ask the participants what 'person-centered care' means to them. Person-centered care is argued here as being a 'buzz word' whose true meaning is poorly understood. Thus, more research is needed on how nurses enact care based on the philosophical underpinnings of person-centered care; that is, understanding, engaging with, and promoting personhood. Of course, a strong conceptual understanding of personhood itself is necessary for such work.

The concept of personhood. Person-centered care represents an approach to care that *fosters personhood* and puts the person at the center of its delivery (Morgan et al., 2012; McCance et al., 2011). In a pilot project by Coker (1998) exploring whether patient personhood is described in health records in long-term facilities, personhood is described as "the very root of one's vulnerability" and "reflects one's values, spirituality, history, and strengths, welded together through years of living" (p.436). According to Coker (1998), when personhood is honoured, one

feels comfortable; when it is not taken into account, one feels depersonalized.

Personhood is a central concept in nursing (Sofronas et al., 2018) and reflects the many different dimensions of a person, including those characteristics, attributes, and strengths that make each person unique. The term “personhood” has been used for centuries in disciplines such as philosophy, cognitive science, nursing, medicine, and bioethics and its definition has developed and changed over time (Sofronas et al., 2018). In the early to mid-1990s, nurse scholars continued to explore the nature, meaning, and impact of the nurse–patient relationship, and concepts of personhood were revealed in these discussions. In a concept analysis of personhood by Sofronas et al. (2018), recognizing and engaging with personhood was found to contribute to better patient outcomes; acknowledging personhood allowed patients to live well with an illness, better manage distressing symptoms, and have a good death.

According to the physician Eric Cassell (1982), personhood consists of a person’s character and personality, a lived past and anticipated future, family, relationships, culture, work, role, physical body, secrets, and spirituality. He goes on to explain that a threat to any aspect of personhood can lead to suffering. Cassell’s seminal work on suffering, and its link to personhood, has been cited internationally by professionals from many disciplines, challenging clinicians to respond not only to physical injury and disease, but also to human suffering (Cassell, 1991). The essence of Cassell’s work is that suffering is “experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychologic entity” (Cassell, 1982, p. 639). Cassell also asserts that suffering may include pain but is not limited to it and that the relief of suffering is an obligation of medicine. In reviewing lay and healthcare literature, Ferrell et al. (2008) were surprised by how often the relief of suffering is attributed to the medical profession alone. Ferrell et al. (2008) speculated that this is likely due to the abovementioned curative culture in which the relief of

suffering is meant to equal the cure of disease—a biomedical perspective that implies that the only true relief of suffering comes from fixing, curing, and eliminating illness.

Ferrell et al. (2008) explore the concept of suffering from a nursing perspective; for them, Cassell's perspectives on suffering are not sufficient to describe the goals of nursing. According to Ferrell et al. (2008), nurses are the professionals that work the closest with patients and their families and, thus, have the greatest opportunity to journey with people in their suffering. According to Ferrell et al. (2008), suffering is an inherent part of illness and minimizing suffering through holistic care is at the very core of nurses' work. Although the focus of Ferrell et al.'s (2008) paper is on the deep and profound experience of suffering, the authors provide examples in which nurses engage with patient personhood at the end of life. Through personal stories from Ferrell, the authors describe the importance of knowing the patient and delivering individualized care. For example, the authors describe a case in which the suffering of a patient who is dying is reduced when a nurse organizes a tea party for the patient and her daughter. In the narrative, the nurse describes learning that the patient and her daughter had tea parties all their lives: "From the time the daughter was a little girl with a floral porcelain tea set to heartier mugs shared over monumental life decisions, the two have sipped tea" (p. 242). Although the patient in the narrative was not to consume fluids by mouth because of a bowel obstruction, the nurse decided to let her have a small cup of tea. This decision was made after the nurse reflected that the primary goal for her patient was comfort and given the enormous pleasure the ritual would give the patient and her daughter. It is evident in this nurse's reflection that viewing the patient as a person first – a person with a family, history, and traditions – ultimately influenced her nursing care.

Florence Nightingale was one of the early nursing scholars to advocate for the importance of focusing on the patient rather than the disease (Lauver et al., 2002). This approach values and

respects the patient as a person first and involves a dialogue between nurse and patient where the needs and preferences of the patient are identified and an ongoing plan is developed collaboratively to meet these needs. Slater (2006) talks about the importance of recognizing personhood as a celebration of individuality in which the nurse aims to understand the present world of the person along with their physical, emotional, and social needs. This is particularly significant in acute care, where patients are, more often than not, treated in terms of their disease rather than a “person living with an illness” (Raudonis, 1993, p. 306).

In a project by Coker (1998) exploring the ways in which patients’ personhood is described in health records in long-term facilities, participants (registered nurses and registered practical nurses) were asked what they considered to be important aspects of personhood. In other words, what would they want their own nurses to know about them if they were being cared for on the unit? The following seven themes emerged from their responses: 1. Respect (e.g. respect for privacy, knowing how the person likes to be addressed, knowing when the person is feeling disrespected); 2. Preferences (e.g. identifying a person’s likes and dislikes, including food, warmth, management of daily activities, hygiene practices, sleep patterns, positioning preferences, and music); 3. Interests/activities (e.g. knowing the person’s daily routine, knowing activities they like to do, knowing their hobbies, knowing what do they like to talk about); 4. Family/social support (e.g. family history, whether they have children and/or grandchildren, knowing who is in their social group, knowing what community groups they are/were involved in), 5. Backgrounds (e.g. knowing their occupation and/or life work, knowing their cultural background), 6. Hopes and dreams (e.g. identifying their hopes, identifying their life goals – both fulfilled and unfulfilled), and 7. Spirituality (e.g. knowing their religious beliefs, non-religious beliefs, existential concerns/questions). Once the themes were identified, the project leader designed a list of questions to elicit information about personhood from patients. After the pilot

study was over, the participants stated that documenting information about personhood was something that all nurses should do. They made comments such as “It makes you look at them as people”, “I learned a lot”, “Our focus is changing – we’re moving away from a medical model”, and “It was so moving...as she (the patient) talked about her own spirituality and wanted to know about mine... I could see that something had been lifted” (p.446). Participants unanimously agreed that coming to know patients-as-persons opened up new possibilities for communicating with patients and their families. In fact, patients and families from the unit of study shared that they were very impressed with nurses taking such an interest in them. The participants also said the knowledge they obtained about their patients’ personhood helped them provide individualized care, however, they gave few examples of this type of care. Further research is needed to investigate how knowing the person affects broader outcomes of care, such as nurse, patient and family experiences. Another limitation of this study is that, although the goal was to determine whether patients’ personhood is described in health records, a lack of documentation about personhood does not necessarily mean that nurses do not engage personhood in practice. The setting of the study is also important to consider as a long-term care setting is significantly different from acute care, therefore, some of the approaches to gathering information on personhood may not be transferable to other units. Coker’s (1998) study led to the development of a ‘personhood profile’ which was included in every patient’s chart. The profile consisted of a list of questions designed to elicit data on patients’ personhood. Participants were asked to choose one resident and to use the questions to guide their gathering of personhood data over one month. A checklist was provided to track and record this information. Here again we see checklist approaches to nursing practice rather than a genuine interaction with patients’ personhoods.

Personhood in acute care settings. As previously mentioned in the above section on acute

care culture, hospital settings are often portrayed as impersonal and routinized, with little attention being paid to issues of personhood (Chochinov et al., 2015). It is widely recognised that hospitals serve to threaten personal identity (Clissett et al., 2013) especially in the face of cognitive impairment (Bahr, 1992; Kitwood, 1997, Clissett et al., 2013). Kitwood viewed personhood not as an innate property of an individual, but rather something that emerges within a social context. In response to the reductionist biomedical view of persons with dementia, Kitwood described personhood as the relational aspects of being human and the importance of being in an inclusive psychosocial environment with people who recognize you as a person with a unique personality and life (Rosvik et al., 2011). Person-centered care is commonly recognised as the ideal approach for caring for people with dementia – as well as *all* people in receipt of healthcare – with the goal of respecting personhood despite cognitive impairment (Clissett et al., 2013). Yet, evidence shows that nurses working in acute care settings struggle to provide care that values personhood (Chochinov et al., 2015).

In a paper written by physicians and nurses, Chochinov et al. (2015) associated the neglect of personhood in acute care with increasing time pressures and the prioritization of delivering task-oriented, evidence-based care. Few would disagree that the acknowledgment of personhood and regarding patients-as-persons ought to be foundational within healthcare culture. However, clinicians find it challenging to enter into conversations on personhood because they believe it will take too long, they are afraid of what may be uncovered – and are unsure how to respond, and they worry it could be emotionally draining for patients and themselves (Chochinov et al., 2015). Despite these challenges to engage personhood, evidence has shown that failure to acknowledge personhood is often the root cause of patient and family dissatisfaction in hospital (Chochinov et al., 2015).

Chochinov et al. (2015) conducted a study in palliative care wherein they tested a brief

way of eliciting information regarding a patient's personhood by asking one question, "What do I need to know about you as a person to give you the best care possible?". The intention behind posing this question, termed the Patient Dignity Question, was to offer a simple and effective way of placing personhood on the radar of nurses and physicians. According to the authors, its influence on patients, family members, and clinicians was substantial (Chochinov et al. 2015). The vast majority of patients and family members reported that the information obtained was accurate, important for clinicians to know, and something they would recommend to others. Almost all of healthcare professionals in the study by Chochinov et al. (2015) indicated that they learned something new from asking the Patient Dignity Question, and more than half of them said they were emotionally affected by it, it influenced their sense of empathy, and ultimately influenced their care (e.g. enhanced emotional connectedness, respect, compassion). Although this study provides valuable insight into how the Patient Dignity Question can elicit personhood and enhance the experiences of patients, families, and healthcare professionals, it should not replace wider conversations with patients and families about their personal situation and what they deem important and wish to be known. Furthermore, the Patient Dignity Question was framed in terms of what participants wanted everyone looking after them to know; not things they would want withheld or only selectively revealed. Thus, it is possible that patients' personhood was not described in their entirety in Chochinov et al.'s (2015) study. Furthermore, the Patient Dignity Question was only asked to patients in palliative care settings, thus, more research is needed in various clinical populations and settings.

Consequences of fostering personhood. The study by Chochinov et al. (2015) reveals that knowing who the patient is as a person has important implications in healthcare. According to the authors, recognizing personhood increases the likelihood that patients feel cared about and, therefore, more content with the care that they receive. Taking an interest in who patients are,

what matters to them, and how they want to be seen enhances trust between patients and clinicians, thus, resulting in stronger therapeutic relationships. Chochinov et al., (2015) also noted that trusting relationships between patients and healthcare professionals increased the likelihood that patients would disclose various personal factors that may influence their medical decision making, thus improving diagnostic accuracy and patient safety.

Gathering information about elements of an individual's personhood can result in knowing the individual as a person. Outcomes of this type of care for the patient may include enabling the individual to identify personal strengths, preventing or minimizing suffering, and more successful advocacy by the caregivers (Coker, 1998). According to Jenny et al. (1995), knowing the person behind the patient "is the integral link between technologic and biobehavioural science and patient outcomes" (p.258). Thus, further supporting the notion that the biomedical model alone is insufficient in caring for patients in acute care. According to Radwin (1995), once the nurse *knows* the patient, then the nurse is able to treat the patient as a distinctly unique person through individualized interventions. Nurses who know their patients as persons can help them achieve well-being and better understand what 'well-being' means to each individual patient.

In her work, Malone (2003) refers to proximal nursing as understanding "patients as unique persons situated within (specific) social worlds, working to shape the hospital as a place of healing, and recognizing knowledge derived from the patient's life as an important part of the care experience" (p. 2323). In contrast to the positive outcomes of engaging personhood, a failure to engage personhood can result in nurses becoming increasingly "distal" to patients in their care (Malone, 2003). Distal nursing refers to spatial–structural ordering that preserves and reinforces existing economic and power relations. For instance, when patients enter the hospital, they can easily feel displaced – in terms of both the physical setting (i.e. going from their home

to an unfamiliar and often highly technical hospital setting), as well as a displacement from their own bodies, which they may feel has betrayed or even abandoned them. Malone (2003) argues that hospital nursing is increasingly constrained by spatial– structural practices that disrupt relationships and reduce or eliminate proximity. She goes on to explain that there are potentially “dangerous” implications in this loss of proximity.

Malone (2003) describes three forms of proximity that are “nested” together: physical, narrative, and moral. Physical refers to the nurse’s nearness to the patient, which eventually sets the nurse up to come “to know the patient” as a whole person (narrative proximity). Moral proximity refers to ways in which the nurse encounters the patient as ‘other’, recognizes that a moral concern to “be for” exists, and solicits to act on a patient’s behalf – often referred to as advocating for the patient. I argue here that Malone’s description of narrative proximity is closely linked with nurses’ engagement with personhood. Thus, if a nurse is unable to sustain physical nearness due to limitations on time and resources as well as system pressures to prioritize task-based care, then they are at risk of becoming “distal nurses”. That is, they are disengaged from patients-as-persons, regard the work of patient care as technical management and efficient production, and are unlikely to perceive or raise difficult issues based on the particularity of any individual patient. The danger in making nursing distal is that as nurses lose their proximities with patients and with one another they will likewise lose their narrative and moral traditions, enacting their work as mere technicians. Malone recounts the narrative of an emergency room nurse who describes “taking time out of her day” (p. 2322) to talk to and “be with” a woman who was crying and seeking healthcare for a drug addiction. That this nurse sees this gesture as *outside* of what is expected of her, even though it was an entirely appropriate and needed intervention, demonstrates that engaging personhood is perceived as ‘extra’ care rather than part of standard nursing practice.

Literature Summary and Gaps

In this review, I have shown that the context of acute care can present significant challenges for nurses striving to deliver quality end-of-life care. Although acute care units are intended for the treatment of acute life-threatening illnesses, patients with terminal diseases are being admitted to these units due to advancements in medicine and technology, multi-morbidities, and the over-burdened healthcare system. It is estimated that more than half of Canadians will die in acute hospitals, yet many healthcare professionals working in these settings do not feel able to provide adequate end-of-life care (Ingleton et al., 2013). Reasons for this include a perceived lack of time, training, and resources along with the overarching challenge of delivering end-of-life care in a cure-oriented environment (Keall et al., 2014). As a result, the needs of dying patients are often overlooked causing patients to experience unnecessary pain and suffering at the end of life.

There is a paucity of research on the experiences of nurses delivering end-of-life care on acute care units. Of the few studies that exist (and as I have reviewed here), the literature focuses mainly on the challenges and barriers encountered by nurses in these settings (e.g. medical factors, patient and family factors, system factors) rather than the ways in which nurses engage with patients at the end of life (Mazzotta, 2015; Oliveira et al., 2016; Thompson et al., 2006). Furthermore, little to no research has been done on the ways in which acute care nurses challenge the constraints of working in a medically-driven care environment as well as a neoliberalist healthcare system.

While a lot of work has been done on person-centered care in palliative and long-term settings (McCormack et al., 2010; McCance et al., 2011), once again there has been little focus on acute care units. More attention should be given to acute hospital settings as the priorities on these units (e.g. rapid diagnosis and therapeutic intervention with short length of stay) can make the delivery of person-centered care difficult to provide. Furthermore, while the nursing

profession has devoted much attention to the notions of person-centered care, only one concept analysis of personhood currently exists in the nursing literature (Sofronas et al., 2018).

Personhood is particularly important to consider in acute care as these settings are often described as highly technical, impersonal, and capable of stripping away patients' identities (Chochinov et al., 2015). After reviewing literature relevant to this study, the abovementioned gaps need to be addressed to allow for an in-depth understanding of how nurses in acute care are able to engage personhood at the end of life within a predominantly biomedical culture of care.

Chapter 3: Methodology

Design

Thorne's (2016) interpretive description qualitative research design orients this research inquiry to better understand the ways in which acute care nurses engage, or fail to engage, with personhood at the end of life. Interpretive description is a qualitative research methodology that aligns with a constructivist and naturalistic approach to inquiry (Thorne, 2016). It aims to generate qualitative research relevant for the clinical context of applied health disciplines. This methodology uses a disciplinary lens to generate a unique understanding of the experience being researched (Thorne et al., 2004). In this study, I apply a lens of nursing ethics to better understand how nurses on acute care units care for patients-as-persons at the end of life. This methodological approach espouses the use of a variety of qualitative research strategies provided by social sciences with the intention of "strengthening qualitative research by realigning it with the epistemological underpinnings of the applied disciplines for which it is being used" (Thorne, 2016, p.72). Interpretive description explicitly recognizes and capitalizes on the researcher as an instrument. Thus, the researcher's actions and thinking play a meaningful role in shaping the nature and outcome of the inquiry. Positioning myself in the study (i.e. positioning the researcher) is important to maintain transparency in my motivations, biases, and consequent angle of interpretive inquiry (Thorne, 2016).

The study is positioned within a constructivist worldview. Constructivism is a worldview that relies on the participants' views to give meaning to human experience (Creswell, 2009). These subjective meanings are contextually focused and are generated through interactions with others. According to Guba et al. (1994), the researcher and participants are assumed to be interactively linked and, thus, co-create the findings as the study progresses. Constructivist researchers recognize that their backgrounds shape their interpretations and, therefore, position themselves in the research to acknowledge how they may influence the study (Creswell, 2009).

A constructivist inquiry into how nurses care for patients at the end of life is appropriate as it provides a lens through which end-of-life nursing care in acute care units can be explored as a subjective, intangible, and experiential reality (Guba et al., 1994). Constructivism also acknowledges how the context of acute care settings influences end-of-life nursing care.

In interpretive description (Thorne, 2016), theoretical scaffolding is broadly described as the background knowledge, assumptions, and disciplinary orientation that will influence the researcher's course and direction throughout the study. Such scaffolding orients the inquiry and identifies the theoretical assumptions that influence the design decisions, data analysis, and writing (Thorne, 2016). There are two critical elements to scaffolding a study: the literature review (chapter 2) and the theoretical forestructure. The theoretical forestructure refers to describing what the researcher will be bringing to the study.

Theoretical Forestructure

Theoretical forestructure has to do with “locating” yourself as a researcher within the disciplinary field (i.e. nursing) and the theoretical world that surrounds it (Thorne, 2016). The theoretical forestructure includes locating theoretical assumptions, locating the disciplinary orientation, and, lastly, positioning the researcher.

Locating Theoretical Assumptions. Theoretical assumptions refer to those aspects of academic thought – the paradigms, concepts, theories, and frameworks – to which a researcher is committed and that frame and orient their approach to inquiry (Thorne, 2016). The following section addresses the theoretical assumptions that I hold with respect to nurses' engagement with personhood in end-of-life care. In locating my theoretical assumptions, there is no single theory that I align with, therefore I built my assumptions about the profound experiences of end-of-life care using both empirical and theoretical literature. My explication of this chapter is oriented around the following main ideas: 1. Personhood as a relevant ethical lens to examine end-of-life nursing practice (in this section I argue that patients dying on acute care units are most

fundamentally human beings living profound personal experiences – including suffering – that deserve attention and engagement); 2. Empty discourses are prevalent in contemporary healthcare (in this section I suggest that ‘person-centered care’ is a popular buzzword devoid of meaning); 3. End-of-life care in acute care is fundamentally a relational practice, therefore, I draw on theoretical notions within the field of nursing ethics (i.e. relational ethics, moral experience, moral community) to advocate for a renewed ethic in acute care that recognizes the moral experiences of nurses and addresses the needs of dying patients and their families.

Personhood as a relevant ethical lens to examine end-of-life nursing practice in acute care. As previously mentioned, the term ‘person-centered care’ is used frequently in healthcare and yet it is described in the literature as vague and varying (Morgan et al., 2012). Rather than focusing on the label of ‘person-centered care’, I suggest revisiting the underlying philosophical idea of personhood. This is particularly important in today’s highly technical hospital settings where patients’ very humanity is at stake (Rodgers et al., 1997). I propose using an underlying framework of personhood to help guide acute care nurses in caring for patients who are dying. This approach to care encourages nurses to recognize, engage with, and promote patients’ personhood with the greater intention of enhancing the experiences of patients, and sometimes alleviating peoples’ suffering, at the end of life. This is a chance for nurses to reconnect with the ideologies of our profession that center around specific values of dignity, quality of life, and holistic care. In this section, I review literature (including empirical literature) that demonstrates that people live profound experiences at the end-of-life. Although much of this literature is empirical, my interpretation is theoretical.

Promoting personhood through nursing practice is both relational and morally significant. For instance, care that focuses on the person is manifested through the empathetic relationship between nurse and patient (Green, 2006; Raudonis, 1993). Empathy represents the nurse’s effort to imagine how the patient is feeling based on their own personal and professional experiences

(Green, 2006). In Tornoe et al.'s (2015) study on nurses' experiences with spiritual and existential care of dying patients in a hospital, nurses emphasized the importance of establishing a trusting rapport with the patient in order to know their patients. Developing a strong nurse-patient relationships rests on the nurse's ability to be present. That is, the nurse's ability to be available as a physical presence and emotional support to dying patients and their families. This presence is further described by Green (2006) as:

“Accepting what the patient has to say or not say, being with them, witnessing tears and emotions, and accepting silences constitute giving full attention to the person” (p. 297).

In order to be present with patients at the end of life, participants in Tornoe et al.'s (2015) study identified that nurses must first be comfortable with themselves and their own values surrounding death and dying. This requires nurses to reflect on their moral identity – the values and beliefs that guide their practice – and how these may influence their end-of-life care. I will return to the notion of moral identity later in this chapter.

Nurses practicing in a way that fosters personhood place emphasis on the unique needs of each patient and include the patient in health care decisions, both of which have been identified as important aspects of improving patients' sense of well-being (McCormack et al., 2006; Morgan et al., 2012). Additionally, caring in this way has also shown to reduce instances of moral distress among nurses in the long term and promote team work among staff (Binnie et al., 1999). Although biomedical tasks are an important part of acute care nursing, the intention behind the task is equally significant. As Gastmans et al. (1998) state:

“Nurses derive their specific identity not only from the set of tasks that they perform, but also from the way in which they commit themselves to the caring process” (p. 53).

In the articles reviewed by Robinson et al. (2014) (see chapter 2), patients and families were more inclined to remember those health professionals who took the time to show empathy and kindness and described having end-of-life experiences in which they felt truly cared for. Using

personhood as an ethical lens is relevant because it enables us to see these patients and their families as people living profound experiences at the end of life.

According to palliative care literature, when patients talk about the end of life, they often do so with sadness, guilt, fear, and despair (Green, 2006). Although few studies address the emotional experience of patients who are dying in acute care, it is plausible to assume that they are experiencing similar emotions. The struggle to find meaning in what is happening when dying is deeply personal and often involves emotional turmoil, questioning, blaming, loss, grief, and mourning, but it can also elicit moments of joy, achievement, and connection. Despite the ethical significance of these experiences, they often go unaddressed in hospital due to the busyness and predominantly biomedical culture of acute care units today (Chan et al., 2017; Thompson et al., 2006).

The end of life is a unique period; there is a sense of urgency that arises as remaining time grows short. During this time, patients are confronted with concerns and sentiments they may not have ever addressed before, whether because they had not been asked about them or because they themselves had not yet given them conscious thought (Coyle, 2006). In a qualitative study by Nguyen (2012) exploring the perspectives of terminally-ill patients in a variety of care settings, the end of life prompted some people to reflect on personal values, while others reflected on what to do with their time remaining and/or what would happen after they died. For instance, one patient who was the primary caregiver to his son reflected on what would happen to his son after he died. Another patient reflected on whether or not he believed in God and the afterlife. These contemplations by patients who were at the end of life illustrate the personal reflections patients work through when confronted with the imminence and certainty of their own death. Many of the patients in Nguyen's (2012) study also spoke of the physical changes that occur at the end of life, as well as their fear of losing things that they felt were crucial to

their identities. One man was angry because he used to be very active and now his illness prevented him from doing any activity at all. Another man who strongly identified as an affectionate, playful grandfather expressed feelings of sadness because his illness prevented him from interacting with his grandchildren the way he used to. ‘Self-identity’ was an overarching theme in Nguyen’s (2012) study and the perceived threat to identity was a significant concern for many of the patients she interviewed. In another study, patients who were terminally-ill struggled with being knowledgeable about their disease, maintaining control, and establishing and maintaining support systems, all the while trying to find meaning and create a legacy at the end of life (Coyle, 2006).

The end of life can also elicit moments of joy and accomplishment when experienced in an environment that is supportive of the person. Some patients use this time to reflect on meaningful life experiences such as childhood memories, travels, professional accomplishments, and friends and family (Nguyen, 2012). Others create a legacy as a form of continued existence after they die (Coyle, 2006). Legacy work provides a unique and powerful opportunity for patients and the people around them to reflect on their life and the moments and people who shaped it, while still planning for the future. Most of the participants in Coyle’s (2006) study – which examines, from the patient’s perspective, the work of trying to live with advanced cancer at the same time as facing the immediacy of death – expressed a sense of achievement and fulfilment in the life they had and the legacy they would leave behind.

In the literature, end-of-life experiences were frequently mentioned in terms of relationships: Relationship with self, relationships with family, and relationships with the healthcare system. At the end of life, patients often mentioned the changes that their illness had caused in their family relationships (Nguyen, 2012; Broom et al., 2012). In one study, patients viewed the end of life as an opportunity to “say goodbye” and “mend fences” (p. 504) with family members (Broom et al.,

2012). While patients in another study described the end of life in terms of guilt, burdening their family, and fear of their families watching them deteriorate:

“I’m not easy to live with in respect of not be able to do anything for myself. Eating. Water. Bathroom. Wipe my eyes. You know, so it takes a toll on [my wife] as well as me” (Nguyen, 2012, p. 49).

In a systematic review by McPherson et al. (2007) on self-perceived burden at the end of life, studies revealed that terminally-ill patients sometimes express hopelessness, particularly when having to ask for help with daily activities. Self-perceived burden is cited by the authors as “empathetic concern engendered from the impact on others of one’s illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self” (McPherson et al., 2007, p.115). Additionally, patients who are dying sometimes express reluctance to discuss their feelings with others because they are concerned that self-disclosure of distress will create further burden to caregivers (McPherson et al., 2007). According to Nguyen (2012), patients felt the need to protect their families and shield them from the realities of their illnesses at the expense of their own need to discuss their issues at the end of life. One patient’s wife was surprised to see him cry when talking about his disease. The patient said he had never discussed these things before because he didn’t want anyone to worry about him.

In a study on patient and family experiences in an inpatient hospice setting, some families highlighted the complex nature of family relations (Broom et al., 2012). Some families were described by patients as “amazing and supportive” (Broom et al., p.508), while other patients spoke of family struggles, lack of family support, and family not being present at the bedside. The end of life is a unique time in a person’s life trajectory and can only truly be understood by the person who is experiencing it, therefore families can sometimes feel helpless in how to

support this person. As nurses, understanding the source of such conflict can help reconcile patients' needs with their families as family dynamics heavily shape the end-of-life experience (Broom et al., 2012).

Turning to relationships with the health care system, patients often feel they have to learn how to navigate and manipulate unfamiliar healthcare systems so as not to be treated as just another 'disease' but as a person. For instance, a patient in Coyle's (2006) study expressed: "I mean the cancer is part of me but not the whole me... I don't want to be a patient, I want to be me" (p. 269). This is echoed by Jim in the video by Canadian Virtual Hospice when he describes wanting to be seen as a "person not a pathology" (6:30). Furthermore, establishing a strong, empathetic nurse-patient relationship was perceived by patients and families as crucial at the end of life (Coyle, 2012). As previously mentioned, nurses who approach patients with empathy and kindness enhance the end-of-life experiences of patients and families, rather than the alternative in which patients are left feeling uncared for and de-humanized (Coyle, 2012).

Suffering at the End-of-Life. The concept of suffering is important to consider when discussing end-of-life experiences; any unexpected and unwanted change to personhood can consequently lead to suffering. Suffering frequently occurs in the face of disease and can emerge with great intensity at the end of life as suffering is linked deeply to the recognition of one's own mortality (Ferrell et al., 2008). For instance, Nguyen (2012) describes one participant who stated he was suffering because of the unpredictability of the end of life:

"It (death) gnaws at you, you know. It's there all the time because you know sooner or later it's gonna come up and bite you. How long are you going to live? How long can you stay alive? [...] Are you going to be able to see the grandkids again? What are you going to do next Christmas? Will you be bedridden? When you are bedridden, what are you gonna do about it?" (p.43).

The concept of suffering is described by Carnevale (2009) as a subjective emotion that is only truly understood by the person who is suffering. It is a deeply personal experience that cannot be measured objectively as it relates only to the sufferer's unique values (Carnevale, 2009). Therefore, one person's experience with suffering will be very different than that of another. Perhaps this partly explains why suffering is often described as lonely and isolating as only the person suffering truly understands what they are going through (Carnevale, 2009; Ferrell et al., 2008). According to Rodgers et al. (1997), negative effects of living through experiences of suffering include withdrawal and significantly decreased quality of life. For example, a terminally-ill father may not want to talk about his distress with his family out of fear of being a burden on them. As a result, the patient internalizes his distress which can cause him to feel alone and withdraw from his family and caregivers. Ferrell et al. (2008) explores suffering from a nursing perspective, according to them, nurses are the professionals that work the closest with patients and their families and thus have the greatest opportunity to accompany people in their suffering. They describe suffering as a subjective experience felt by patients and families that is often associated with loss, intense emotions, spiritual distress, and an inability to express those experiences. Suffering is often viewed as an inherent part of illness and addressing suffering through holistic care – that is, helping the person to heal through attention to body, mind, emotion, spirit and environment – is at the very core of nurses' work (Ferrell et al., 2008; Selanders et al., 2012).

Of course, the end of life is not necessarily synonymous with suffering. Some people experience growth and realize personal values during this time. For instance, one terminally-ill patient from Coyle's (2006) study stated that he valued teaching through example and role modeling. Therefore, he wanted to teach his family "how to die" so that "something good and positive comes out of it" (Coyle, 2006, p. 272). Another positive aspect of end-of-life

experiences – for some – is finding “grace and beauty” in receiving the care and nurturing of others, as in the following example:

“They clean my bottom for me and they do it with such grace and beauty, they don’t make me feel like some sort of unhuman person. I am paralyzed, I need their strength, they don’t turn away from me” (Coyle, 2006, p.270).

This section has highlighted the profound experiences – both difficult and meaningful – that patients live at the end of life, including experiences of suffering and threats to personhood. I suggest that only once acute care nurses are oriented towards care that focuses on personhood can they appreciate these significant experiences and recognize how they shape each person’s unique end of life.

Empty discourses in contemporary healthcare. Notions of person-centered care are frequently used in healthcare and often used in organizational discourse, despite evidence of limited enactment of these values at the level of direct nursing care (Bolster et al., 2010; McCance et al., 2011). For instance, buzzwords like ‘person-centered care’ are frequently seen in the mission statements, policies, and initiatives of healthcare institutions, but without the resources required to promote personhood, such as adequate staffing, training, and infrastructure for the delivery of individualized care (Nolan et al., 2004). Using person-centered care as ‘tokenism’ puts it at risk of becoming an empty discourse. That is, nurses may think they are delivering care that looks like one thing, but in reality, is quite another (recall the study by Bolster et al., 2010, on person-centered care during medication administration in chapter 2).

For this study, my focus on the person intends to address the current imbalance of end-of-life care in acute care settings, in hopes of moving away from a predominantly biomedical discourse, towards one that focuses on personhood and biomedicine equally. This is not a novel idea by any means. Several studies have explored alternate care approaches in acute care settings

demonstrating the need for a cultural shift. For instance, in Stavarski's (2018) article, the author advocates for a nursing care approach that engenders hope while caring for patients in a medical-surgical unit. In an article by Moore et al. (2014), they describe ethical issues experienced by medical-oncology nurses and argue for the use of relational ethics as a guide for nurses caring for patients with cancer. Despite these recommendations for alternate approaches to care, a dominating biomedical culture continues to prevail in acute care settings.

With new, highly technical hospital facilities patients are often unimpressed by the modernity of their surroundings and grieve the loss of their identities (Coughlan et al., 2007). Specifically, staff shortages and task-based care risk overlooking the needs of dying patients which, in turn, diminish patients' dignity, emphasizes their loss of independence, and takes away opportunities for relationship building (Coughlan et al., 2007). Moreover, neglecting the needs of patients who are dying raises ethical concerns for nursing practice which can lead to moral distress in acute care nurses.

It is important to note that caring for patients in a way that recognizes and promotes their personhood cannot be the sole responsibility of individual nurses. Rather, true 'person-centered care' is only possible when the culture of the nursing work environment reflects an authentic commitment to this value. In this way, individual nurses and nursing leaders need to work together to bring about a cultural shift in which the needs of dying patients and their families are taken seriously. Therefore, this approach needs to be taken up both by individual nurses and the people who organize nurses' work.

According to the VIPS (Values people, Individual needs, Perspective of service user, Supportive social psychology) framework (recall 'person-centered care' in chapter 2), which is built upon Kitwood's philosophy of person-centered care for persons with dementia, establishing a care practice that values personhood is the responsibility of the management at a senior level in

the organization (Brooker, 2007). Organizational leaders are in positions to influence change within high acuity areas by recognizing the work nurses do, supporting a team approach to care, and addressing the need for holistic care. Those responsible for setting care standards and procedures, such as nurse managers and clinical educators, have the responsibility for organizing and promoting a care approach that fosters personhood. Lastly, it takes the whole staff to create a positive social environment that is inclusive and offers activities adjusted to the individual needs of each person.

Relational ethics, moral experience and moral community in end-of-life nursing practice within acute care.

Relational Ethics. In caring for others, nurses enter into a relational space as one human responding to another (Wright et al., 2009; Gastmans et al., 1998). According to Jopling (1993), “relational space is where one enacts responsiveness and responsibility, not just for oneself or the other, but within the space of being for and with oneself and the other” (p. 486). The nurse-patient relationship is one of reciprocity in which the nurse and patient engage in ongoing moral decisions while maintaining a certain degree of openness with one another (Frank, 2004). This is important in end-of-life care because terminally-ill patients and their families are often confronted with ethically significant decisions (e.g. level of care, discontinuing treatments, advanced directives) and often turn to their caregiver (i.e. their nurse) for guidance and support.

End-of-life nursing practice that focuses on personhood can be considered through a lens of relational ethics in which the quality of relationships is valued as well as reaching care goals through genuine dialogue with patients and their families (Pollard, 2015; Carnevale et al., 2017). I argue that care that focuses on personhood automatically includes the patient and their relationships (McCormack et al., 2010). Thus, the nurse not only enters a relational space with the patient but with the people that are important them (e.g. family, friends, caregivers). According to palliative care literature, family members also look to connect with nurses during

end-of-life experiences. This desire to connect is relevant to end-of-life nursing practice as strong nurse-patient and nurse-family relationships can promote wholeness, even in the face of death (Leung et al., 2010; Egnew, 2005). A relational ethics model is comprised of four major themes: mutual respect, engagement, embodiment, and environment.

Mutual respect is the central theme of relational ethics and is described as an interactive and reciprocal relationship between clinician and patient (Leung, 2010). Mutual respect is the attitude of others towards us and our attitude towards others that fundamentally connect us and reveal how we interactively help or are helped by others (Bergum 2004). The basic premise of relational ethics is that ethical decisions and actions are made within the context of a relationship. Furthermore, it is important to note that within the relational ethics framework, mutual respect provides a means of interacting with people who hold different values through recognition that “our differences complement rather than exclude one another” (Benhabib, 1987, p.87).

Engagement refers to developing an authentic connection through true presence and personal responsiveness. According to Pollard et al. (2015), to establish an engaged relationship nurses must position themselves with the patient by recognizing the patient as a person first and foremost. As a result, the nurse is able to nurture an understanding of their patient’s humanity and individuality allowing them to ‘hear’ the patient’s voice (Pollard et al., 2015). Relational ethics requires that nurses not imagine themselves in the place of their patients; they must identify the unique needs, talents, and capacities of their patients. When nurses do not recognize or respond to the needs of dying patients, this lack of engagement can be understood as an ethical concern (Bergum 2004). That is, if nurses are not caring for patients as persons then they risk losing their sustaining narrative and moral traditions and will take up their work as mere technicians (Malone, 2003).

Embodiment is described as knowledge derived from the nurse's cognitive, affective and emotional experiences (Bergum, 2004). Rather than decision-making based on strictly intellectual/academic knowledge, relational ethics encourages nurses to use past learning and experience as a guide. Embodiment also assures that the feeling body and thinking mind are equally valued in the nurse-patient relationship (Wright et al., 2011). According to Wright et al. (2011), "we experience the world through our bodies, and our sense of our own body is inexorably linked to our sense of self [...] Recognition of every person as an embodied being-in-the-world is fundamental to ethical nursing practice" (p. 25). Lastly, the environment not only includes the relational space between the nurse and the patient but extends beyond the individual level and explores the relationship of the patient to the healthcare system, community, and world (Bergum, 2004). This is significant to this study because of the aforementioned biomedical culture and ethos of 'busyness' in acute care which may influence the patient's relationship with the environment.

Healthcare models are dominated by biomedical discourses that often overshadow the moral concern of end-of-life care (Bjorklund 2004). Nurses in acute care often feel unable to build spaces that allow them to be present for, talk with, and listen to patients' end-of-life experiences due to contextual barriers (e.g. ward busyness, lack of privacy, elevated noise levels, lack of time and resources, prioritization of tasks) (Leung, 2010; May, 1995). In contrast, relational ethics emphasizes the *quality* of relationships and values a process of setting and reaching common goals through dialogue with patients and their families that can morally shape the experiences and actions of those involved (Bergum 2004).

Moral Experience. Nurses are the healthcare professionals that work the closest with patients and are faced with ethical issues frequently. According to Pavlish (2014), the majority of ethical conflicts described by nurses on acute medical units involve seriously ill patients nearing the end

of life. These conflicts include: decisions around level of care and informed consent; concerns regarding quality of life and futile invasive treatments; difficult conversations and poor prognoses; and whether or not to consult palliative care. Nurses also report challenges, such as administering treatments that cause suffering and being honest without removing hope that often thwarted the goals of care (Pavlish, 2014). These situations are described as complex and emotionally charged and can leave nurses feeling sad, angry, guilty, and fearful. In other words, ethical conflicts can make nurses vulnerable to moral distress.

Moral distress is a moral experience that occurs when a nurse is unable to act in a way that reflects their moral identity. That is, when there is an inconsistency between one's beliefs and one's actions. According to Jameton (1984), this inconsistency often happens because "one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p. 6). This vulnerability to moral distress is evident in previous sections of this thesis, where I describe acute care nurses feeling forced to be task-oriented in order to get through their shift, thus leaving them unable to care for patients in the way they believed to be most ethical. The culture of these units is such that nurses feel forced to set aside deeply held beliefs, values and principles (e.g. holistic nursing) in order to make it through their shift. Although the influence of workplace culture may not be what typically comes to mind when thinking of an ethical challenge, day-to-day nursing practice is inherently moral (Hardingham, 2004). Although perhaps not aware at the time, nurses who repeatedly put aside their own values as a means of 'making it through the shift' can experience moral distress over time. With moral distress, nurses can become emotionally exhausted, morally insensitive (Hamric, 2012), and disengaged from work (Maiden et al., 2011). Although the alleviation of nurses' distress caused by their work is not well studied, the literature suggests that unresolved moral distress can lead to emotional exhaustion, burnout, poor quality of care and even to large

numbers decreasing their work hours or considering leaving the profession entirely (Hamric, 2012; Maiden et al., 2011).

Moral community. Moral communities are described by nurses and clinical ethicists as ethically sensitive and responsive environments (Pavlish, 2014) where members engage in relationships built on trust, mutual respect, and shared understanding of care goals between patients, families, healthcare providers, and administrators. It is a place, both literally and figuratively, that fosters open dialogue about moral identities, moral agency, mutual responsibilities, and the values and beliefs of its members (Liaschenko et al., 2016). It is a place where community members are encouraged to bring ethical concerns to light and to deal with them as group. In order for this to happen, interdisciplinary teams must be able to communicate and collaborate effectively. Moral communities play an important role in ‘holding’ the moral identities of its members (e.g. nurses). According to Peter et al. (2018), moral identities are relational because they are developed and maintained through interactions with other people who ‘hold’ our identities. When moral identities are held well, nurses are able to deliver care in a way that reflects their values and beliefs which, in turn, facilitates their ability to foster the identities of their patients. Contrary to this, if the moral identities of nurses are held badly, nurses, and their patients, suffer.

According to Pavlish (2014), healthcare environments as moral communities can promote comfortable dialogue about moral differences and prevent or diminish ethical conflicts and the moral distress that often follows. Unfortunately, addressing ethical concerns in today’s healthcare system is not easy. Most healthcare institutions have an ethical committee that is contacted during ethically challenging situations. However, these committees do not address the morally significant experiences of everyday nursing practice. According to the sociologist Daniel Chambliss (1996), moral and ethical challenges in nursing are systemic features of the contemporary hospital. That is, they are a normal part of the hospital’s operations rather than

external or accidental. The organization's structure determines both what are seen as problems and how those problems are managed (Chambliss, 1996). In order for a cultural shift to occur in acute care settings, nurses and nursing leaders must work together to build a moral community in which the needs of patients who are dying and their families are considered important.

According to Liaschenko et al. (2016), moral community in healthcare is "a community in which there is coherence between what a healthcare organization publicly professes to be, and what employees, patients and others both witness and participate in" (p. 338). Working towards a discourse of moral community will mean changes at all levels of care, from the bedside to the boardroom. A shared commitment to high-quality care that focuses on the person requires comfortable, honest, evidence- and ethics-based conversations between patients, families, and healthcare teams, as well as within systems of care.

Locating disciplinary orientation. According to Thorne (2016), the ultimate reason one does research within an applied profession is disciplinary knowledge development. For instance, in qualitative nursing research, the problem to be studied should be justified as a clinically relevant issue that must be addressed to improve care. Disciplinary orientation shapes the researcher's thinking, their means of enacting research, and the writing of the final research product (Thorne, 2016). Thus, recognizing the influence of disciplinary orientation is fundamental to the research forestructure. According to Thorne (2016), in the field of nursing, the researcher's disciplinary orientation is their epistemological positioning. Although Thorne (2016) is concerned with the researcher doing a study that is positioned within their discipline, my disciplinary orientation is two-fold: 1) Interpretive description is designed to ask and answer nursing questions, therefore this is appropriate for my study; and 2) I am grounded in a discipline of nursing and nursing ethics, therefore, an appropriate construct through which to explore disciplinary orientation is moral identity.

At an individual nurse level, moral identity is described as the nurse's awareness of themselves based on personal values and ideas which then guide their nursing practice (McAndrew et al., 2016; Peter et al., 2016); these values are shaped by their professional group membership, personal and professional experiences, and their relationships to institutions and other healthcare professionals. A nurse's moral identity is not necessarily the same as the moral identity of the nursing discipline; the identities of individual nurses evolve based on on-going experiences and interactions with patients, families, and other healthcare professionals. According to Peter et al. (2016), many nurses describe their moral identities in terms of making a difference in the lives of individuals and communities, as well as fostering the identities of vulnerable individuals. According to Liaschenko et al. (2016) when moral identity is maintained nurses flourish as human beings both personally and socially, but when it is not supported, moral agency becomes restricted. Moral agency is the capacity to make and act on a choice about the best course of action based on an evaluation and judgement of a particular ethical situation (Holt et al., 2012). Importantly, nurses as moral agents must be capable of justifying the choices they make as opposed to simply following the law or a code of ethics. In order for nurses to care in a way that promotes personhood and maintains their moral identity and ability to be moral agents, nurses need to be situated in moral communities that enable the provision of safe, compassionate, competent and ethical care (CNA, 2017). According to Liaschenko et al. (2016), in spite of the corporatism that dominates contemporary healthcare, hospitals and other healthcare facilities can be moral communities that develop and nurture moral agency and respond well to their members, thereby having the potential to sustain positive moral identities.

According to Peter et al. (2016), nurses strongly value recognizing patients as unique individuals during times of vulnerability. This approach to care is possible in acute care when nurses resist the routinization and task-orientation of these units and, instead, approach their patients in ways that foster personhood and, in turn, reinforce their own moral identities. This

approach to care would also be possible if the orientation of acute care changed its focus to one that centers on patients-as-persons. This is done not by omitting acute care tasks, but rather practicing in a way that recognizes the person who stands to benefit from the task.

The professional identity of nurses, which includes its moral identity, is defined as the values (moral and work) and beliefs held by nurses that guide their thinking, actions, and interactions with patients (Fagermoen, 1997). Moral identity also includes the values and images that are associated with being a ‘good nurse’ (Peter et al., 2016). In a study exploring nurses’ narratives of moral identity by Peter et al. (2016), being a good or ethical nurse has been associated with caring for or attending to the needs of others while valuing patients-as-persons, advocating for patients and their families, and shared decision-making. It also includes collaboration, having professional courage and pride, adhering to professional standards and codes, being knowledgeable and seeking professional development. According to the Canadian Nurses Association’s (CNA) (2017) Code of Ethics, nursing values and ethical responsibilities are grounded in the relationships between nurses and persons receiving care. The seven primary values of nursing are: 1. Providing safe, compassionate, competent and ethical care; 2. Promoting health and well-being; 3. Promoting and respecting informed decision-making; 4. Honouring dignity; 5. Maintaining privacy and confidentiality; 6. Promoting justice; 7. Being accountable. In a study by Fagermoen (1997) exploring the values that inform nurses’ professional identity as expressed through what is meaningful in nurses’ work, honouring human dignity was uncovered as a core value along with valuing personhood. These values were reflected in actions that emphasized the inherent worth of the patient (i.e. taking patient care needs seriously) and knowing and treating patients-as-persons in their individuality, and not as mere medical cases. The authors in this study also looked at transcultural nursing identity (Canada, America, and Scotland) which revealed the following four common values: dignity, personhood, being a fellow human, and reciprocal trust (Fagermoen, 1997). According to

Fagermoen's (1997) study findings, nurses emphasized the importance of interactions aimed at knowing the patient as a person, exploring the patient's perceptions of the situation, and creating a sense of trust in the nurse. These values were actualized through strong empathetic relationships between nurses and their patients.

The CNA (2017) Code of Ethics provides guidance for nurses working through ethical encounters, including day-to-day moral experiences that arise in practice with persons receiving care and with other healthcare professionals. It is also reflective of nurses' moral identity. The Code is intended for nurses in all contexts and practice settings (i.e. clinical, education, administration, research and policy) and at all levels of decision-making. Practice environments have a significant influence on nurses' abilities to act in ways that uphold their moral identities and, as previously mentioned, the moral identities of acute care nurses are at risk of being damaged due to physical and cultural constraints of the work environment. When acute care nurses are forced to continuously put their values aside and act in ways that do not align with their moral identities, they are at risk of moral distress. This lack of enacting nursing values is not limited to the bedside but, rather, extends through the different levels of the healthcare organization (e.g. organizational leaders and policy makers).

I am intentionally taking an 'activist' voice in writing this study, with the intent of instigating change at the practice level and, ultimately, enhancing the experiences of nurses providing end-of-life care to patients and families in acute care. I was inspired by the Nursing Manifesto (2008), written by three activist scholars – Cowling, Chinn, and Hagedorn – whose objective was to promote emancipatory nursing research, practice, and education within a praxis of social justice. The intent of the Manifesto was expressly meant as “a call to consciousness and action” (Cowling et al., 2009, para. 3), with the purpose “to raise awareness [...] inspire action [...] and open discussion of issues that are vital to nursing and health care around the globe” (Cowling et al., 2009, para. 3). Furthermore, the manifesto resonated with my focus on personhood and

nursing ethics by calling on nurses to reawaken their personal and professional sovereignty and to resist “patterns that we create, or that are imposed upon us, that inhibit the full expression of our beings as nurses and persons” (Cowling et al., 2009, para. 7). Although this study is situated in a constructivist inquiry (discussed in chapter 3), rather than critical social theory, I argue here that constructivist inquiry has space to support research that joins philosophical and theoretical ideas with potential practices that might help change nursing practice. According to Lincoln et al. (1985), constructivist inquiry should be stimulated through experiences, interest, and knowledge of the researcher. Thus, my experience as an acute care nurse and the challenges I faced in this care environment inspired me to generate research that both contributes to nursing literature, as well as instigate change at a practice level. According to Kagan et al. (2009), nurses have an ethical responsibility to work towards humanizing healthcare practices and promoting the ideals of social justice. Furthermore, Rose et al. (2008) argue that researchers need to utilise holistic and humanistic approaches to create opportunities for empowerment and transformation and to move beyond the explanation of ‘what has been’ and currently ‘what is’ in nursing, to most importantly, enhance the opportunities of ‘what could be’. Thus, I hope knowledge gained from this study may serve as a means for creating social and organizational change in terms of re-orienting the predominantly biomedical discourse in acute care towards one that also recognizes, engages with, and fosters personhood at the end of life.

Positioning the researcher. In interpretive description, it is important to acknowledge what inspired the researcher to pursue the research topic. Such acknowledgment maintains transparency about my motivation for doing this study as well as any professional experience that may influence it. First and foremost, I position myself as a registered nurse, more specifically as an acute care nurse. Over the last six years I have worked on two different acute medical-surgical units in two different cities and the struggle to address the needs of patients

who are dying was evident in both places. At first, I associated my own struggle in addressing the needs of dying patients with being a new nurse and the fact that I was still figuring out how to manage my time effectively on a busy ward. I then developed the mindset of not having enough experience to be able to engage with patients' emotional needs at the end of life.

Eventually, I blamed the busy care environment for preventing me from being able to care for patients in a way that aligned with my personal and professional values. It wasn't until I was caring for Richard, the man described in chapter 1, that I stopped to reflect on why everything seemed so hard. Why was it so hard to care for this man? Why was I struggling to go into his room? And why was it getting harder for me to come in to work? Knowing that I needed a change, without having a specific research question in mind, I decided to pursue my Master's degree with the greater intention of gaining insight into other nurses' experiences caring for patients who are dying in acute care.

It wasn't until halfway through my first semester of graduate school, in a seminar course about palliative and end-of-life care, that I realized my preoccupations concerned the concepts of suffering and personhood at the end of life. Over the last two years, I have come to realize that my own moral identity was being damaged in acute care and that the moral distress that I was experiencing was actually the catalyst for this research project. I hope that insights from this project can contribute to current nursing research on end-of-life care in acute care units and inspire nurses and nursing leaders to reconnect with the guiding values of our discipline by enacting and/or supporting care that treats patients as the people that they are.

Setting

The study takes place on an acute medical-surgical ward in a tertiary teaching hospital in Eastern Ontario. This unit cares for patients post-operatively after major oncological surgical procedures, as well as for patients admitted due to acute and chronic respiratory illnesses. This

ward has an eight-bed observation unit designed to monitor patients with complex needs immediately after surgery. For the most part, the observation unit maintains a 2 to 1 nurse-patient ratio and patients are monitored using continuous cardiac and respiratory monitoring systems. Although the observation unit is designed principally for the care of patients post-operatively, patients presenting with acute medical crises are also admitted to the observation unit. The general ward consists of 36 in-patient beds (including four-bedded rooms, two-bedded rooms, and private rooms). The average nurse to patient ratio is 1:4 on day shifts and 1:6 on night shifts. On average, the general ward maintains an equal number of medical and surgical patients. Despite the high average turn-over of patients on this unit, many patients are cared for here at the end of life due to the severity and complexity of their illnesses. One population of patients with a particular chronic illness is known on this unit for recurring hospitalizations due to exacerbations of their symptoms. Therefore, nurses on the general ward are accustomed to caring for these patients over time and across multiple admissions. The nature of the illness is withheld to protect the confidentiality of the unit.

The healthcare institution in which this study takes place does not have a designated palliative care unit. Rather it has a palliative care consult team that consists of specialist physicians, an advanced practice nurse, a palliative care nurse specialist, nurse consultants, social workers, and management support, all of whom have specialized training in supportive and palliative care. When consulted, the palliative care team will visit patients and families on in-patient units.

I worked on this unit for two years full-time before recently changing workplaces. This experience provides me with a unique 'insider' understanding of the study context. According to Dyer et al. (2009), being an 'insider' researcher allows researchers more rapid and more complete acceptance by their participants. Therefore, participants are typically more open with 'insider' researchers and data may be gathered in greater depth. Talbot (1998-99) described this

phenomenon in her study of mothers who had experienced the death of an only child. She wrote, “At the end of their interviews, several mothers said they would never have shared certain aspects of their experience if I had not been a bereaved mother also” (Talbot, 1998-99, p. 172). I believe my membership as an acute care nurse on the unit of study provided a level of trust and openness in my participants that would likely not have been present otherwise. I have also maintained good professional relationships with the nurses and nurse leaders on this unit, which I believe helped put the participants, and myself, at ease during the interviews and facilitated deeper, honest, more insightful conversations than would otherwise have been possible were I a stranger to these nurses. Reflexivity will be discussed later in the chapter.

Sampling

The focus of qualitative research is on the quality of the data rather than the sample size. Thus, qualitative studies can have a range of sample sizes, in some cases a sample as small as one may be appropriate. According to Thorne (2016), the number of study participants is unrestricted as long as the researcher acknowledges that the larger the sample size, the potential for more variations and diversities there will be on the topic of study. Thorne (2016) also reflects that, depending on the phenomenon of interest, it may be more appropriate to engage with a small number of individuals, which is the case for this study, when a more in-depth exploration of the subjective experience of the phenomenon is needed. The sample of this study consists of eight acute care nurses from an acute medical-surgical ward of a tertiary care hospital. After confirming eligibility, purposive sampling was used to ensure that the participants represented nurses who had experience caring for patients at the end of life. Participants eligible for the study met the following criteria: be a registered nurse employed full-time or part-time on the unit, have cared for one or more patients at the end of life, be English or French speaking.

Prior to recruitment, I met with the unit's clinical manager and clinical care leader to explain the study's purpose, aims, and methods, as well as to ask permission to conduct the study and seek guidance on how to recruit participants without interfering with the nurses' work. Once ethics approval was received by the Research Ethics Boards of the hospital and the university, I initiated recruitment by distributing posters within the unit on bulletin boards in the nursing station and in staff lunch rooms. These posters described the study's purpose, data collection methods, inclusion criteria, and requested nurses to contact me via e-mail or phone if they were interested in participating in the study. I also attended a total of six staff meetings over a two-week period to present my study and meet nurses working on different sets of shifts. I then stayed on the unit for one hour after each meeting to answer any questions or inquiries about the study. Participants who were interested in the study were asked to sign two copies of the consent form, one which they retained and the other was kept in a locked cabinet in a locked office at the university. Informed consent was voluntarily given by all of the participants after being informed of the methods, procedures and risks and benefits of the study. I also answered any questions that arose at this time. If participants chose to proceed with the study, an interview at a convenient time for the nurse and within a private room at the hospital was then scheduled.

Eight nurses participated in the study, all of whom were women. The study participants are demographically reflective of the nurses employed on this acute medical-surgical unit. All of the participants were English speaking. Five of the participants worked on the general unit and three worked in the observation unit. Four out of the five nurses that worked on the general unit also had experience working in the observation unit. The participants' years of nursing experience ranged from just over 1 year to 25 years. The median years of experience was eleven years. With regards to education, two participants had a nursing diploma, and the others possessed Undergraduate university degrees in nursing.

Data Collection

Face-to-face, semi-structured interviews were conducted with each participant in a private room within the hospital where they worked. These interviews allowed for each nurse to recall and share personal experiences related to end-of-life nursing care on the acute care unit. Initially, I had designed the interviews to be about nurses' experiences of caring for patients who were thought to be suffering at the end of life. The original focus on suffering stems from my personal experience working as a nurse in acute care and my own struggle to address patient suffering in practice. However, after conducting the first three interviews, all of the participants veered away from the topic of suffering to describe the ethics of end-of-life care experiences more generally. This sensitized me to the idea that perhaps I was approaching this topic too narrowly and needed to step back to allow space for participants to tell their stories more broadly. The research question was re-oriented to address what nurses' stories reveal about the ways in which they engage, or fail to engage, personhood in end-of-life care. Ultimately, this study has always been about humanity and the ways in which acute care nurses recognize patients as people living profound experiences at the end of life. Thus, widening the study question from engaging suffering – a personal experience and emotion – to engaging personhood was appropriate. Furthermore, in staying true to a constructivist worldview in which knowledge is co-created by researcher and participants, I decided to re-orient my research question to provide a more authentic fit with the stories that the participants felt were important and wanted to tell.

Within the interviews, participants were first asked to reflect upon what it is like to be a nurse on an acute care unit and to describe 'a typical day in acute care' including interactions with other nurses, nurse leaders, and other healthcare professionals. Interactions with patients and families were revealed in their stories and through some prompts. They were then asked to

share a story about one or more patients whom they cared for at the end of life. Participants were asked to elaborate upon situations where they perceived a patient to be suffering or situations in which they felt conflicted. The interviews did not focus explicitly on personhood. I chose to conduct the interviews around the broader subject of end-of-life care to facilitate conversations about the participants' own experiences and whatever they found meaningful and important to talk about. I intentionally avoided using the term 'person-centered care' to avoid a high-level discussion about a theoretical approach that may or may not be enacted in practice (recall section on empty discourses in contemporary healthcare). Furthermore, I chose to avoid the term 'personhood' as it is not a word used in everyday English language and could have led to confusion and/or fragmented storytelling. The decision to emphasize the concept of suffering was deliberate because it is a major concept in many studies of end-of-life care and it is a topic that is frequently discussed in healthcare. It is also an inherently ethical concept; the moral basis of palliative care is grounded in the potential alleviation of suffering whenever possible. Suffering is a topic that I was particularly interested in based on my experience caring for Richard (chapter 1). Thus, the topic of suffering was helpful in initiating conversations about ethical end-of-life care. Though the option to do the interview in French was available, all of the interviews were completed in English. Interviews were between 30 and 85 minutes in length (with an average of 55 minutes) and audio-recorded. Verbatim transcription of each interview was completed (See Appendix A: Interview Guide).

In interpretive description, in-depth conversations are typically the primary source of data (Thorne et al., 2016). Interviews allow for an exploration of the deeply personal experiences of each participant (Smith et al., 2007). If a participant experienced emotional distress during the interview, I was prepared to stop the interview and offer support. Although some participants were emotional at times, no one felt the need to stop the interview. Participants had the opportunity to debrief with me after the interview. Debriefing was an opportunity for me to

‘check in’ with each participant and ask how they were feeling after sharing some emotionally charged stories as well as gain a deeper understanding of participants' thoughts (Polit et al., 2010). It also provided a space for participants to ask any new questions about the study and provide feedback on the interview process.

Once the data were analyzed (described next), I contacted the five participants who consented to receiving a follow-up phone call to share the findings from the study. Three out of the five participants were available for a follow-up phone call. Phone calls lasted between 20 and 45 minutes. These follow-up phone calls provided an opportunity for member reflections, which allow for sharing and dialoguing with participants about the study's findings, and providing opportunities for questions, critique, feedback, affirmation, and even collaboration. Member reflections are different from member checking in that they go far beyond the goal of checking that the data is right or accurate (Tracey, 2010). Member reflections allow for new ideas “which throw fresh light on the investigation and which provide a spur for deeper and richer analyses” (Bloor, 2001, p. 395). Following the completion of the data analysis, I held member reflections with three of the eight study participants. The participants were provided with a three-page, single-spaced summary of the data analysis that included the research question, research objective, and descriptions of each theme. The member reflections consisted primarily of participants describing the study findings as comprehensible, meaningful, and reflective of their experiences. All participants emphasized their support of re-orienting the research question to address end-of-life care experiences more broadly. For instance, Brenda stated in the follow-up phone call: “Yeah, I think it was good that you changed the question. I found the concept of suffering difficult to talk about specifically – it’s a complex phenomenon”. Another participant said that re-orienting the research question “captures the challenge of providing end-of-life care and what nurses grapple with. We don’t know how to talk about a lot of these things” (Judy).

One participant, Lauren, stated that the findings accurately reflected her experience of providing end-of-life care. She also offered new insights on teamwork and organizational priorities, which I will reference throughout the findings (chapter 4).

Data Analysis

According to Thorne (2016), interpretive description requires an analytic form that extends beyond simply taking things apart and putting them back together. Rather, it requires the researcher to see beyond the obvious, carefully deconstruct what they think they see, question and explore any hunches they have, and take ownership over the potential meaning and impact of the outcomes (Thorne, 2016). Thorne (2016) describes data analysis as “the most painfully difficult and yet the most essential element” (p. 155) in ensuring a credible interpretive description.

Once the interviews were transcribed verbatim, within 24 hours, I engaged with the data by re-listening to the interviews and re-reading the transcripts to react to the initial pieces of data that stood out to me. I reflected on the overall messages the participants appeared to convey, whether intentional or unintentional, as well as why certain choice words or phrases jumped out at me. I slowly became attuned to patterns and ideas that addressed parts of my research question. Initially, I grouped specific quotes together and compared data across the first four transcripts. This was done purposefully to ensure that I was building patterns inductively. Once some preliminary themes were identified, I proceeded to analyze the last four transcripts. If ever I felt that I was losing sight of the data, I would return to my research question (What do nurses’ stories reveal about the ways in which they engage, or fail to engage, with personhood in end-of-life care in acute care units?) and my theoretical scaffolding (Personhood as an ethical lens for studying death and dying; Empty discourses in contemporary healthcare; Relational ethics, moral experience, and moral community in end-of-life nursing practice). According to Thorne (2016)

the theoretical scaffolding serves as the analytic lens through which the researcher distinguishes patterns from the data. Thus, my theoretical scaffolding was highly useful in keeping me on track throughout the analysis process. During the data analysis, I went back and forth on themes and quotes with my thesis supervisor before, eventually, submitting a full draft of the analysis to the thesis committee members for feedback. To ensure ongoing awareness of how I came to draw the study findings and conclusions, I engaged in critical reflection through reflexive journaling throughout the analysis process. I kept a notebook with me at all times during the analysis phase in which I jotted down lists of emerging ideas, themes, patterns, and questions such as “I wonder if...?” and “Have I seen this before...?” and “How does this relate to...?”. I also made field notes during participant interviews, which consisted of notes on my own subjective feelings and understandings of the data. Self-reflexivity will be discussed in the following section on rigour.

Rigour

Aspects from both Lincoln et al.'s (1985) Framework for Trustworthiness and Tracey's (2010) Criteria for Excellent Qualitative Research were used as guiding strategies to ensure rigor throughout the research process. Lincoln et al. (1985) state that trustworthiness of a research study is important to evaluating its worth. Trustworthiness involves establishing credibility, transferability, confirmability, and dependability (Lincoln et al., 1985; Polit et al., 2010). In 1994, Guba and Lincoln added a fifth criterion, authenticity. Credibility refers to confidence that the study findings are ‘true’ (Lincoln et al., 1985). In a constructivist sense, ‘true’ means that the findings represent the participants’ views on the phenomena of interest. Tracey's (2010) aforementioned member reflections are used to enhance credibility. Recall from above, member reflections are opportunities for sharing and dialoguing with participants about the study's findings, and providing opportunities for questions, critique, feedback, affirmation, and collaboration. Tracey (2010) also discusses crystallization, which refers to the practice of using multiple data sources, researchers, and lenses with the intention of unveiling a more complex, in-

depth understanding of the topic of study. According to Tracey (2010), multiple types of data, researcher viewpoints and theoretical frames allow different facets of problems to be explored, increases scope, deepens understanding, and encourages consistent interpretation (Tracey, 2010). Crystallization was achieved through the development of a theoretical scaffold and collaboration with members of the thesis committee. Members of the committee are experts in end-of-life nursing care, acute care nursing, nursing ethics, and qualitative research methods. My own experience as an acute care nurse on the unit of study also enhances credibility due to my insider knowledge about the care environment. Although earlier I addressed the benefits of being an insider researcher, being an ‘insider’ may have led me to take for granted certain ideas raised by participants that were situated in acute care culture. In situations like this, having a thesis committee comprised of nurses with different nursing backgrounds was helpful as they challenged ideas that I may have overlooked.

Transferability is the degree to which the results of the study are applicable to other contexts and is made possible through thick description (Lincoln et al., 1985; Polit et al., 2010). Thick description is a thorough and contextual description of the study setting and participants. It allows readers to evaluate the extent to which the conclusions drawn are transferable to other settings, situations, and people. According to Tracey (2010), thick description requires immersion in the study setting in order for the researcher to ascertain “tacit knowledge” – often unarticulated, contextual understanding that guide participants’ actions. Development of tacit knowledge takes significant time in the field, part of which I already had from prior experience working as a nurse on this unit, in addition to the 10 weeks I spent recruiting and conducting interviews as a researcher. Over the process of data collection, I also had the opportunity to attend two unit-specific education sessions that were offered over the duration of the study (one in-service on post-operative pain management and another in-service on post-operative nutrition

for patients). Although I did not collect information from these education sessions for direct use in the study, attendance allowed me to gain an understanding of some of the education offered to nurses in my study context. Transferability was also addressed through evocative storytelling of participants' experiences, which allows the reader to reflect on situations in which they may have experienced similar feelings or emotions in another setting (Tracey, 2010). In fact, as part of my analysis, I presented my preliminary study findings in a meeting of the Nursing Palliative Care Research and Education Unit at my university. Two attendees stated that the findings resonated with their own experience as registered nurses; one participant was a nurse on an acute medical unit in Ontario and the other was a nurse in a pediatric hospice. The latter demonstrates that the findings from this study may be relevant not only to acute care nurses but nurses working in a variety of care settings as well.

Confirmability refers to the extent that the study results from participants' experiences rather than the investigator's biases or suppositions (Polit et al., 2010). Confirmability was addressed through self-reflexivity and journaling, which involves analyzing and making note of any personal values that could influence data collection and interpretation (Tracey, 2016). According to Tracey (2010), self-reflexivity promotes honesty and authenticity with one's self, one's research, and one's audience. The process of reflexive journaling contributes to the overall authenticity of the study, whereby the inevitable influence of the researcher on the research setting and interpretation of study results is explicitly taken into account. Before starting data collection, I journaled a personal narrative of my own experience caring for a dying patient in acute care (narrative in chapter 1). This narrative clarified my position upon entering this research study, which I continually revisited using reflexive journaling. During data collection, I was mindful of my past experience as a nurse on this unit as well as my new role entering this setting as a novice researcher. To remind the reader of my presence and influence throughout the study process, I purposefully use the first-person voice throughout this thesis, including

presentation of findings and discussion. According to Lincoln et al. (1985), confirmability is also enhanced when multiple investigators have examined the data's meaning. My thesis supervisor and I worked closely together in analysis of interview transcripts and development of themes.

Dependability denotes how stable the data remains over time and whether the findings would be reproducible if the study was replicated. However, this approach can be problematic in a constructivist inquiry as engagement with the data is a personal process where the researcher's thoughts, feelings, and experiences shape their interpretation of the data. (Tracey, 2010). Furthermore, findings are co-constructed through the researcher-participant relationship, therefore, a different researcher may have a different interpretation of the study findings. I maintained an audit trail – a detailed account of all methodological considerations and decisions – throughout the research process as an explicit trail that explained my reasoning behind study-related decisions. I also engaged in the abovementioned reflexivity, whereby the study's rigour is maintained by my description and interpretation of my experience as a researcher. Lastly, authenticity refers to the ability and extent to which the researcher expresses the feelings and emotions of the participants' experiences in a faithful manner (Guba et al., 1994; Polit et al., 2012). I addressed authenticity by using a descriptive approach including the use of direct participant quotes throughout the findings chapter. Additionally, during the member reflections, participants were asked directly whether they felt as though their feelings and emotions had been represented fairly in the study findings, all of whom acknowledged that they were.

Ethical Considerations

This study received Research Ethics Board approval from the Ottawa Health Science Network Research Ethics Board and the University of Ottawa Health Sciences and Science Research Ethics Board. Additionally, the use of written informed consent and maintenance of confidentiality throughout the study was done to ensure the protection of human rights.

Participants were notified of their rights according to the Tri-Council Policy Statement II (2014). I also provided the participants with my own contact information and the contact information of the Ottawa Health Science Network Research Ethics Board and the University of Ottawa Health Sciences and Science Research Ethics Board during the debriefing session (See Appendix B: Consent Form).

In order to maintain confidentiality, information collected by each participant was identified with a unique study number and did not contain any identifying information. The interview transcriptions were kept in a password-protected folder on a password-protected computer on a secure network drive at the University of Ottawa. Signed consent forms were kept in a locked filing cabinet in a locked office at the University of Ottawa. The information shared by the participants was used solely for the purpose of this research. Any documents that left the University of Ottawa contained only the unique study numbers. I later assigned pseudonyms to each of the participants during the writing of the findings chapter (chapter 4). These pseudonyms will be used in any future publications and presentations resulting from this study. Participants had the right to withdraw from the study at any point. Research records, including audio recordings, will be kept for a minimum of 10 years, as required by the Ottawa Health Science Network Research Ethics Board. Participants were asked on the consent form whether they give permission to the research team to use their data in potential future secondary analyses. This permission was separate from their consent to participate in this study. As an ‘insider’ researcher, I was mindful of the fact that these nurses may also feel obligated to support me in my endeavors. Therefore, I purposefully stressed during the recruitment process that participation in this study would be strictly voluntary. If at any point in the future, no secondary analysis of the data is planned, electronic files will be securely deleted.

Chapter 4: Findings

In the following chapter I will answer the research question of what acute care nurses' stories reveal about the ways in which they engage, or fail to engage, with personhood at the end of life by describing the six themes that were revealed from interviewing eight acute care nurses. As previously mentioned, although the focus of these interviews was initially about nurses caring for patients who were thought to be suffering at the end of life, participants veered away from this specific topic and shared stories about end-of-life care more broadly. This chapter will present an overview of the study's findings, followed by the themes. To support the identified themes, direct quotes will be used from the participants. All of the participants' names are pseudonyms. At times, during the analysis, I went back to the literature to clarify ideas and/or address any questions that arose. Thus, occasional references from the literature will be used in this chapter. A fuller consideration of the findings in relation to exact literature, however, is presented in the discussion.

My overall finding is that acute care nurses are caught oscillating between their moral identities and the biomedical culture of acute care. As a result, nurses engage with personhood 'behind the scenes' while simultaneously juggling the many care responsibilities of their unit. This oscillation can be described using the metaphor of 'tug-of-war' in which a rope is being pulled back and forth between two opposing forces (i.e. nurses' moral identity and biomedicine). Over time, this constant tugging between forces can cause the rope to fray and eventually unravel. The rope in this metaphor represents the nurse's moral integrity. As described in chapter 3, nurses working in environments that constrain their values and ability to act on these values can experience moral distress. Over time, when nurses are continually pulled in different directions they can experience moral distress and become emotionally exhausted, desensitized,

and disengaged from work (Hamric, 2012; Maiden et al., 2011). As nurses' moral integrity becomes unraveled, their moral identity risks becoming damaged.

Although the literature in chapter 2 suggests that acute care nurses do not have the time or resources to engage personhood, all of the participants describe ways in which they strive to make their patients feel "human" and cared for at the end of life. Given the research question: What do nurses' stories reveal about the ways in which they engage, or fail to engage, with personhood at the end-of-life in acute care, this chapter first opens with a consideration for what 'engaging personhood' means in this context. Thus, the first theme explores the meaning of engaging personhood through participants' descriptions of so-called "little things". According to Walker (2003), nurses' stories reveal moral thinking reflective of their identities. Thus, values that uphold participants' moral identities are also explored in this theme. *Nursing "with blinders on"* describes how nurses set aside these values and feel forced to put on metaphorical blinders to avoid 'seeing' the personhood of patients in order to accomplish the tasks laid out in the "overarching ominous schedule" of their unit. The third theme presents a counter-narrative to this blindness, in which nurses describe that, with experience, they become "less distracted by nursing *while* nursing" and use nursing tasks as opportunities to engage personhood. The theme, *suffering as a "dark, emotional, twisty thing"*, reveals that participants have rich and sophisticated insights into the notion of suffering at the end of life. However, as explored in the fifth theme "*I don't think I'm ever really going to get it right*", participants also feel uncertain about the ways in which they address suffering in practice. This uncertainty threatens participants' moral integrity and risks damaging their moral identities. The final theme of "*The things we do to patients here are not nice*" highlights participants' vulnerability to moral distress and the tension between the end-of-life care they feel they ought to provide and the cure-oriented care driven by the medical team. The relationships between participants and their nursing

colleagues also reveal a point of tension when one nurse feels alone in shouldering the responsibility of providing ethical care to patients who are dying on their unit.

Engaging Personhood Through “Little Things”

“And it’s those little things, in the grand scheme of things, the ones that don’t require an order that make a difference” (Helen).

In answering the research question ‘What do nurses’ stories reveal about the ways in which they engage, or fail to engage, with personhood at the end-of-life?’, it is important to determine what ‘engaging personhood’ means to the participants in this context. The meaning of engaging personhood is revealed through participants’ descriptions of so-called “little things” wherein participants use supposed small gestures to remind themselves, their patients, and their families that they are caring for persons and not merely diseases. These gestures are seemingly done behind the scenes where they often go unnoticed and are even, at times, in opposition of the priorities of organizational leaders. Although nurses refer to these acts as “little”, they are more meaningful and have a stronger impact than the credit they are given. Furthermore, in telling stories about “little things”, aspects of participants’ moral identities are revealed. As described in chapter 3, moral identity is the nurse’s awareness of themselves based on personal values and ideas which then guide their nursing practice (Peter et al., 2016; McCarthy et al., 2015); these values are shaped by their professional group membership, personal and professional experiences, and their relationships to institutions and other healthcare professionals. Although participants do not explicitly mention the concept of moral identity, their descriptions of “little things” shed light on their values and how these values guide their practice.

Participants described “little things” such as making patients feel human, setting up the care environment, being present for patients and their families, and including patients and families in decision-making and end-of-life care. Participants’ values, which are realized through their descriptions of “little things”, include advocating for patients, seeing patients as people,

fostering relationships, and ensuring a ‘good death’ for patients and a ‘quality bereavement’ for families. Thus, engaging personhood ultimately consists of caring for the person in a way that reflects these values.

Participants describe the importance of making patients feel human at the end of life by focusing on hygiene care and engaging in conversations about the person’s family, hobbies, and occupation. For instance, when providing hygiene care, Brenda, who has been a nurse for 12 years and works mostly in the observation unit, will purposefully talk to patients about *“whatever they want, whatever their interests are just to make them feel a bit more human and less of a patient”*. Brenda also describes her “type of nursing” as treating patients like family:

“My type of nursing is that I go in taking care of patients like they’re my family. Just because I’ve been on the other side of being a family member, the person laying in the bed or sitting next to the bed has no control. So, you do the best that you can because it’s the only thing that can make them feel better [...] I just try to treat them the way I would my own Grandpa, Grandma, or sister. I treat them the way that I would treat my family”.

Brenda’s approach to treating patients like family demonstrates that she sees and strives to care for patients as people. Judy, who has been a nurse for 25 years, also talks about making patients feel human by prioritizing hygiene care, which according to other participants, is often “written off altogether” when the unit is busy:

“I focus on – well if you ask our clinical manager she may say ‘that’s not a priority’ but in some cases it becomes a priority to get shaved, get your teeth brushed, get your hair shampooed, you know, to feel like you’re a human”.

This quote demonstrates that, despite going against the priorities set by her clinical manager, Judy focuses her care on helping patients to feel “human” which, in turn, preserves her moral integrity. Nurses who practice with moral integrity possess a strong sense of self and act in ways that are consistent with what they understand is the right thing to do. Judy is also critically

reflective about what is at stake when certain practices (e.g. hygiene care) are considered low-priority (e.g. loss of control, dehumanization). In a follow-up member reflection, Lauren similarly describes going against the priorities of her unit. Lauren was providing end-of-life care to a patient who used to be a musician and wanted to find a music player to put at the patient's bedside:

"I called multiple places but I couldn't find one anywhere. People, like, our manager and care leader were interested that I was doing this but they weren't going to help me. It was like it was considered extra. I also felt kind of guilty about looking for this music player when I could have been charting or doing other things. It's like those meaningful gestures were not considered necessary".

It is interesting to note the tension between Lauren's description of this gesture (finding a music player) as meaningful while simultaneously feeling "guilty" for doing the act because it goes against the priorities of her unit.

Returning to ways in which participants make their patients feel human, Kim explains that she makes a point to talk to patients by name, even if they are unconscious, because it reminds her that she is caring for a person; a person with a family and a history:

"I think one thing too that I sort of try to keep in mind at end-of-life, like, if the patient is maybe not lucid is that I still talk to them, like, I use their name [...] then I feel like I'm caring for a person".

Kim explains that she also does this for the family's sake to let them know that she cares about their loved one. Making patients feel human upholds the values of seeing patients as people and fostering relationships at the end of life and allows participants to act in ways that reflect their moral identity. Helen describes making patients feel human by providing *"the nice bed bath, the back rub, the positioning, the pillows, the head in just the right way, the lights dimmed, the*

sheets straight". This participant also explains that she does this for the family, so they can see that the patient is relaxed and comfortable before they die.

In recognizing patients as people, participants also recognize that patients are vulnerable at the end of life and, thus, they feel it is their responsibility to advocate for their patients. Several participants identify themselves and their nursing colleagues as strong patient advocates. Participants mostly describe advocating for upstream integration of palliative care, improved pain medication, and discussions surrounding goals of care. Kelly, who has worked on the general unit for 9 years, describes herself as being "a very strong advocate" for her patients at the end of life because she has cared for many dying patients and, therefore, has a background of experience to compare these patients to. Stephanie believes that patients have better outcomes on her unit *because* the nurses on this unit are strong patient advocates:

"I feel like our patients have better outcomes because we advocate a lot for our patients and we are sometimes really pushing for the things we think are appropriate or the things we don't think are appropriate and need to be addressed. I think that's sort of a blanket statement about everybody that works here. You know, we have a feeling of what's right and we want that for our patients".

Stephanie's remark on nurses having a "feeling" of what is "right" and wanting the "right" care for their patients suggests that these nurses have tacit knowledge about ethical nursing care and, therefore, advocate for care that reflects this approach. Helen, who has been working as an acute care nurse for 25 years, explains that experience has played a role in how she advocates for her patients. She talks about advocating for the upstream integration for palliative care and explains that she has no reservations in initiating conversations with the medical team about "making a shift" from active treatment to palliative care. Despite saying this, Helen does not spontaneously offer examples of how she does this in practice.

Another “little thing” described by participants is setting up the care environment at the end of life. Brenda describes setting up the environment in a way that it is comfortable and inviting for the family so they do not feel rushed or unwelcome in the space. She describes placing chairs around the bed for family members as well as bringing them coffee and tea. When asked if this is something she does often Brenda responds:

“Every time. Every time. Yeah. I do it also for people that are just there for a long time. If there are people coming in I grab all the chairs that I can and place them around because I ask how many people are coming around, I place them all there. I have the hot water kettle there, the supplies, I draw the curtain, and put a bunch of Kleenex in different spots. Because I find if you don’t do that they (the family) feel like they have to leave faster [...] It’s important that when they’re sitting there, they can talk”.

Brenda’s description of setting up the room demonstrates her ability to facilitate a quality bereavement for the family by leaving them with a “peaceful smile”:

“Every family’s different. Let’s say a mother has passed away and all the family comes in, even if it was traumatic and it wasn’t expected – which I’ve had. It was unexpected completely; a patient had a pulmonary aneurysm and it happened in the middle of the night. So, I set up all the chairs and the patient’s family were actually nurses in the hospital. They knew the system already so I didn’t need to talk to them about too many things but I still set up the room and they sat around. And at one point they were, not joking, but they were laughing. They were able to tell stories about their mum. So, leaving them with that, with that peaceful kind of smile. You know, they had time to talk and say goodbye”.

Brenda’s ability to create space for the family to share memories of their mother reinforces her moral identity of seeing patients as people and facilitating a quality bereavement for the family. Brenda tells her own story of being a family member of a dying patient in the intensive care unit

and how, in her experience, she felt as though the healthcare team did not care about her loved one. She explains that the team did not let the family stay at the bedside when her partner was actively dying and the nurse did not do or say anything to comfort the family after he had died. Brenda explains that her own unfortunate experience with death and grief helped her realize her own values as a nurse and guides her current end-of-life practice. Heather, who works on the general unit, also talks about how setting up the environment is an important part of her end-of-life practice. In setting up the environment, Heather will move the patient to a private room whenever possible and place chairs around the patient's bed for friends and family to sit. Heather describes thoughtfully setting up the room so that the patient is accessible to both the family and the nurse. She draws on her past experience as a community nurse caring for dying patients in their homes to guide her current end-of-life care. Heather explains that when families come into the hospital they are seemingly afraid to touch the patient because they are in an unfamiliar environment:

"In the home, people are more comfortable. They know they might die, the family is more involved, people are less scared of death in the community when they go home than when they're here. Here, they don't touch the patient, whereas at home they'll touch the patient, they'll lay with the patient".

Therefore, Heather facilitates the patient and family's experience by encouraging the family to sit close to the patient, hold the patient's hand, and talk to the patient. Heather's gentle encouragement reflects her value to facilitate 'good deaths' for her patients by ensuring that they do not feel alone at the end of life. This value is further reflected in the following quote:

"[I] explain to them (the family), you know, even though he's not conscious you can still touch his hand, talk to him, and stuff like that [...] I just feel like even if you're not responding at that point but your last senses are hearing and touch. I think so. Like, the family can still be there talking to them, comforting them, they'll still know that someone

is there even though they're not responding. I think that would make them (the patient) feel more at peace, you know, at the back of your mind while you're dying. There's someone there talking to you and holding you".

Encouraging the family to engage with the patient, even when the patient is not responding, also allows the family to feel like they accompanied the patient and helped them feel at peace at the end of life. These gestures also reinforce the nurse's relationship with the family.

Participants describe 'being present' as being available both physically and emotionally for patients and their families. It is important to note that all participants include family, without prompting, in their stories of end-of-life care. As previously mentioned in chapter 3, one's personhood is inclusive of all the people who are close to the person, including family, friends, and caregivers. Therefore, caring for family is considered part of 'engaging personhood'. Judy talks about how, in caring for patients, she also cares for the family. She describes going to the funeral of a patient who had died so that she could "be there" for the wife.

"I did go to his service and the wife was very happy. Because the other thing with nursing is that people kind of open their lives to you. They know that you know what their husband went through compared to anyone else that's there [...] I mean, when I was able to be there for her (the wife), it helped her".

This notion of people "opening their lives" to nurses suggests that patients and families are vulnerable and that it is the responsibility of the nurse to ensure that they are cared for holistically. Brenda talks about the importance of being present for the family during their bereavement:

"Give them time, like say 'Do you guys need anything?' and they usually say 'Oh no, it's okay' or they'll just nod and you walk away. But sometimes you let people sit down and you stay in the room for a little bit and you wait a bit. It's an awkward moment when you do that but sometimes people come up to you and ask you about something".

Although Brenda recognizes that silence can be uncomfortable, she explains that by resisting the urge to leave the room and remaining present for the family she shows them that she cares:

“Because even just you being there, like just for a few minutes while they settle down, that moment, it shows that you care. Because I didn’t have that [in] my own experience. I didn’t have that and it felt quite awful. I just felt like no one cared [...] And nurses do care it’s just that sometimes, when you haven’t been on the other side, you don’t realize that these kinds of little things really help”.

Stephanie insightfully remarks: *“It may be as simple as saying that you’re sorry for their loss or maybe just saying nothing”*. This quote suggests that Stephanie feels as though her presence can be meaningful to the family, even in silence. When asked how Kim approaches patients who are at the end of life, she says she does so with her presence. She explains that she does this by intentionally slowing down her movements and making the patient feel that they are her priority:

“Trying not to rush interactions with them and making them know that they are a priority even though I know in the back of my mind I have a billion things to do. And even if I’m only interacting with them for a minute or two I try to make the best of it”.

‘Being present’ is also described by participants as a means of fostering relationships with patients and families. One nurse talks about how the simple gesture of putting a thermometer under the patient’s arm instead of in their mouth helps her get to know her patient as a person and foster the nurse-patient relationship:

“Like, I’ll purposefully put their thermometers under their armpits instead of their mouths so that I can talk to them. Those little things. That’s 2 minutes where you can talk to them. You have that moment to talk to them. Or their blood pressure, you’re holding their hand anyway, because otherwise they move (their arm) so you have that moment. You’re already close enough to hold their hand. That rapport is already beginning”
(Brenda).

This same participant talks about how being present for the family and asking them about the patient after they have died is also important:

“It can be little things. It can be when they’re (the family) in the room you either ask them, depending on who, let’s say their father was a funny guy, you ask them to tell you a funny story about them. And somebody will pipe up and they’ll start laughing. And it’s just that little – they’ll cry right after and it’s fine – but it’s just that little moment where they’re like ‘Oh I remember that’ and you encourage them to speak about that”.

This quote highlights two important ideas. In one regard, the participant is encouraging the family to talk about their loved one to cultivate a good experience for the family. However, I also interpret this gesture (asking the family to tell a story about the patient) as an opportunity for the nurse to come to know her patient in a new light. Moments like this help the nurse know her patient on a deeper level through the family’s narratives, which reinforces her own relationship with the patient. The nurse’s desire to know her patient – even after death – reflects an inclination toward personal care and connections. Another participant, Lauren describes being present for a patient who was dying by listening when he talked about death and dying. Lauren, describes how her physical presence at the bedside helped this patient “feel safe” when he was having episodes of dyspnea, which reflects trust in the nurse-patient relationship. Another way nurses’ stories reveal that patients trust them is in their interpretation of patients choosing to die when the nurse is in the room. Both Helen and Kim talk about how patients seemingly choose the moment they die. That, often times, patients die when the family has stepped out for a moment. If patients have control over the timing of their own death, then Helen perceives ‘being there’ when a patient dies as a privilege:

“Somebody said, ‘Wow, how do you deal with that (being present when a patient dies)?’ And you know, I look at it as a privilege to be there. That somebody actually wants you there. Because, you know, there are families that come and sit and wait and wait, and you

can tell – you can hear it and you can see it, they get mottled, and their heart rate stretches out. But some patients are bound and determined that they don't want their families to see them die. And the family leaves the room for a second and that's when the patient dies. And how many times that has happened”.

Helen offers insight into the nature of the nurse-patient relationship. In describing the agency of a patient at the very end of life, she highlights the value of mutual respect and the reciprocal nature of the nurse-patient relationship, even when patients are no longer conscious.

Lastly, participants describe doing “little things” as a means of including the patient and family in end-of-life care and decision-making. For instance, Brenda describes teaching the family how to re-positioning their loved one and to provide mouth care. She further includes them in detecting signs that the patient may be uncomfortable:

“It's not just about doing mouth care or fluffing the pillow, you can teach the family, like, these are the signs that he's uncomfortable, if I'm not around please ring the bell and I'll give him medication and I'll let you know what I'm giving. At least get them involved, give them some control. You can build a relationship with the family by teaching them things”.

Recall earlier when Heather describes families as being “scared” to touch the patient. The seemingly little gestures described by Brenda can empower family members and reinforce their importance at the bedside as well as their sense of purpose in their loved one's end-of-life experience. As Brenda remarks at the end of the quote, by including the family in the care this also fosters the nurses' relationship with the family. Stephanie describes the importance of including patients in end-of-life care decision as a means of ensuring a ‘good death’. She describes fostering a “collaborative” relationship with a terminally-ill patient who was on her unit for several weeks by checking with the patient to make sure the goals of the healthcare team reflected his own end-of-life needs. She states:

“After being here for a while, he (the patient) had a great deal of trust in us and what we were trying to do and what our goals are and recognized that our goals were in line with what he wanted. And if there was something he wasn’t sure about, we would talk to him or find someone that could talk to him, and so it was a lot of collaborative effort [and] involving him heavily in our team”.

The participant’s use of the words “trust”, “collaborative”, and “team” highlights the possibility for relational care experiences in acute care that consist of reciprocity between the nurse and the patient.

It is evident in nurses’ stories about “little things” that engaging personhood consists of making the patient feel human (which aligns with values of seeing patients as people and advocating for patients), setting up the care environment (which facilitates a ‘good death’ for the patient and a quality bereavement for the family), being present through physical touch, emotional support, and silence (which helps foster the nurse’s relationship with patients and families), and lastly, including the patient and family in decision-making and end-of-life care (which can empower the patient and their family and foster good end-of-life experiences). The link between these so-called little things and participants’ values highlights that ‘engaging personhood’ is a reflection of these nurses’ moral identity.

Nursing “With Blinders On”

This leads to the second theme which, despite participants having moral identities that center on treating patients-as-persons, they also describe having to intentionally put on metaphorical blinders in order to make it through their shift without “drowning”. Nurses’ stories reveal that they struggle to engage personhood at the end of life because of the “big overarching ominous schedule” of acute care. Although the concept of personhood is not explicitly mentioned by participants, as discussed above, they repeatedly mention the importance of making patients feel “human” while in their care. They also talk about patients’ families as

extensions of the patient, which demonstrates an understanding of the significance of these personal relationships. Unfortunately, participants also talk about how their ability to care for patients-as-persons is constrained by the care environment. Participants describe feeling like they have to wear metaphorical “blindness” in order to accomplish all the tasks laid out in the schedule, in order to not be distracted by personhood.

When asked to describe ‘a day in the life of an acute care nurse’, participants use words like “busy” and “out of control”. Almost all of the participants mention having to prioritize their care based on patient acuity where “really sick” patients require most of their time. According to the participants, the term “really sick” is used to reference patients who are acutely ill (*“It could be a respiratory patient, afib (atrial fibrillation) uncontrolled, [...] low blood pressure, heart rate of 170”*) which represents a biomedical perspective on the term ‘sick’. Participants explain that their shifts are divided into fixed times for specific tasks (e.g. medication administration, vital signs, and dressing changes) that are measurable and easy to document in charts and flowsheets. One nurse explains that if, by the end of her shift, she has given all of her medication on time then she feels like she has done her job. The concept of time comes up frequently in the interviews. Participants speak of organizing their shifts around fixed time points like physical assessments, vital signs and medication administration, as well not being able to spend equal amounts of time with each of their patients – especially if one of their patients is “really sick” and requires more attention. In the following quote, Lauren describes a sense of obligation to maintain the abovementioned ‘acute care schedule’ and manage her time accordingly. It is interesting to note the tense language that she uses (e.g. rigid and stressful) in describing her attempts to maintain the schedule of her unit:

“I would say there is very much a big fixation on milestones of the day. Like what time meds are, what time assessments are, when are discharge rounds going to happen, and when are the people that I need – i.e. usually the residents! – going to be around so I can

find them and make sure things happen. So, I think that there are a lot of fixed time points, mostly around meds and vital signs and some assessments that feel very rigid and when you get around them and you're not meeting those time points it can be very stressful. And then there's sort of stuff that feels like it's less of a priority, like maybe a patient's hygiene care – and sometimes that gets written off completely depending on the day [...] but I think that big overarching ominous schedule still sort of happens and all the wheels still turn. And like sometimes things are pushed back and they are late, so to speak, but I feel a lot of pressure in order to not have it go that way. It feels like if things are on time then I've done my job and anything that happens then it's not my fault".

Lauren's description of "fixed time points" and "rigid" schedules reinforces the discourse that acute care nurses do not have time to engage with personhood. Lauren critically reflects, however, that this approach to patient care is more "narrow" than what nurses are supposed to provide:

"[It] sounds like such a narrow view of how to provide care but it's just sort of the way things work and it's the easiest way to manage the fact that you have hundreds of tasks to complete in a day and all of them need to be done".

This acknowledgement – that something is lost in a task-focused approach to acute care nursing – is echoed, and then justified, by Stephanie who states: *"It (task-based care) sounds kind of cold but it's really the only way you can make it through your day and not be, like, crying at the end of the day"*. Although participants acknowledge that a task-based approach to care represents a "narrow view" and may be perceived as "cold" by patients and their families, they justify using this approach to care because it is the only way to make it through the shift. The following quote demonstrates a disconnect between the type of care Stephanie wants to give to her patients and the type of care she feels forced to deliver due to time constraints. Note that in this quote, 'Mary'

is not a real person, but rather a symbol for all of the patients neglected when nurses are unable to respond to the emotional dimensions of their patients' experiences.

“Like, obviously I understand that there is an emotional component (to end-of-life care) and some people need a bit of a hand hold and that’s totally fine. But for the most [...] everything else you do is so laid out in terms of times, like you have medication to give at these times, you have dressings to do at these times, it falls into – Okay you have straight morphine so I have to check your [pump] every four hours or I have to make sure you’re wearing your oxygen and I have to do all these things so it becomes more task-oriented. Rather than, like, oh I’d actually like to go sit with ‘Mary’ for a while and make sure she’s doing okay. Instead, it’s like at 8 o’clock I have this, at 10 o’clock I have this, at 12 o’clock I have this, and I just have to keep moving through my day”.

She goes on to explain that she feels forced to put on metaphorical blinders in order to make it through her shift:

“I just find in acute care nursing everything you do is so time- and task-based that if you don’t want to be drowning by the middle of the day you need to keep your blinders on and focus on what you’re doing at those times as much as you can. Scratch things off as you go. And your poor little palliative Mary just gets scratched off that list as well”.

When Stephanie refers to keeping her “blinders on” to focus on specific tasks, she is describing herself as actively avoiding aspects of care that address the person (e.g. emotional and existential needs).

The metaphor of “drowning” and “keeping your head above water” is used by several participants. Occasionally it is used as a figure of speech (e.g. *“You don’t want to leave anyone to feel like they’re drowning or anything”*), but most of the time participants use ‘drowning’ as a metaphor to emphasize the immensity of their workload as well as the pressure they feel to juggle multiple care responsibilities at the same time: *“Sometimes you just feel like you can’t*

keep your head above water and that you're not giving the quality of care that you're capable of and that you'd want to because you just can't" (Kim). This quote also demonstrates tension between the quality of care participants want to give and the care they feel pressured to deliver due to the pace of the unit. Participants also use the drowning metaphor to justify being more task-based in their care and not having enough time to address the emotional needs of their patients. In other words, these nurses' metaphorical survival is at stake.

In contrast to the first theme where engaging personhood was realized through "little things" that reflect the participants' values, here participants have to make an active effort to *avoid* engaging personhood by putting on blinders in order to keep from drowning in their workload. For instance, Judy describes how she avoids sensitive conversations, particularly around emotional suffering and end-of-life issues, due to the perceived busyness of the unit. Sensitive conversations are important opportunities to engage personhood at the end of life. However, Judy feels that she must avoid these conversations out of fear of being pulled away to do something else which, to her, is worse than not engaging in the first place:

"I'm worried that they (the patient) will feel that I don't think it's important. You know saying like 'Oh sorry I have to go'. You know, because some people are okay to sit there and chat but I'm not. You know, if my other (patient) bell is ringing and nobody's going to get it then I have to go get it. You know, I've talked to patients about what to expect (at the end-of-life) and that. But for me, if you open it but then kind of abruptly close it... it's like the 'typical doctor', you know, it's not fair. So that's why I don't bring it up" (Judy).

Judy understands that dying patients are vulnerable and that sensitive conversations can expose their vulnerability. Therefore, she recognizes that it is unfair to expose a person's vulnerability without having the time to stay with the patient and be present with them. In essence, Judy recognizes that engaging personhood is so important that she refuses to put herself and her

patient in a situation where it may not be done well. It is significant that Judy is able to reflect on how the busyness of her unit influences her end-of-life care as well as recognize what is at stake for these patients.

Acute care units are known to be busy and demanding, which has led to a discourse of acute care nurses feeling as though they do not have the time or resources to adequately care for patients at the end of life. Although participants' stories reveal that they feel forced to put on blinders in order to accomplish the "hundreds of tasks to complete in a day", they are also critically reflective of this type of care and the implications it has for patients and their families.

Being "Less Distracted by Nursing *While Nursing*"

Although participants describe the need to put on metaphorical blinders in order to accomplish the tasks laid out in the "ominous schedule" of acute care, their stories also reveal ways in which they are able to use these same tasks as opportunities to "get to know" their patients and promote their humanness. For instance, Brenda describes using hygiene care as a chance to genuinely talk to her patients: *"I try to talk about whatever they want, whatever their interests are just to make them feel a bit more human and less of a patient"*. Kim similarly describes using tasks as opportunities to enhance the patient's experience in hospital:

"Yeah I mean when I'm doing tasks that I have to do you're definitely making conversation at the same time and then if you happen to have extra time you spend that time just chatting with your patient because you know, most patients don't want to be in the hospital so you want to make it as pleasant as possible".

Another participant talks about using hygiene care as an opportunity to do "a bit of pampering" and provide "TLC" to dying patients. She describes spending extra time to wash and cut patients' hair to help them forget, even if temporarily, about why they are in the hospital. She also remarks on how the haircut helps to "lift the load" physically and metaphorically, describing the weight

felt by someone who is processing their end of life. As quoted earlier, in checking a patient's temperature, Brenda purposefully chooses to put the thermometer under the patient's arm instead of in their mouth so that they can have those two minutes to talk to each other. Lauren echoes this idea of engaging personhood during tasks while also describing the need to be comfortable with "hard skills" in order to do this:

"[Engaging personhood] just kind of creeps in when you're changing someone's bed or asking them how they slept when you're taking their blood pressure. Like I never go into a room and just sit down and talk to someone [...] you have to build it in with everything else. So, to that extent you have to be really good with your hard skills. Things like medications and dressings, because once you're comfortable with that then you have the time and space to do the rest".

Given the above theme on *Nursing "with blinders on"*, wherein acute care nurses have to actively put on metaphorical blinders in order to avoid engaging personhood, a counter-narrative of *being "less distracted by nursing while nursing"* was revealed. Participants describe opportunities to use tasks as a means of engaging with their patients. This depends, in part, on experience. According to participants, once they have gained enough experience to be comfortable with their technical skills (e.g. medication administration and dressing changes) then they sometimes use these tasks as opportunities to engage with their patients. The difference between these two approaches is intentionality; as a new nurse, the intention lies in performing the task safely and effectively, whereas nurses who are comfortable with their technical skills perform their tasks while simultaneously 'seeing' the patient as a person. Several participants talk about the role of experience and how, as a new nurse, care tends to be more task-oriented until they become comfortable with their technical skills. Kelly, a nurse with 12 years of experience, similarly describes the role of experience and the tendency of newer nurses to be more task-oriented in their approaches:

“[A] lot of us, especially for the newer nurses, are task-oriented and they don’t necessarily see the whole picture. If they haven’t been exposed to a lot of deaths – Like, they’re task-oriented, like, I need to do your dressing, I need to get you up. Like, the patient’s not breathing well, is this really a good time to get up?”.

Lauren goes on to explain that experience has made it easier to “get to know” her patients without compromising the task at hand:

“Yeah I’m considerably less distracted by nursing while nursing. Like, I don’t think that I have magical therapeutic relationships with my patients, but I now (after one year of working as a nurse) actually feel like I have time to get to know them and know what’s going on with their life while they’re in hospital and not feel that I’m somehow skipping out on charting or what else is waiting for me in another room”.

Lauren explains that it took her at least one year of working in acute care to be confident in her hard skills and be “less distracted by nursing while nursing”. This notion of being distracted by nursing while nursing demonstrates the ethical tension between being a ‘good’ acute care practitioner while upholding the values that reflect one’s wider nursing identity. This ethical tension is further explained by Helen when she describes “the acute care nurse” as merely one layer of her nursing identity that she can then “shed” once she is caring for a patient at the end of life.

“There’s a whole other role that happens (in providing end-of-life care). I want to call it the caregiver. I feel like there’s the acute care nurse and then I get to shed all of that stuff. The things I thought when I was a new nurse or becoming a nurse – the be all the end all were doing vital signs and giving meds – oh If I could just get rid of that stuff now. If I could just nurse and not chart. Oh my word, what a great day that would be! When you no longer have those things, you know, the busy work of nursing, when you no longer have those things then you focus on the things that are purely comfort”.

Helen's description of shedding the acute care nurse and focusing on providing comfort care reflects what she feels is important in nursing. It is clear in this passage that what Helen values is being a caregiver, a role that is thwarted by what she calls the "busy work of nursing" (e.g. charting, vital signs, giving meds).

This counter-narrative challenges the overly simplistic discourse of acute care nurses not having enough time to engage personhood at the end of life and reveals the complex nature of being an acute care nurse. Despite sometimes feeling forced to put on blinders in order to 'survive' their shift, in telling their stories about end-of-life care, participants also demonstrate the creative ways they use scheduled tasks as opportunities to help patients feel "*a bit more human and less of a patient*" (Brenda).

Suffering as a "Dark, Emotional, Twisty Thing"

Recall from chapter 3 that suffering is a deeply personal, subjective emotion experienced by persons (Carnevale, 2009). Suffering is an important dimension of end-of-life experience, therefore, an account of how nurses engage personhood in end-of-life care benefits from explicit consideration of how these nurses understand and engage suffering. Also, recall that nurses' experience with patients who were thought to be suffering at the end of life was an explicit focus of the interviews. Therefore, in this section I analyze how nurses engage with patients who are thought to be suffering at the end of life. In telling their stories, participants demonstrate that they have rich and sophisticated insights into the notion of suffering that transcends suffering as merely physical.

When asked what suffering means to them, participants described a dichotomy between physical and emotional suffering, referring to suffering as "*a dual thing*". However, in telling their stories, participants veer away from this dichotomization to reveal a deeper understanding of suffering as a complex emotion that can emerge at the end of life. According to participants, "obvious" views of suffering are described in terms of bodily symptoms:

“Broadly, I would say that there is obviously bodily suffering that, in a place like a hospital, like you can think of things like pain and nausea and shortness of breath and all of the bodily symptoms [...] That’s like quite obvious and I think that a lot of the time when we talk about people suffering, that’s what we talk about the most [...] the bodily suffering. Like, the displeasure of being in one’s own body when they’re either sick or at the end of life” (Lauren).

“And then obviously there’s physical suffering. Like completely dyspneic and respiratory distress and having pain crises and that kind of thing. That’s like an obvious vision of suffering” (Stephanie).

Participants also talk about how bodily suffering seems more tangible because it fits into the aforementioned schedule of acute care:

“There’s suffering like pain, which is created by surgery. And I feel like that is more tangible, we can really put it on a scale for most patients [...] from 0 to 10” (Helen).

“[Bodily suffering] fits very nicely into our schedule and, like, we have all this charting with boxes and numbers and things given on time. You can be like ‘Patient in pain, Morphine sub-cue given every 2 hours’. It just seems easy to, not to say we always fix it, but it’s easy to make it look like we’ve fixed it or we’ve done something” (Lauren).

Lauren’s reflection relates to the earlier theme of *nursing “with blinders on”*, wherein participants describe focusing on nursing tasks that are measurable and easy to document. According to participants, suffering related to somatic pain and other symptoms is easily treated and documented and, thus, aligns well with the schedule of their unit. When asked to describe suffering, most of the participants give examples of patients who experience difficulty breathing as well as the mental agitation that accompanies this difficulty.

Participants describe a “broader” view of suffering as *“people that are struggling with coming to the end of their life [and] having to contemplate their own death” (Lauren)*. Under the

notion of broader suffering, participants use words like emotional pain, emotional suffering, mental suffering, emotional turmoil and distress. One participant describes broader suffering as an “existential something” in describing a patient who talked about what it means to die young as well as his fear of being a burden on his family. Another participant describes emotional pain as patients who feel “powerless” and “helpless” at the end of life. She explains that this view of suffering is seen in dying patients because *“some people aren’t ready to go. They have stuff to do or felt they’d been [cheated]”* (Judy). The idea of ‘not being ready to die’ is mentioned by almost all of the participants. When asked about suffering, Stephanie describes the emotional turmoil experienced by patients who are not ready to die:

“Patients who are in emotional distress about their situation and, obviously worried about dying and worried about their families being left. There’s that emotional turmoil that they are going through. So, it’s not even necessarily a physical agony or dyspnea or anything like that but it’s their state of mind about like ‘I’m not ready. I’m not ready’ [...] Like, coming to grips with the fact that [the end-of-life is] inevitable”.

Kelly describes what she calls “emotional suffering” as patients who are *“not ready or they don’t know what to expect [at the end of life] so it’s fear and anxiety towards that”*. Lauren talks about a patient who told her he was not ready to die because he had too many things to organize in his estate. This is the same patient who expressed fear of being a burden on his family:

“I didn’t really hang around his family enough to know exactly what their relationship was like but I do know that he had a huge fear of being a burden. That was something that he talked about a lot so I wouldn’t have been surprised if he was reluctant to reveal himself in a vulnerable fashion to people out of fear of putting a big emotional burden on them”.

This quote demonstrates how suffering can be an isolating experience for patients and aligns with McPherson et al.’s (2007) research on self-perceived burden (chapter 3). This article

revealed that dying patients express reluctance to discuss their feelings with others because they are concerned that self-disclosure of distress will create further burden on their family and caregivers. Lauren acknowledges this potential for loneliness by explaining that nurses have a responsibility to ‘take on’ some of the emotional concerns of their patients:

“Which, like, reinforces my belief that healthcare professionals need to be open to that (the emotional concerns of patients) even if they’re not sitting down and having long conversations to that end because there are things – there’s that idea that if someone (the nurse) is coming into your space with a certain degree of power over you (the patient) then they should be trusted to be able to take back some of your own emotional concerns. I feel like, in that respect, [the nurse has] an obligation to allow for people’s dark emotional, twisty things to be shared with [them]”.

Lauren’s reflection sheds light on the complex nature of the nurse-patient relationship, especially at the end of life. In one respect, her previous quote *“I didn’t really hang around his family enough...”* demonstrates a lack of engagement by not knowing much about the patient’s relationship with his family. However, she also describes a sense of responsibility in addressing the emotional needs of dying patients.

Brenda talks about the *“many different complex things that [patients are] suffering though”* and describes factors associated with being in hospital that may contribute to patient suffering:

“[...] Whether you’re not able to sleep, you have to deal with a stranger taking care of you that you might not like, you might not like the medications even if the pain medication might help but they don’t make you feel right, or you have to get up in the morning and wash even if you’re tired. There are so many different degrees (of suffering) in that whole process of being hospitalized”.

Several participants mention how the compounding factors of being in the hospital *while* dying can cause people to suffer due to a perceived loss of control. Brenda explains that she knows what it's like to be a family member of a patient dying in hospital and explains that *"the person laying in the bed or sitting next to the bed has no control"*.

In addition to this broader suffering, participants talk about specific emotions that they witness in patients at the end of life that indicate suffering. Heather and Stephanie talk about patients who experience loneliness and guilt and give examples of patients who are terminally-ill and estranged from their families. When asked to talk about patients that she felt were suffering at the end of life, Judy reflects on two specific patients that she felt were "angry" because they were both *"short with their wives"*. Stephanie describes one of her patients who was terminally-ill as "angry" and "disrespectful" towards nurses and doctors because *"it's the one thing he could control [...] the way that he treated people and that's what he was clinging to"*. Other participants describe patients that were "afraid to die" and feared becoming emotional and financial burdens on their families. Some of the participants spoke of their own emotions with regards to experiences of caring for patients who were suffering at the end of life. For instance, Lauren expresses feeling distressed when she was unable to make her patient comfortable when he died. Another participant describes *feeling* the family's suffering after their loved one had died. Judy, in an effort to imagine how a suffering patient may be feeling, draws on her past experience of recovering in the hospital after a miscarriage.

"You've got the incision like you had your surgery, you've got the epidural like you've had your surgery, you're in the unit with people that have had their surgeries, and then you're having to go home. Like having to go through feeling... Well, I don't know how they're feeling. I just remember when I miscarried, it must be very similar. It's like, what the hell am I doing here?".

Judy reflects on how a patient who is dying may feel ‘out of place’ on an acute care unit – a setting where most patients are expected to recover and go home.

In talking about suffering, all of the participants mention ways in which the family also suffers. This consideration for the family’s emotions demonstrates recognition of the importance of relationships in connection to the person. For instance, Judy remarks that in developing a relationship with her patient she is also able to help the family:

“Yeah and I definitely think the longer you’re with them, in acute care, the more likely they’re going to open up [and you] develop relationships with the family so that you can help the patient or help the wife. Sometimes what will happen is it’s not just the patient that’s suffering it’s the significant others as well. We’re often there for them as well”.

Participants relate family suffering to the anticipated loss of a loved one as well as worrying about a loved one being in the care of others. Brenda specifically talks about how families can suffer from a perceived lack of control. She explains that family members may not feel comfortable in the hospital because they are worried about being in the way or causing the patient to become fatigued:

“I just find they (family members) all kind of suffer a little bit. And as nice as you can be, there’s still a degree of it because you find you don’t have control. You come in and you don’t have full access to your family’s information, [...] you don’t stay too long because you don’t want to make them too tired [...] and you can’t stay as long as you’d like to. I just find mentally the family suffers also”.

Although their unit has a 24-hour visiting policy for family, Brenda explains that the busyness of acute care can cause families to feel unwelcome, especially once their loved one has died. When families feel unwanted and unsupported in the care environment they are less likely to stay with the patient after they have died, which can ultimately leave them with a negative memory of their

family member's end-of-life experience. Helen talks about becoming attached to patients and their families and being able to feel the family's suffering when the patient dies:

"You can get very attached. I know that there were at least one or two that I was very attached to. It was hard. I think it was hardest because of the reaction of the family [...] You know, you feel their suffering at that time. The family's suffering and what they've lost, and how they're going to go forward, and manage, and know that you're not going to see them".

This reflection sheds light on the power of relationships and that, in caring for the patient, the nurse also cares for the family as an extension of the person. This idea aligns with using personhood as an ethical lens (chapter 2), wherein nurses who care for persons are also caring for those who are important to the person.

Researchers that situate themselves in a constructivist worldview recognize participants as having unique experiences, thus, data analysis is not merely about generalizing the findings but highlighting unique experiences. Therefore, it is important to mention that Lauren is the only participant to describe "another type of suffering" as taking place when patients do not realize they are dying. In describing this other type of suffering, Lauren distinguishes between patient and nurse suffering without fully separating them, implying that she does not see them as disconnected. Although this point of nurse and patient suffering as interconnected is very interesting, it is only mentioned by this one participant:

"Then there's another type of suffering, which I find like the worst, bizarrely, to witness is when people don't realize they're dying. And I don't know if that's more nurse suffering than patient suffering. I find it hard to know that people would want things differently if they realized the state that their health was in. Whether it be not pursuing aggressive treatment or spending more time with their family or whatever. It's just, that's something that just seems unjust at a higher level".

Lauren's reflection on nurse and patient suffering being interconnected resonates with Carnevale's (2009) work on suffering. According to Carnevale (2009), bodily symptoms can signal thoughts and fears about the uncontrollability of disease and its potentially imminent threat to the person's life and, therefore, contribute to broader suffering. It is possible that nurses who witness bodily suffering in patients, such as dyspnea and the agitation that often accompanies it, are also confronted with their own thoughts about death and dying.

"I Don't Think I'm Ever Really Going to Get it Right"

Participants' stories reveal in-depth knowledge about the complexities of suffering at the end of life. However, participants also express uncertainty in their knowledge and ability to address suffering in practice, which leads to the fifth theme "*I don't think I'm ever really going to get it right*". That is, there is a lack of clarity that exists between participants' knowledge of suffering and their perceived ability to address suffering in practice.

The following theme explores participants' uncertainty in addressing end-of-life issues in practice with a specific focus on suffering. Despite having knowledge of varying views of suffering, participants acknowledge that the abovementioned broader suffering (that cannot be "fixed" with medication) is more difficult to address. Lauren describes broader suffering as "*sticky and difficult*" and hard to grasp. She explains that broader suffering is not only complex but it "*doesn't fall in nicely to the way we like to chart*". Throughout their stories, participants will say things like, "*I don't think I'm ever really going to get it right*" when describing how they address suffering in practice. Participants' stories are riddled with contradictions between what they know about suffering and the uncertainties they express in how to address it in practice. Take the following quote, in which Kim describes feeling insecure about the ways in which she approaches family members at the end of life, followed immediately by a thoughtful portrayal of her own engagement:

“I don’t think I’m ever really going to get it right but being present there. And taking cues like when they want their privacy, to be close to their loved one, or when they just want somebody there. A lot of the times family members like to talk about their history with their loved one and who they are and share some of those memories. Yeah”.

Despite feeling uncertain in her ability to care for the family of a dying patient, Kim here describes the importance of presence and knowing what family members need at this time (i.e. talking and sharing stories about their loved one). Another example of this knowing-not knowing in addressing suffering is when Brenda initially talks about how she does not have the knowledge to address suffering at the end of life, despite showing otherwise in a later quote.

“Me, personally, I don’t find I have enough knowledge in how to deal with that. Like, suffering at the end-of-life is a lot different. There’s no, like, there are so many different aspects to it. Like, what if you have no hope at the end, you have to deal with those five steps of grieving. Whether it’s that person or the family, and again you have to deal with their pain, how’s it going to go? How’s it going to last? You know?”

Furthermore, when asked if she finds it challenging to approach patients who may be experiencing this broader vision of suffering, she says: *“Yeah, definitely. Definitely because they look to you for answers. And you don’t have them”*. But, in contrast to the doubt elicited in her words above, Brenda later provides an example of how she *does* engage with patients who may be suffering emotionally by talking to the patient, taking the time to sit and be present with them, and helping them to set goals:

“First of all, you have to go and talk to that patient. Yeah so basically, if you think someone is suffering emotionally, the best thing to do is come into the room when it is an appropriate time. First of all, you knock on the door because you don’t want to just walk in. If they’re already feeling bad they may have already put up a wall so you knock on the door and say ‘Oh hi is it okay if I come in for a minute?’ And maybe before you even talk

about anything you pull the curtain, you ask, you don't want to say what's wrong, but you want to provoke them to talk. Usually it's open-ended questions, you want to be at eye level so you can either sit on the bed or maybe you bring a chair up next to them. Ask them 'do you have a few minutes?', and then you let them – again, sometimes it's just silence. You don't really know why they're emotionally stressed or how you can help them. You may not be able to get rid of all of it because if it's end-of-life, they may be suffering because of that. Well, you can't take it all away but you can ease some of it. You know, focus their attention somewhere else. Even if it's the end of life, you can still set goals for yourself'.

Similarly, Kelly talks about not knowing how to address family suffering when a patient is dying (“I don't feel like I really know what to say”) despite later describing how she addresses family suffering by turning their attention away from the monitors towards the patient:

“If they're on 100% [oxygen] there is no more oxygen I can give them, so why don't we stop looking at the numbers. Let's look at the patient. Are they comfortable? Like, trying to guide the families. Especially, our respirology population, they're so focused on the numbers. They've had these chronic diseases they have their own little monitors. Let's take that monitor away. The number doesn't matter, what matters is how they feel”.

Despite her insecurity in not knowing what to say, Kelly demonstrates that she does have knowledge to help the family to be with the person behind the technology. Other participants express similar insecurities. For instance, Stephanie worries about causing harm to her patients through engagement:

“I think it's a matter of – Am I going to say the right thing? Am I going to upset you more? There's no real way to convey how I feel to you. I probably don't know how you're feeling. It's almost like a socially awkward thing. Like I don't want to make things worse

and I don't know really how to talk to you and you're already upset and what can I say that can possibly make this a more tolerable time?"

Stephanie's uncertainty and fear of saying the wrong thing is echoed by several participants. Kelly explains that, although conversations about the end of life – including the suffering that accompanies it – are not easy for her, she pulls on past experiences to guide her care and know what to expect. Participants also refer to consulting spiritual and palliative care because *"they've had more experience with these situations than we have"*. Of course, this deferral to the expertise of others raises an interesting question: Do palliative care clinicians have more knowledge about death and dying or are they merely more comfortable with the ambiguity that often accompanies the end of life? Regardless, participants express needing support to address patient suffering. Brenda, for example, mentions the importance of having mentors – “the older nurses” – to teach new nurses how to approach suffering. In contrast, two other participants talk about how knowing how to address suffering is more of a “personality thing”. According to Stephanie, who has been working in acute care for 9 years, there are certain nurses who can put people at ease, regardless of their experience:

"Like, I don't know what to say to you, like, I'm sorry for your loss but I don't know what to do. But there are some nurses that we work with who are just these warm, fuzzy angels that can make people feel at ease and get them through it and all that stuff. And can just kind of 'smooth it all out' [...] I honestly think it's more of a personality thing. Because there are nurses who have worked here for thirty years that couldn't calm down the calmest of patients. But there are brand new nurses who can talk to a patient or family member and make them feel at ease and make them see that this is not the end, it's totally normal to feel this way, and like everything is going to be okay. But I find, myself, I'm much better in a crisis. I can keep my hat on a swivel when shit is hitting the fan, but the

second there is like a very emotional, tense situation – I don't really know what to do, I don't know what to say".

It is important to note, that when Stephanie describes being “better in a crisis” than addressing emotional situations at the end of life, it seems that she does not equate a “very emotional, tense situation” as a crisis. Kim similarly describes certain nurses as being “*much better with family members and dealing with grief*” than she is. She goes on to explain that her insecurities come from being afraid of saying the wrong thing to grieving family members:

“I think part of it is I'm afraid to say the wrong thing so I just don't say much at all.

Whereas those nurses tend to like get right in there and they just seem to know what to say. Sometimes it's just like a hand on their shoulder, but I'm not really a touchy-feely kind of person with strangers so if it doesn't feel real to me then I'm not going to force it or fake it”.

Kim's fear of saying the wrong thing aligns with the literature review in chapter 2 wherein nurses were reluctant to approach suffering out of fear of not knowing what to say or how to ‘fix it’. It is interesting to note, however, that Brenda is one of the only participants to acknowledge that nurses do not have to “get rid of suffering” but, rather, nurses can “ease some of it”. This is supported by Kim who also acknowledges that when a person is suffering: “*Sometimes you don't want someone to fix things you just want someone to listen*”. Participants also acknowledge that this type of care requires an emotional investment by the nurse which can make them feel vulnerable. When Lauren talks about the nurse's responsibility to “take back” some of their patients' emotional suffering, she also acknowledges that addressing this broader view of suffering can “anchor (the nurse) too much”. Judy describes her tendency to become emotionally involved with her patients as her “*downfall in nursing [because] once she's in, she's in*”. Therefore, she avoids sensitive conversations out of fear of making herself vulnerable.

Helen, who has 25 years of experience working in acute care, states that once she has established a good relationship with the patient, then she is comfortable addressing their suffering. It is important to note, that Helen is the only participant who did not express uncertainty in addressing suffering in practice. Helen describes suffering as “other” pain that persists despite the nurse trying everything to help the patient feel better (*“I’ve bent over backwards and upside down to help but yet we haven’t made any progress in 0-10”*). She explains:

“I have to have a rapport with the patient then I approach it by saying, ‘I can see by your face that you have pain. I understand that you have pain which is created by surgery but I also see that you have other types of pain. Pain that may be affecting your emotional well-being or how you feel about things. You’re not being overt about telling me when you don’t like something or if something’s not going the way you think or the fact that your chin is quivering or you haven’t smiled all day’”.

Helen does explain, however, that she finds it challenging to address suffering when the patient is not ready to talk about it:

“I find that it’s very hard to delve into that (emotional pain) with a patient. A) because sometimes they don’t want to, and b) because they don’t even acknowledge it themselves, they don’t understand what their pain is. You know, they’ve been putting it on the backburner for so long that they learn to not acknowledge their own emotions” (Helen).

Judy similarly describes patients who come to her unit after surgery only to find out that their disease is terminal as being “too acute” to talk about their suffering. That is, Judy believes these patients have not had time to process what is happening to them. Judy draws on personal experience to inform her understanding of how patients may be feeling in this situation:

“I don’t know if it’s because it’s acute, you know, and it’s too early and they’re still recovering. You know ‘cause they’re still working to recover. I know for me, and I know

it's totally different but somewhat similar, when I miscarried I was sick with low blood pressure and so I was busy dealing with that and my husband was really upset so I was consoling him. But it wasn't until after I felt better that then I was upset. You know what I mean? Because my body was too busy physically healing that I didn't even think about it".

Despite demonstrating rich insight on a range of different views of suffering (as discussed in the previous theme), almost all of the participants express uncertainty in how to address suffering in practice. The disconnect in knowledge and practice represents a point of tension for acute care nurses and their ability to engage suffering at the end of life.

“The Things we do to Patients Here are not Nice”

As previously mentioned in my introduction of the ‘rope’ metaphor, when nurses are constantly being pulled in opposite directions their moral integrity risks becoming unraveled. Participants’ stories reveal points of tension when they continue to perform invasive treatments to patients they feel ought to be receiving end-of-life care instead. Although participants are oriented towards seeing patients-as-people, as evident in the first theme *engaging personhood through “little things”*, they also actively participate in subjecting patients to painful interventions that are considered “not nice”. Situations in which participants feel conflicted about the type of care they are delivering to patients at the end of life are evident in several of their stories. As previously mentioned in chapter 3, moral distress occurs when a nurse is unable to act in a way that reflects their moral identity. That is, when there is an inconsistency between one’s beliefs and one’s actions. The following quote by Kim provides insight into how the acute care environment constrains her ability to give the quality of care that she feels she ought to be providing:

“Challenges, there are always challenges. Time itself is a challenge. Equipment or lack thereof. Sometimes the pace, it’s just hard to keep up. Sometimes you just feel like you can’t keep your head above water and that you’re not giving the quality of care that you’re capable of and that you’d want to because you just can’t”.

Helen describes being unable to “shed” the role of the acute care nurse, as she described in the theme *being “less distracted by nursing while nursing”*, until palliative care has been consulted for the patient by the medical team. When asked how the acute care environment influences her end-of-life care, she reflects:

“It does affect it because until we have decided that a patient is going to move into that comfort zone – that full-on dignity zone – we can’t move there completely until that category status has been decided. If they’re still a category two, they’re not at that point where you can make them completely comfortable. You know, I’m still poking them for something, I’m still sticking oxygen in their nose, I’m still doing things. When I continue to do things then I don’t think we can make that shift completely. But sometimes the argument then is – we need to make that shift”.

Helen’s description of being unable to provide dignified care to a patient – whom she believes should be receiving comfort care – until it has been decided by the medical team is an example of constrained moral agency. Helen goes on to say that situations like this have caused her to feel “distressed” and ask herself ethical questions such as, *“Why have we done this to this patient?”* and *“Why are we continuing to do this to this patient?”*. When asked to elaborate on what she means by being unable to make patients completely comfortable, she explains:

“The things we do to patients here are not nice. Like, I would say that 98% of the things we do here are not nice, they don’t give you a warm fuzzy (feeling) to have an IV or a rectal tube”.

Over time, performing procedures that are in direct opposition to the type of care Helen feels she ought to be providing to patients nearing the end of life may cause her to eventually ‘unravel’.

Brenda describes a situation where the family of a dying patient was completely inconsolable causing her to feel distressed because she felt like no one (physicians and nurses included) had taken the time to prepare the family appropriately: *“I just feel like, we should have done better [...] the family wasn’t prepared and they were focused on different things. It was quite awful”*.

Another participant, Lauren, wishes she could have spent more time engaging in conversations about the end of life with her patient who was denied a potentially life-saving intervention. She reflects on high nurse to patient ratios as being a barrier in her ability to provide quality end-of-life care:

“If I had had a lower patient ratio then I would’ve spent more time with him at the bedside and I could tell at the time that that was important to him. And he wanted to talk about death with me and it wasn’t a difficult conversation to open up with him, like you just had to not change the subject when he brought it up. Like, I wish that I had had more time to engage in those conversations”.

Lauren’s words describe feelings of regret in being unable to spend more time with her dying patient. Her reflection on how limited staff resources hindered her ability to be present for her patient at the end of life and facilitate a ‘good death’ is a cause for concern.

When asked to describe how the acute care unit influences end-of-life care, all of the participants describe, in some way or another, how the philosophy of ‘curative versus palliative care’ is prominent on their unit. Participants associate this culture of care to the general attitude amongst physicians – particularly surgeons – who, according to participants, believe that consulting palliative care equates failure on their part. Participants’ stories reveal tension between the types of care these nurses feel dying patient ought to receive and the care they end up receiving due to the cure-oriented culture of their unit. Helen reflects:

“I feel like – It’s not as bad as it used to be but I feel physicians, in particular, are hesitant with palliative care. Especially in surgery because we’re in the business of keeping people alive. I was told one time ‘Why would you want to discuss that’ or, you know, ‘We have invested too much in this patient’”.

This sentiment is reiterated by Stephanie who states:

“It’s unfortunate but that situation (reluctance to consult palliative care) happens relatively often with surgical services, especially. I don’t know if there’s this mentality of ‘we have to fix it’, ‘our job is to fix it’, ‘we’re not going to make you a category 3’ and ‘oh palliation is the last-ditch effort’. I don’t know if there’s some kind of shame that goes into allowing palliative care to do their job or allowing us to palliate our patients. It doesn’t mean they’re dying right now. They’re just going to die in a way that they want to. Like, why not let them have a good end-of-life?”

Stephanie’s remarks on the surgical team not “allowing palliative care to do their job” or not “allowing [nurses] to palliate their patients” highlights tension between nurses and physicians in acute care. Stephanie’s frustration with the surgical team is also evident in this passage, which, if left unaddressed, can ultimately affect her relationship with the medical team. Kelly talks about how the medical team “*sort of passes the bucket*” – referring to physicians trying one life-prolonging intervention after another on dying patients. Participants also speak to how the stigma around palliative care is not only held by the medical team but by patients and families too. All of the participants advocate for the need for early integration of palliative care in terms of providing better pain management and symptom control, as well as guidance for acute care nurses in how to address sensitive end-of-life issues:

“Well I think it’s that whole perception ‘Well, we’re going to give up on this patient’ [...] And I think that’s what people take away from palliative care is that we’re giving up

the fight here. When in fact, no, we're not necessarily giving up the fight. You keep your category one status but still have palliative care and be looked at from both sides. We can treat you acutely but we can also treat symptoms and have symptom management and also have somebody to talk to that understands that side of living that's almost near the end. And helping patients understand what end-of-life and palliative means" (Helen).

"I definitely think that even the word palliative care has a negative connotation that comes with it, like it means end-of-life and that's it. Like, it needs to be talked about sooner rather than later but people don't want to talk about it...I think patients come to an acute care hospital to get better and they're hopeful and that's what we do in hospitals, we make people better. They don't think they come here to never leave again" (Kim).

In describing what it is like to be an acute care nurse, all of the participants mention the importance of teamwork on their unit and describe having trusting relationships with their nursing colleagues. Stephanie and Heather often mention how much they rely on their colleagues, especially when they have a patient who is acutely ill:

"We're spoiled on this unit as far as colleagues go because we all get along super well [...] We can sort of leave things onto each other and trust that it will get done. If ever there's a crisis we can trust that our co-workers will be there to back us up, which is unbelievably helpful. I can't imagine working with some of the acuity that we have and being out there on your own".

Heather similarly remarks:

"I definitely could not work without having people (nurse colleagues) that you rely on. Like, go check this patient or go do everything for that patient. And I would just assume when they said 'yes' that it would be done".

Both of these passages reflect a strong degree of trust between the nurses on this unit. It is interesting to note, however, that few participants talk about how their colleagues help them with end-of-life care. Participants focus predominantly on the role of teamwork in terms of helping each other during acute medical crises and staying on track with their tasks. In the follow-up member reflections, Lauren adds to this idea of teamwork in end-of-life care by saying that nurses on her unit *“only really come together in the last few hours of a patient dying and it’s more about ganging up on the physician”*. She explains:

“Like, if the patient is suffering, we all get together and tell the physician that we need better meds on board or we need to insert a foley. When someone is dying and it is known on the unit then we all become involved so that we can have a stronger voice to advocate for the patient’s needs. But I’m talking about meds and stuff. We don’t help each other with, like, the emotional stuff”.

Importantly, although providing whole person care is an important value reflected in many of the participants’ stories, they also suggest that some of their nursing colleagues are not of the same mindset. Lauren, who has just over one year of nursing experience reflects:

“I think it depends on the way that you view your role as a nurse and also what you – I mean, some people, and not to say that I don’t have colleagues that are great nurses, but some people here wouldn’t consider that (addressing emotional suffering) part of their job [...] They want to get their work done. And by work they mean get their meds and dressings and charting done [...] I don’t know whether or not acute care nurses are the types of nurses that are supposed to be doing that (emotional care). Some people might say no, but I don’t know [...] I think it has to be part of our role”.

That Lauren appears to value holistic care of dying patients on an acute care ward and takes responsibility for their care, combined with her feeling that she is working with colleagues who

do not take this same responsibility, means that she is at risk of constrained moral agency in enacting whole person care for her dying patients. In the following passage, Lauren describes finding ‘to-do’ lists written by a patient of hers who had died merely weeks after being denied a potentially life-saving intervention. One of the lists had “Convince [medical] team to change their mind” written on it. When asked how she felt when she found these lists Lauren says:

“I felt like everyone really gave up on him after they found out that he wasn’t going to get [treatment]. And a lot of the nurses were like, ‘Wow he really declined fast after he was rejected’ but I was kind of like, we stopped trying too [...] It was, in a sense, very appropriately responsive care but I think he needed more [...] You could be like, people who are palliative should go to hospice but they don’t have enough beds and we couldn’t transport him anywhere because he was on too much oxygen. So, many of our people die within a day or two. I think the vast majority of people don’t die in hospice so you could be like, ‘That’s not what I do’ but it ends up being what you do”.

In addition to a perceived lack of teamwork in end-of-life care practices, participants often do not talk about their experiences providing ethical end-of-life care with their nurse colleagues. Take the following narratives in which two of the study participants describe the *same* patient’s death with two very different interpretations. For context, the patient is the same patient described above – a middle-aged man who was unexpectedly refused a potentially life-saving intervention. As a result, he was told that he had merely weeks, maybe months to live. This man remained on this acute care unit for just over two weeks before dying. Here is the first narrative by Stephanie:

“We had a patient recently who was with us for a long time and he was just this super super lovely man and had this lovely family. Initially he came in because his oxygen

requirements were increasing and he [needed a life-saving intervention]. So, they did his teleconference while he was in hospital and not doing super well and eventually he was declined [the intervention]. After that it was a matter of palliation and do you want to go home versus hospice and then he never got well enough to discuss transferring him somewhere. Palliative care was involved with him, social work was involved, his family was really involved, he was organizing his affairs himself. His sisters were going to the bank for him, he was on the phone with his lawyers and everything just trying to get everything together because he knew the end was coming. It was inevitable. So, I think he died on a Tuesday, and I looked after him on Sunday and I did not see it coming. But apparently, he was very comfortable and we were on top of his meds and, apparently, his oxygen was off and he was just peaceful. Everything was ready. So, it was really nice. Obviously, it's terrible that he died, but in the grand scheme of things for somebody who was dealt the blow of being denied a [life-saving intervention] and the way that he took that and got everything organized so that the end of his life was peaceful was so nice".

In contrast to this story, Lauren describes the same death with a different interpretation. Lauren had looked after this patient for 3 days while he was being worked up for the life-saving intervention. She then left for vacation while the medical team was deciding whether or not he was a suitable candidate for the procedure:

"When I got back 2 weeks later he was still here and I was like 'Oh you're still here' and he said 'Yeah they decided not to take me after all'. That was only two weeks later and he declined very rapidly after that. He went from being on 7 litres (of oxygen) to always being on 15 litres, then he was on 15 litres with a non-rebreather on top. Then he was on 15 litres with a non-rebreather on top with cool humidity sort of on the side. Then also he needs a neb to breathe so now he has four things of oxygen and at night he's so scared

that his oxygen's going to fall off that he needs the light on all the time [...] Because he went from being independent to not being able to care for himself at all, not being able to get out of bed, barely being able to feed himself, like he was just basically sitting there holding all of his oxygen to his face lest he die. So, he wasn't keen on dying right then but he was having these big episodes of de-satting where I couldn't get his oxygen up and my second night he went through a big one out of the blue. And palliative care was consulted, they were involved [...] But he told me that he had too many things in his estate right now that he didn't want his family to have to deal with. Like, 'I'm not ready to die' [...] He had, like, these checklists, he was like, 'Well tomorrow I'm going to call the bank about this, and after that I going to do this, and I've figured out my apartment already'. He was, like, thinking into the future but, clinically, it didn't look that way to me. I wasn't certain he was going to die but I had a pretty bad feeling about it. [...] So, I called palliative and got some new orders and then an hour later he died. His oxygen just slipped off his face and I came in and found him".

At first glance these participants appear to be describing two very different deaths, however, in some of the overlapping details it became apparent that these participants were talking about the same person. The stark contrast between Stephanie and Lauren's descriptions of this person's end-of-life demonstrates how individual nurses' interpretations and associated meanings are highly subjective, that there is a lack of communication between nurses on this unit regarding ethical end-of-life experiences, as well as potential for missed opportunities that may be taking place as a result. For instance, Lauren regrets not having enough time to sit and talk to this patient before he died. She also comments on the fact that it seemed as though no other healthcare professionals had engaged in end-of-life conversations with the patient. In the follow-up member reflections, Lauren adds that nurses on her unit are "discouraged" to talk about end-of-life care experiences that they found to be difficult or challenging:

“Talking about the aftermath of death is discouraged. Like, people who want to talk about difficult things or are ‘taking things home’ with them are seen as, like, not coping. Nurses may talk about the patient superficially – sometimes the story is recounted and we talk about the patient like ‘Oh he was such a nice man’ but the nurse will not say ‘This was upsetting to me’. That’s not encouraged here. It’s like this idea that nurses see death all the time so we should be able to cope with it or ‘deal with it’”.

This idea that nurses are expected to ‘cope with’ and ‘deal with’ death alone resonates with the ‘fix it’ mentality of biomedicine. Lauren insightfully remarked that nurses who are perceived as ‘not coping’ do not need to ‘fix’ how they are feeling because *“they may actually be doing good work”*. She explained, however, that these nurses do not have a place where they can talk openly about their experiences so they end up “bottling things up” and becoming “desensitized”.

Summary of the Findings

The themes presented in this chapter highlight the overall challenge of acute care nurses oscillating between providing care that reflects their moral identities and providing care reflective of the ‘cure-oriented’ culture of their unit. This tension is evident in nurses’ descriptions of feeling forced to put on blinders in order to keep from “drowning” in the workload, while subsequently revealing ways in which they make space to engage with patients during their care. Another strain is noted in participants’ uncertainty in their ability to address suffering in practice, despite revealing rich insight on different views of suffering, and the value of personhood. Lastly, nurses’ stories reveal tension when they are unable to facilitate dying patients’ transitions to appropriate end-of-life care. The main reason for this inability is working in an environment that prioritizes task- and cure-oriented care.

These findings portray participants as wavering back and forth between two forces (i.e. moral identity and biomedicine) which results in engaging personhood ‘behind the scenes’. Over time,

as participants continue to be pulled in opposing directions without acknowledging and reconciling the ethical tensions that are happening, their moral integrity is at risk of unravelling, which will damage their moral identities. This ‘tug of war’ needs to be brought out from behind the scenes and acknowledged by organizations and nurse leaders. Ideas about how this might happen are presented in the next chapter.

Chapter 5: Discussion

For this study I analyzed the perspectives of eight acute care nurses about providing end-of-life care to patients. An interpretive description qualitative research design oriented the research inquiry to better understand the ways in which acute care nurses engage, or fail to engage, with personhood at the end of life. Recall from chapter 3, interpretive description involves description of and interpretation about a shared phenomenon from the perspective of those who live it (Thorne, 2016). Exploring end-of-life care experiences from the perspective of acute care nurses contributes directly to our understanding of how they experience this type of care as well as tensions that need to be exposed and addressed to enhance the end-of-life care experiences of nurses, patients, and families. Interpretive description is a means by which nurses can derive clinical knowledge applicable to developing their practice science. Thus, I hope insights from this study will contribute to nursing research and theory, as well as raise awareness and instigate change towards supporting acute care nurses' engagement with personhood in end-of-life care at a practice level. Implications for nursing practice, education, and research will be discussed at the end of this chapter.

Theoretical Perspectives

In chapter 3, I proposed using a nursing ethics lens to frame and orient my approach to inquiry with a specific focus on: Personhood as a relevant ethical lens to examine end-of-life nursing practice, empty discourses in contemporary healthcare, and end-of-life care in acute care as a fundamentally relational practice. In interpretive description, the theoretical assumptions represent a beginning point rather than an organizing structure for what is found in the inquiry, therefore, it is typically challenged as the inductive analysis proceeds (Thorne et al., 1997). Connections – and points of departure – between my theoretical assumptions and my study

findings will be explored. To briefly summarize some of the main findings of this study, I found that:

- Engaging personhood at the end of life in the acute care context is done through specific nursing practices (or so-called “little things”). These acts are supposed small but meaningful gestures carried out by nurses that remind themselves, the patient, and the family that they are caring for a person and not merely a disease.
- Participants’ stories revealed that they are unable to engage personhood fully due to the task- and efficiency-based priorities of their acute care unit. A tension is apparent where participants described feeling constrained in their ability to engage personhood completely despite demonstrating the knowledge and willingness to do so. This tension was evident in nurses’ descriptions of feeling forced to put on metaphorical blinders in order to keep from “drowning” in the workload, while subsequently revealing ways in which they made space to engage with patients during completion of their nursing tasks.
- Participants are caught oscillating between engaging personhood in a way that reflects their values, and the biomedical culture that dominates their workplace. As a result, participants engaged with personhood behind the scenes while simultaneously juggling the many care responsibilities of their unit. This oscillation can be described using the metaphor of ‘tug-of-war’ in which a rope (nurses’ moral integrity) is being pulled back and forth between two opposing forces (nurses’ moral identity and the culture of biomedicine). Over time, as nurses continue to be pulled in opposing directions without acknowledging the ethical tensions that are happening, their moral integrity is at risk of unravelling which can lead to moral distress and damage to their moral identities.

My intention here is not to resolve these tensions but rather shed light on how these tensions reveal the nuances and complexities of navigating ethical end-of-life care in an acute care setting. This approach is consistent with a constructivist worldview, in which single explanations for complex phenomena are neither possible nor desirable (Lincoln et al., 1986; Wright, 2012). Rather, by developing multiple interpretations about the studied phenomenon (acute care nurses' engagement with personhood in end-of-life care), seemingly contradictory ideas are highlighted and provide for a more authentic, relevant, and useful portrayal of the culture studied (Appleton et al., 1997; Lincoln et al., 1986). These tensions – or contradictory ideas – do not cancel each other out but rather reflect the multiple realities that are assumed in a constructivist inquiry. The back and forth nature of participants' experiences also demonstrates the reflective process that participants engaged in as they worked to clarify their own thoughts and ideas during the interview process.

The following section is organized into five main sections that will guide the discussion of the study findings: Partial engagement of personhood in acute care nursing, biomedical constraints on moral agency, the language of so-called “little things” in end-of-life care, moral ramifications: distress and damaged identity and, lastly, moral distress as a springboard for action. Implications for practice, education, and research are discussed through a frame of moral community. The chapter concludes with study limitations as well as a personal reflection on my experience conducting this research. Given that nursing identity is revealed through relationships with others (Liaschenko et al., 2016; Maeve, 1998; Peter et al., 2006), connections to ideas in relational ethics will be woven throughout the discussion.

Partial Engagement of Personhood in Acute Care Nursing

Participants' stories revealed that they recognize patients who are dying as people living profound experiences at the end of life. This recognition was evident in their descriptions of

patient suffering with consideration given to what it is like to die in acute care units specifically (e.g. dehumanization and loss of control). According to Maeve (1998), possessing this kind of rich insight on patients' end-of-life experiences is only possible when nurses are fully present to patients and their situations. Although being present with patients and families was a recurring notion in the study findings, participants' stories wavered back and forth between being present with patients and actively avoiding personhood because of competing priorities. As a result, participants were not engaging personhood fully. When a nurse is fully engaged in the nurse-patient relationship this results in the nurse sharing the meaning of each individual patient's experience (Maeve, 1998). This means that the nurse shares "any pain or suffering an individual patient might be experiencing, as well as the joys" (Maeve, 1998, p. 13).

Rather than decision-making based on strictly intellectual/academic knowledge, relational ethics encourages nurses to use past learning and experience as a guide (Gadow, 1989). Several participants drew on their own personal experiences with death and grieving when describing end-of-life care and how their experience shaped their end-of-life practice today. Engagement specifically refers to the idea that nurses who are fully present to patients and their situations, are also fully present to, and aware of, their own identity directly in relation to the experience of caring for an individual patient (Gadow, 1989; Schroeder 1992). In other words, engaged nurses recognize and associate, wholly, the experience of the other. According to Maeve (1998), nurses can be fully present to the experience of another in such a way that it becomes part of their own experience as well. The importance of presence and 'being with' patients at the end of life was both mentioned explicitly and suggested implicitly throughout participants' stories. Participants described being present for patients who were dying in terms of physical touch – where one participant talked about holding a dying patient in her arms, as well as stories of presence through acts of sitting with, listening to, and sharing silences with patients and families. Although participants described the importance of being present, they also described

struggling to “remain present” with patients while simultaneously thinking about their other care responsibilities. For instance, participants stated that being present with patients who are dying can cause the nurse to feel “stressed by the time pressure of getting meds in all of [their] other patients” (Lauren). Therefore, participants were unable to engage with patients fully while simultaneously thinking about “the hundreds of tasks” (Kim) they still had to complete in their shift.

Participants’ recurring descriptions of presence as an important aspect of engaging personhood resonates with Naef’s (2006) work on ‘bearing witness’ as a moral way of engaging in the nurse-patient relationship. According to Naef (2006), nurses are present with persons who experience changes in their health and quality of life, who live intense and profound moments, and who are vulnerable, suffering, or dying. Therefore, Naef (2006) proposes that bearing witness – a human mode of coexistence and a special way of being with persons – is a central concept for nursing. Based on Parse’s (1998) nursing theory of human becoming, Naef (2006) argues that bearing witness is an important way of being with persons because it involves being attentive to lived experiences and truths, honouring uniqueness, supporting persons’ choices, espousing the belief that persons know themselves best, and recognizing human interconnectedness (Parse, 1998). Bearing witness also involves the nurse being attentive to moment-to-moment changes in meaning. Thus, it is not just a way of practicing nursing in the face of suffering or death, but also a way of being with patients in day-to-day, micro-ethical moments (McMillan, 2018; Naef, 2006). Bearing witness also involves seeing, honouring, respecting and remembering a person’s experience of suffering. One of the ways participants demonstrated bearing witness was by remembering and recounting patient experiences of suffering through storytelling. According to Malone (2003), nurses who are ‘distal’ – or “disengaged from patients as persons” (p.2323) – are unable to remember particular details about their patients’ stories. In contrast, ‘proximal nurses’ understand patients as particular persons

situated within social worlds and privilege and remember knowledge derived from the patient's life and the experience of providing care. Although participants remembered patient experiences of suffering, this is only a part of bearing witness. Recall the themes *Suffering as a "dark, emotional, twisty thing"* and *"I don't think I'm ever really going to get it right"* wherein participants revealed that they have rich insight into the experience of suffering, but sometimes stop short of engaging with it in practice. If bearing witness is a way for the nurse and patient to coexist and share experiences of health and illness (Naef, 2006) then the participants were not bearing witness fully. This is described by Naef (2006) as 'turning away'.

By using the term 'turning away', Naef (2006) suggests that *not* bearing witness is an active choice – similar to participants choosing to put on metaphorical blinders to make it through their shift. Mitchell et al. (2003), also writing from a human becoming perspective, used the metaphor of "the abyss" to illustrate the challenges and opportunities that lie in choosing to bear witness to others in profound times and intense life moments. The authors define the abyss as follows: "The abyss is risking being present to the explicit-tacit truth of a situation" (Mitchell et al., 2003, p.123). They go on to explain that:

"Engaging the abyss is really about risking and choosing [...] The abyss is mystery, uncertainty, and potentiality. Engaging the abyss requires courage because there is a knowing that one will be changed by being with the truth expressed there [...] What is feared in the engaging with the abyss is the imagined unknown. Sometimes people are afraid of getting entwined, enmeshed, overwhelmed [...] When nurses and others are called to be with persons during intense times there is an imagining about what it will be like to abide there and the fear related to the risking of the unknown slams some doors shut" (p.123).

According to Mitchell et al. (2003), this metaphor of the abyss can help shed light on why nurses choose to either engage or turn away from situations where patients are confronted with deep and

existential questions and concerns at the end of life. While participants spoke predominantly about how the acute care setting constrained their ability to engage personhood fully, their stories also revealed uncertainty in how to address emotionally difficult situations (e.g. not knowing what to say, fear of making things worse, and fear of becoming vulnerable themselves). Participants' uncertainty about what to say and fear of making things worse is part of the risk of choosing to engage personhood fully.

Importantly, choosing to 'turn away' also poses significant risks. For instance, in turning away the nurse leaves the patient to live through his or her suffering alone, which, in turn, causes the nurse to wonder what might have been had they stayed. Thus, if fear "of the unknown, of the human connection, of the closeness to suffering, of being overwhelmed by the truth" (Mitchell et al., 2003, p.126) overtakes the nurse, then the question of 'what if' will linger. This lingering question of 'what if' constitutes a missed opportunity; that of engaging one's moral responsibility, or agency, to turn towards the other, to bear witness and to share in another's experience. This missed opportunity resonates with my own experience of caring for Richard (chapter 1) at his end of life. After Richard died, I was left wondering – and I still wonder to this day – about why I turned away from him and left him to live through his suffering alone. I still ask myself whether addressing his suffering might have made a difference and whether taking the time to sit and be present with him would have helped him. This idea of missed opportunity also resonates with my study findings, where participants expressed regret in not engaging in more existential conversations with patients before they died. In these situations, we, as nurses, need to acknowledge these missed opportunities, recognize that we are human and may not always know what to say, forgive ourselves and move forward with the intention of engaging fully whenever possible in the future. According to Naef (2006) bearing witness—not bearing witness (Cody, 2001), or abiding with the abyss—turning away (Mitchell et al., 2003), are normal

patterns that arise in the negotiation of the nurse–person relationship; engaging personhood fully, partially, or not at all, is part of this negotiation.

It is important to mention that bearing witness is not easy, and the challenging work of witnessing another person’s suffering is often unacknowledged in practice (Malone, 2000). According to Malone (2000), it is *agonizing* to bear witness to suffering, as “witnessing is qualitatively distinct from mere looking; witnessing *engages* the witness as a bearer of truth that the suffering person cannot tell” (added emphasis, p. 8). Bearing witness not only requires nurses to appreciate the vulnerability of their patients but also challenges them to confront their own vulnerability.

Biomedical Constraints on Moral Agency

According to Liaschenko et al. (2016), it is possible that the most challenging moral problem of the twenty-first century will be the relationship between the individual moral agent and the practices and institutions in which the moral agent is embedded. According to Peter et al. (2004) in healthcare environments “[t]here is an air of dehumanization, fragmentation, and focus on doing more, faster, and better. Intelligent, caring, and committed people feel alone, powerless, and voiceless in the midst of the demands” (p. 19). The inappropriate application of knowledge from business and engineering in restructuring our healthcare organizations has led to problems such as unsustainable staffing reductions and excessive demands on shrinking numbers of practitioners (Peter et al., 2004). This inappropriate restructuring of healthcare is supported by Malone’s (2003) work on proximity wherein she argues that hospital nursing is being constrained by spatial–structural changes that are disrupting nurses’ relationships with patients. According to Malone (2003), one of the biggest problems with healthcare systems adopting business models of care (i.e. work redesign strategies that prioritize cost reduction) is that it reduces nurse–patient proximity. This reduction in proximity minimizes possibilities for the

sustained engagement with patients required by nurses to develop relationships and knowledge of the patient as a person (Weiss et al., 2002).

Acute hospital environments are places where value resides in efficient, economical, objective, and task-oriented approaches to care (Liaschenko et al., 2016; Peter et al., 2004). As a result, nurses experience a devaluation of their work, particularly ‘invisible’ work (e.g. “little things”), emotional labour, and ancillary tasks (e.g. hygiene care) (Rodney et al., 2001; CNA, 2002). This devaluation resonates with study participants seemingly engaging personhood ‘behind the scenes’ where nurses do not talk about such engagement and where it often goes unnoticed by colleagues and management. As a result, participants feel as though they are shouldering the responsibility of providing ethical end-of-life care that focuses on personhood alone. This sense of aloneness exemplifies constrained moral agency where nurses are unable to make and act on a choice about the best course of action. As a result, the preservation of nurses’ core caring identity is challenged in institutions that focus more on economic imperatives than on caring.

According to Chan et al. (2017), improving end-of-life care on acute care units requires examining how care practices are shaped by the cultures of care in this cure-oriented setting and how these practices impact patient and family experience. In an earlier paper by Chan et al. (2009) that examined dying in hospital through a cultural lens, one characteristic of the biomedical culture is its reductionist approach. According to the authors, biomedical thinking reflects the idea that “phenomena are better understood outside their context, separated from related people or objects and emotions and meaning that patients associate with them” (Chan et al., 2009, p. 118). In this culture of care, clinicians invalidate other (non-biomedical) ways of knowing and understanding experiences of illness, death and dying, therefore overlooking important aspects of the end-of-life experience of many people (Chan et al., 2009).

In the following section, I discuss how culture of care impacts the moral experiences of nurses delivering end-of-life care in acute medicine. The influence of biomedicine was evident throughout participants' stories in their descriptions of the acute care setting, competing philosophies of care and physicians' hesitancy to address death and dying, as well as their descriptions of relationships with their nurse and physician colleagues. The biomedical influence was also revealed in some of the language used by participants during their storytelling.

The acute care setting. Participants described their acute medical-surgical unit as “busy” and “out of control” causing them to feel as though they were “drowning” in the workload. When asked how they go about planning their shifts, participants described organizing their care in terms of the “big overarching ominous schedule” of acute care which prioritizes tasks-oriented care over whole person care. Participants initially described their practice as a series of actions that get “scratched off” a checklist over the course of the shift. Focusing on this checklist results in nurses actively avoiding engagements of personhood with patients who are dying. Although critically reflective of this type of care, participants also justified it as the only way to make it through the shift. This justification of task-based care relates to Sharp et al.'s (2018) study on the tension between person-centered and task focused-care in an acute surgical setting, in which nurses described organizing their work in response to the urgency of the task at hand and routine as opposed to individualized care based on the patient's unique needs. The authors explain that efficient treatment of physiological ailments located within a biomedical model is a common goal in healthcare institutions for patients admitted to high acuity areas so that healthcare professionals can describe, predict, and treat outcomes based on empirical evidence (Sharp et al., 2018). Mazzotta et al. (2015) explain that this goal in healthcare is a result of the biomedical influence that places an emphasis on evidence-based practice with measurable outcomes; ultimately, resembling “an audit culture with the undertone of a business model” (p. 94). The

influence of biomedicine is further reinforced in Peter et al.'s (2004) study in which work environments were perceived as dominated by medical and business values where nursing perspectives were marginalized. According to Weiss et al. (2002) the push for efficiency has resulted in system restructuring that allows less time for nursing care and assumes an indifferent, if not dismissive, stance towards the relational practices in which nurses engage to ensure the security, well-being, and humanity of their patients. Redesigned systems that view nursing care through the lens of an industrial production model have compelled nurses to act secretively to sustain care practices that ensure patients and families a safe and humane passage (Weiss et al., 2002). These 'secretive acts' resonate with my interpretation of participants' engaging personhood behind the scenes as a means of preserving their moral identity and the identities of their patients. According to Weiss et al. (2002), when clinicians feel rushed and harried, "their ability to engage with patients and families is impaired, resulting in a disruption of their self-identity as healers" (p. 360).

Sharp et al. (2018) explain that care based on efficiency stands in contrast to 'person-centered care' because the latter may actually slow down procedures and require holistic approaches, rather than segmented care. This lack of person-centered care in practice ties back to the theoretical discussion on 'empty discourses in contemporary healthcare', wherein buzzwords like 'person-centered care' are frequently seen in the mission statements, policies, and initiatives of healthcare institutions, but without the resources required to promote personhood (Nolan et al., 2004). Prioritizing tasks over care that focuses on the person was further reinforced by participants who described the treatment of physiological ailments as easy to 'fix': "It's easy to make it look like we've fixed it or we've done something. It's easy to recognize, it's just so simple" (Lauren). Interestingly, Cody (2001) suggests that biomedical knowledge tends to be highly valued because of the assumption that it is complex, important, and intellectually

challenging, whereas bearing witness is devalued as simple, easy to learn, and “okay when there is time” (Cody, 2001, p. 21). This view stands in contrast to participants’ description of treating physiological ailments as “easy” and “simple”, which suggests that care that focuses on the person is more complex, nuanced and meaningful than the recognition that it is given in contemporary healthcare. This is supported by Liaschenko et al. (2016) who describe the act of caring as a complex social practice requiring knowledge and competence. These authors argue that nurses need to provide counterstories that represent the caring of nurses as skilled and intelligent and that convey an image of nurses as powerful and ethical. Such counterstories will be considered further in the section on implications for practice.

Preoccupation with efficiency was reflected in participants’ descriptions of time or lack thereof. The concept of time was recurring in participant interviews when they described organizing their shifts around fixed time points like physical assessments, vital signs and medication administration, as well not being able to spend equal amounts of time with each of their patients – especially if one of their patients was “really sick” and required more attention. Temporality is mentioned by Weiss et al. (2002) with regards to operating room (OR) nurses and the impact of their institution’s efforts to reduce the turnover time between patients’ entry into the OR suite from the pre-operative room and their departure for the recovery room. Although this time was viewed as “superfluous” (p. 350) by their organizational leaders, the OR nurses regarded this time as essential to preserving the patient’s humanity and security in a highly threatening, highly technological atmosphere. Weiss et al. (2002) highlighted that nurses resisted viewing this process in terms of industrial production — “with the patient moving along a sort of surgical conveyor belt as the nurses stand ready to administer therapies to one patient after another” (p. 350). Rather, the patient was delivered “into the hands” (Weiss et al., 2002, p.350) of the next nurse, which suggested an awareness of the trust placed in them by patients and

families and the nurses' responsibility to ensure the safe passage of their patients. Time, in this view, does not consist merely of the minutes it takes to perform a particular task. Rather, time provides a space for meaningful and ethical human interaction to occur (Weiss et al., 2002).

Team relationships in acute care. According to Thompson et al. (2006), in providing adequate end-of-life care, acute care nurses must also negotiate their collegial relationships. Relationships between nurses and physicians are acknowledged in the literature as 'complex' and 'conflict-laden', which is supported by my study findings. When asked about their relationships with physicians, all of the participants initially describe them as "good" before then providing a more complex description of the hierarchal nurse-physician relationship.

Literature on nurse-physician relationships suggests that, where collaboration and strong collegial relationships exist, effective communication and trust are enhanced. Effective communication was identified by both Thompson et al. (2006) and Oliveira et al. (2016) as essential in facilitating and maintaining a transition from curative to palliative care. Nurses in Thompson et al.'s (2006) study expressed how, without trust or rapport with physicians, their ability to advocate for terminally-ill patients was greatly reduced. This inability to advocate for patients is evident in the theme "*The things we do to patients here are not nice*" when Helen felt unable to provide dignified care to a patient – whom she believed should be receiving comfort care – until it had been decided by the medical team. The role of physicians in determining the provision of palliative care is supported by Oliveira et al.'s (2016) study on the lived experience of nurses providing end-of-life care to patients on an acute medical unit. The participants felt that, despite voicing their professional opinions, they often felt a lack of respect from the medical team and that physicians were ultimately the drivers of care when it came to end-of-life care decisions. A similar reluctance of acute medical doctors consulting palliative is in Chan et al.'s (2017) study wherein the authors describe how acute care units often portray the idea of

competing philosophies of care – curative versus palliative – in which curative, life-prolonging approaches prevail in acute care culture. Chan et al. (2017) associated this dichotomous approach of life-prolonging care versus palliative care with the staff, in particular physician, uncertainty about prognosticating the end of life. Physicians in Chan’s (2017) study would say, ‘She’s almost palliative’ or ‘It’s too soon to consult palliative care’, implying that there is a right time to label someone as ‘palliative’, initiate palliative care, or involve a palliative care team. This hesitancy to consult palliative care resonates with participants’ experiences in advocating for palliative care to physician colleagues only to be met with responses like “Why would you want to discuss that?” and “We have invested too much in this patient”. When nurse–physician relationships fail to support and value nurses’ caring beliefs and behaviours, as well as patient and family autonomy, nurse dissatisfaction and frustration can ensue.

As previously mentioned in chapter 4, in describing what it is like to be an acute care nurse, all of the participants mentioned the importance of teamwork on their unit and described having trusting relationships with their nursing colleagues. However, none of the participants talked about how their nursing colleagues assisted with end-of-life care specifically; participants focused predominantly on the role of teamwork in terms of helping each other during acute medical crises and staying on track with their tasks. As a result, participants were not only engaging personhood behind the scenes but they were seemingly doing it *alone*. A lack of communication between nurses about the ways in which they engage personhood at the end of life can cause nurses to feel alone in shouldering the responsibility of providing ethical palliative care to patients (Wright et al., 2017). Recall from chapter 4, when one participant described valuing holistic care of dying patients and taking responsibility for their care, she also felt that she was working with colleagues who did not share this same responsibility. This tension places the nurse at risk of constrained moral agency. Furthermore, if this participant felt as though she

was alone in taking on the responsibility for providing ethical care to dying patients on her unit, there is cause for concern about the sustainability of her caregiving actions and there is a real possibility she will experience moral distress.

In Peter et al.'s (2004) study on the moral habitability of the nursing work environment, nursing colleagues were depicted as being both part of the solution and part of the problem in that they often reinforced this pressure to be 'on time' with tasks. This tension raises the question of what is at stake for nurses and patients if ethical end-of-life care issues are not communicated amongst colleagues. Recall from the findings when two participants described the same patient death with two very different interpretations. These contrasting narratives of the same death not only exemplified the lack of communication between nurses on this unit regarding end-of-life experiences, but also shed light on the potential for missed opportunities of engagement as a result.

The language of biomedicine. The influence of biomedicine was evident in some of the words and expressions used by participants. For instance, several participants referred to patients on their unit as being "really sick" and requiring a lot of their time and energy. When asked what they meant by "really sick", participants described patients who were experiencing acute medical problems such as atrial fibrillation, respiratory distress, and hypotension. Social research in healthcare settings suggests that cultural definitions and social meanings attached to illness, disability, and aging have a powerful influence on the development and operations of care settings, as well as the social, behavioral, and therapeutic processes occurring within these settings (Vittoria, 1999). The significance of language in specific healthcare contexts aligns with O'Connor et al.'s (2006) work on discourse analysis methods – which are concerned with investigating how language and written texts shape and influence behaviours and provide ways of constructing the world. Discourse analysis is firmly based in the study of language, its usage,

the meanings behind words, and the specific values that words imply (O'Connor et al., 2006). According to O'Connor et al. (2006), if society is symbolised by the words that are used to describe it, then language is an important part of society's construction.

Returning to participants' use of the term "really sick" as representing patients experiencing acute medical problems, this specific use of the term 'sick' is socially constructed based on the acute care environment within which these participants work. That is, the perception of a "really sick" patient in acute care will differ from a "really sick" patient in a hospice setting. For instance, one could argue that no person is sicker than someone who is at their end-of-life. According to O'Connor et al. (2006), it is often assumed in qualitative nursing research that the language elicited in interviews and focus groups provide a direct insight into the thoughts and feelings of participants. As an alternative, O'Connor et al. (2006) argue for methodological approaches that consider how language both shapes and reflects social behaviour and provides a means to elicit the implicit values and power positions in society. In a study by Vittoria (1999), the author explored the use of language on a specialized Alzheimer unit wherein nurses challenged the medical model through the use of their "own little language" (p. 2). For example, from the perspective of the medical model, the word 'patient' is the common term for individuals receiving medical care. However, the nursing staff in this study rarely spoke of persons within their care as patients, preferring instead to use the word "residents" or the given name of the person. Avoiding the term 'patient' resonates with my study findings in which participants purposefully called patients by their names to make them feel more like a person. Furthermore, participants in Vittoria's (1999) study referred to tasks that are often considered 'mundane' (e.g. helping a resident get dressed) as "acts of significance" (p. 381). This recognition is relevant to my findings wherein participants frequently referred to significant acts

as “little things”. I argue here that nurses and nurse researchers need to re-think terms such as ‘little things’ and ‘small acts’, to better represent how meaningful these gestures really are.

Although it was likely not their intention, when participants did not refer to dying patients on their unit as “really sick”, they reinforced the prioritization of acutely ill patients over the needs of patients who are dying. Discourse analysis, however, can help identify and deconstruct ways of talking or writing (O’Connor et al., 2006). For example, O’Connor et al. (2006) describe ways in which representations of people as they near the end of life may differ depending on the language used by healthcare professionals: “Patients who are dying as ‘medical failures’, ‘heroes’ (e.g. in fighting cancer), or as ‘victims’” (p. 829). Referring to patients who are dying in acute care as not “really sick” demonstrates the dominant discourse of biomedicine that exists in this setting. Another example of the ‘language of biomedicine’ is in participants’ use of the term “crisis”. One participant explained that she is better in a “crisis” than she is in a “very emotional, tense situation”. Again, in an end-of-life context, a highly emotional and tense situation wherein patients and/or families are upset should be perceived as a crisis. However, in this description, crisis refers exclusively to a sudden change in patient acuity, symptom exacerbation, and the need for constant monitoring.

Social meanings and cultural definitions attached to illness, disability, and aging have a powerful influence on the development and operations of patient care (Vittoria, 1999). Therefore, I argue here that words like “crisis” and “sick” have been co-opted by the biomedical model to mean acute health problems, which are reinforced by healthcare literature and nursing language used in acute care settings. It is important for nurses and nursing researchers to be mindful of how language is used as the ‘language of biomedicine’ can further reinforce the divide between biomedicine and palliative and end-of-life care philosophies on acute care units. For instance, despite advocating for upstream integration of palliative care, which is a stance

consistent with contemporary palliative care movements (CNA, 2015), participants tended to separate acute care from end-of-life care. This distinction between terms can further reinforce the dichotomization of these care practices.

The Language of So-Called “Little Things” in End-of-Life Care

The literature review in chapter 2 revealed a discourse of acute care nurses not having enough time or resources to engage personhood in end-of-life care due to an ethos of ‘busyness’ and workplace values that focus on efficiency and task-based care (Chan et al., 2017; Chochinov et al., 2015; Sharp et al., 2018). In contrast to this literature, however, participants’ stories reveal that they are oriented towards personhood and that they *do* engage personhood at least partially through so-called “little things”.

Participants’ descriptions of “little things” align with the work of Peter et al. (2016) who describe “simple caring gestures” (p. 6) and “simple acts such as bed baths” (p. 6) as meaningful moments between nurses and patients that lead to recognition of the patient as a person, as well as affirmation of the meaning of ‘good nursing’. Recall from chapter 3 that moral identity includes the values and images that are associated with being a ‘good nurse’. For instance, when Brenda purposefully chooses to put a thermometer under her patient’s arm instead of in their mouth so they can talk to each other, this gesture communicates to the patient, even if implicitly, that the nurse values them as person with whom she wants to talk and “get to know”. Furthermore, it reinforces the nurse-patient relationship as one of reciprocity and acknowledgment of two humans entering a relational space together. The notion of reciprocity resonates with a lens of relational ethics which states that relational space “is where one enacts responsiveness and responsibility, not just for oneself or the other, but within the space of being for and with oneself and the other” (Bergum, 2004, p. 486). Peter et al. (2016) expand on this

idea of reciprocity in saying that “little or ordinary things” can lead to interactions that result in the reciprocal holding of identity. Identity ‘holding’ refers to genuinely recognizing, acknowledging, and preserving a person’s identity. This identity preserving work of nurses has a long history in nursing ethics (Peter et al., 2016). Engaging personhood through significant acts (e.g. giving a patient a haircut, holding a hand, and calling a patient by their first name) can be understood as ways in which participants ‘hold’ the identities of their patients. For example, recall when Brenda used hygiene care to talk to her patients about “whatever they want” to help them feel “a bit more human and less of a patient”. Holding the identities of patients aligns with Coyle’s (2006) work on the end-of-life experiences of patients who are dying, wherein a patient living with terminal cancer says “I mean the cancer is part of me but not the whole me. I don’t want to be a patient, I want to be me” (p. 269). According to the literature, today’s highly technical hospital environments threaten to strip patients of their identities (Mazzotta et al., 2015; Thompson et al., 2006). Thus, holding identities is more important than ever. Recall when Helen described making dying patients feel human by “giving the nice bed bath, the back rub, the positioning, the pillows, the head in just the right way, the lights dimmed, the sheets straight”. She went on to say: “Then I feel like I’ve done my job”. This participant’s reflection of feeling like she’s ‘done her job’ can be interpreted as her feeling like a ‘good nurse’.

Although participants referred to these acts as “little”, they are more meaningful and have a stronger impact than this word conveys. This reflection is reinforced by Peter et al. (2016) who acknowledge these acts as “small but important” and “meaningful” (p.5). For instance, the authors shared an excerpt from the narrative of a nurse who described reading and watching television with a patient as important and demonstrative of the “enormous responsibility” nurses possess to “not forget that inside broken bodies are people” (p. 34). These so-called “little things” also resonate with McMillan’s (2018) description of micro-ethical moments. In

McMillan's (2018) study on the nature of frontline nurses' experiences of living with organizational change in a tertiary health care institution, she describes micro-ethical moments as "small" but "meaningful" (p. 39) encounters in day-to-day nursing practice that can either empower nurses or challenge them and leave them feeling guilty and inadequate. This finding is supported by Mercy et al. (2017) who suggest, "it is through micro-level interactional episodes that identity is transacted and that individual worth is developed or damaged" (p. 40). Thus, in one respect, engaging personhood through these significant acts not only benefit the patient but also reinforce the nurse's worth. For instance, in McMillan's study (2018), nurses attempted to minimize or rectify morally distressing situations through micro-ethical moments to enact their moral disposition (e.g. overriding medication scanners by manually verifying medications to avoid delays in medication administration during a pain crisis). In doing so, nurses often felt they had to defy the organization's expectations in order to live up to their own. This feeling of going against organizational expectations resonates with my findings where participants described prioritizing humanistic care (e.g. helping a patient shave and brush their teeth) over the task-oriented priorities set by their clinical manager ("Well if you ask our clinical manager she may say 'that's not a priority'" (Judy)). In McMillan's study (2018), a dominant 'culture of service' – which prioritized cost-savings and efficiency resulting in nurses losing the time and resources required to provide quality, safe care – led nurses to feel unable to care in a way that reflected their moral disposition. Using terms such as 'little things' and 'small gestures' to represent meaningful interactions between nurses, patients, and families – as evident in participants' words as well as the language used by nursing researchers – undermines the true significance of these acts (Cody, 2001). The very identity of patients – and their nurses – is at stake, and protected through these not-so-little practices. I encourage nurses at all levels to re-think using terms like 'little', 'small', and 'simple' when describing these meaningful gestures and consider talking about them in a way that truly reflects their importance.

Moral Ramifications: Distress and Damaged Identity

Practice environments influence nurses' abilities to act in ways that uphold their moral identities. As previously mentioned, when acute care nurses are forced to continuously put their values aside and act in ways that do not align with their moral identities, they are at risk of moral distress (Jameton, 1984, Hardingham et al., 2004). Moral distress occurs when a nurse is unable to act in a way that reflects their moral identity. That is, when there is an inconsistency between one's beliefs and one's actions (Hardingham et al., 2004). In a study by Peter et al. (2004) on the moral habitability of the hospital nursing environment, the authors found that nurses perceived the work environment to be morally uninhabitable due to oppressive work environment, incoherent moral understandings, moral suffering and moral influence and resistance. The social and spatial positioning of nurses left them vulnerable to being overburdened by and unsure of their responsibilities. In fact, nurses often found themselves in the position of compromising their moral integrity in order to maintain their self-survival in the hospital or healthcare environment. This compromise resonates with the 'tug-of-war' metaphor that I used to describe participants' moral integrity as being torn between care they felt they ought to be providing and care that was expected of them in their working environment. It also relates to the 'drowning' metaphor used by participants to describe how their metaphorical survival was at stake. Peter et al. (2004) explain that when integrity is threatened, nurses can experience moral distress, moral residue, and in some cases, leave the profession. For example, nurses in their study described a range of emotions that characterized their own suffering, including emotional exhaustion, feelings of abandonment by their organizations and a lack of respect and belonging (Peter et al., 2004). Others in their study spoke of "value conflicts" (p. 361) that made them consider leaving nursing, such as the predicament of not being able to provide quality care and the perception that nurses had become "technicians" and "task-oriented" instead of "caring" professionals.

According to Peter et al. (2004), nurses' spatial positioning also uniquely situated their moral agency within the work environment. Their proximity to patients, often at the bedside, intensified their sense of accountability and prevented them from walking away, as other professionals might do, during ethically challenging situations. Take the following quote by Jameton (2013):

“In their position at the bedside, when patients were overtreated and suffered for it, nurses were often hit hard with distress. Sometimes, they witnessed suffering they could not justify and were hands-on in causing that suffering with suctioning, shots, transporting patients, adjusting ventilators, and so on. To nurses, up close physically and emotionally to suffering, unnecessary pain felt like abuse of patients, and in being complicit in and witnesses to abuse, they themselves experienced abuse. Meanwhile, they resentfully saw physicians enter the patient's room and write orders, only to depart quickly and leave the management of suffering to nurses” (p. 299).

This quote highlights difficult situations in which nurses may feel responsible for causing, or contributing to, the suffering of a patient. This relates to my consideration of suffering as caused by acute care interventions in chapter 2. This quote further resonates with the findings described in my theme of *“The things we do to patients here are not nice”*, in which participants described feeling distressed when they were performing highly interventive procedures to patients whom they felt should have been receiving comfort care instead. This is not to say, however, that nurses' proximity to patients is not good. Proximity is necessary for nurses to understand patients as persons, so that they can appreciate the moral significance of patients' concerns and act on their behalf, particularly when they are incapable of doing so themselves (Malone 2003). The problem is that the current work environment does not support the sustainability of this kind of proximity. Proximity is paradoxical in this regard because, while it propels nurses to act, it can also propel nurses to ignore or abandon personhood. For instance, in a concept analysis of

personhood by Sofronas et al. (2018), nurses in other studies were described as having to bracket their patients' personhood in order to perform invasive, violent, and painful interventions that are often required during resuscitation.

This paradox of proximity (potentially prompting abandonment instead of engagement), as well as the aforementioned notion of bearing witness or turning away, is further understood in Malone's (2000) work on dimensions of vulnerability in emergency department (ED) nursing. ED's are characterized by a rapidly changing pool of patients and the temporal constraints of urgency, which may serve to distract clinicians from engaging with patient vulnerability as well as from confronting their own vulnerability. In her work, Malone talks about how ED nurses find so-called "frequent flyers" – patients who use the ED repeatedly – more 'difficult' as patients because the familiarity that develops disrupts "the thin protection against existential vulnerability" (p. 3) that operates within the normal pace and climate of ED nursing. This challenge of patients becoming "familiar" relates to acute care settings where, despite being designed for acute medical crises and frequent turnover of patients, patients who are terminally-ill often remain on these units. Malone (2000) writes that "knowing the patient solicits a different kind of engagement - and, in turn, creates a different exposure to existential vulnerability - than merely processing the patient's body" (p. 3). Malone's description of non-engagement in the ED aligns with my interpretation of not engaging personhood within an ethos of 'busyness'. In acute care, engaging with dying patients' personhood disrupts the normal pace and climate of this setting.

Malone (2000) explains, however, that two understandings of vulnerability are possible:

1. Vulnerability is equated with susceptibility to particular harmful agents, conditions, or events and is considered something to be avoided or resisted; and
2. Vulnerability as the ever-present, common condition of all sentient beings and a condition of nurses' access to understanding patients' experiences.

According to Malone (2000), authentic nursing practice requires a

willingness to engage with patients by acknowledging “mutual vulnerability”. Malone (2000) challenges the notion of vulnerability as something to be avoided and protected against. Rather, she suggests that acknowledging and even embracing their own vulnerability provides nurses with opportunities for a richer and more authentic relationship with patients. This fear of acknowledging both patient and nurse vulnerability was evident in participants’ descriptions of their own uncertainty in addressing end-of-life issues in practice. Their stories revealed that they were afraid of exposing the vulnerability of their patients as well as their own vulnerability to become too emotionally involved or “attached to” their patients. However, in accepting the ‘risk’ of bearing witness – as described by Naef (2006) – participants can engage personhood more fully. This notion of risk resonates with the following quote by Malone (2000): “This is the paradox of vulnerability; it can be either bond or barrier between nurse and patient, and it is sometimes both” (p. 9). These two different understandings of vulnerability align with the aforementioned choices of bearing witness or turning away. When vulnerability is perceived as something to be avoided, nurses are more likely to choose to ‘turn away’ from opportunities to engage with patients, leaving patients to live through these profound experiences alone. Malone (2000) similarly describes this act of avoiding engagement as “walling off” (p. 6) where nurses explicitly distance themselves from patients and perform nursing as a series of tasks instead of bearing witness to patient vulnerability.

Susceptibility to moral distress is evident in the tensions I describe in the study findings, which ultimately left participants oscillating between engaging personhood in a way that reflects their values and the biomedical culture that prioritizes life-saving interventions and efficiency. The culture of these units is such that nurses feel forced to set aside deeply held beliefs, values and principles in order to make it through their shift. This is supported by nurses in Peter et al.’s (2004) study who were found to work in environments that were dominated by the values of others; hence they were inhibited from fully realizing and being honoured for their own values. If

left unaddressed, moral distress can lead to damaged moral identities (Peter et al., 2004).

According to Nelson et al. (2001), a person's moral identity is damaged when a powerful social group (healthcare organization) views members of a less powerful group (nurses) as unworthy of full moral respect. Liaschenko et al. (2016) describe destructive master narratives that portray members of a social group as socially and morally substandard: "Master narratives are cultural stories that function as summaries of shared social understandings that represent the norms and expectations we have of situations and groups we encounter" (p. 20). These narratives become unconsciously internalized by the group, and may come to direct their values and practices (Liaschenko et al., 2016). One way master narratives may make nurses particularly susceptible to the development of damaged moral identities is when such narratives are overly sentimental and do not adequately portray nurses as knowledgeable and skilled. For example, in a recent literature review by Hoeve et al. (2013) on the public image of nurses and its potential impact on nurses' professional identity, the authors discovered that nurses still suffer from the impact of traditional oppressive norms and stereotypes that lead to the invisibility of their work. For instance, nurses are still often viewed as lacking in leadership and clinical decision-making abilities because of their subordination to physicians, resulting in identity damage (Liaschenko et al., 2016). Damaged identities resonate with my study findings, where participants described the hierarchal power of physicians over nurses in end-of-life care decision-making. The above-cited literature and the large amount of literature that currently exists on moral distress are ample evidence that institutions have the capacity to and often do constrain the moral agency of those who work in them. Furthermore, if left unaddressed, moral distress and damaged moral identities can cause nurses to become burnt-out and disengaged from work. When nurses are disengaged, patients suffer. Nurses may even reduce their working hours or consider leaving the profession entirely.

Moral Distress as a Springboard for Action

Moral distress is described by Varcoe et al. (2012) as a relational concept. That is, moral distress is shaped not only by the characteristics of each individual (e.g., moral character, values, beliefs) but also by the multiple contexts within which the individual is operating, including the immediate interpersonal context, the health care environment and the wider socio-political and cultural context. Thus, context is crucial to understand moral distress. Varcoe et al. (2012) argue that, in Canada, health care restructuring and cutbacks are demoralizing and reflective of a political economy that is based on neo-liberal values that underpin shifts to more business focused and efficiency models of health care. Although a contextual understanding of moral distress brings into starker relief the magnitude of the problem, understanding moral distress as rooted in socio-political and institutional contexts can also point to directions for action (Varcoe et al., 2012).

Rodney et al. (2013) echo this idea by advocating for nurses to be agents who have the opportunity to prevent, ameliorate, and learn from moral distress, rather than see themselves as helpless ‘victims’ of moral distressing circumstances. Building on this focus on *agency* in relation to their organizational and sociopolitical contexts, there is an emerging interest in participatory engagement to develop strategies to help healthcare professionals improve the moral climate of their practice. Such strategies include supportive colleague-to-colleague dialogue, regular interprofessional team debriefings, and improved transparency of communication between administration and practice practitioners (Rodney et al., 2013). Additionally, Nelson et al. (2001) describe the significance of ‘counterstories’, designed to help repair and restore the damaged moral identities of nurses. Lindemann (2014) echoes this suggestion of using counterstories to prevent moral distress and repair damaged moral identities by challenging the aforementioned master narratives that circulate about nursing practice. For

Lindemann (2014), “[A] counterstory is a story that resists an oppressive identity and attempts to replace it with one that commands respect” (p.20). According to Peter et al. (2013) since identities are created narratively, they can also be repaired narratively. As discussed above, one source of moral distress is the result of damage to nurses’ moral identity in circumstances where their values are not supported by others or the knowledge they possess is not recognized. Thus, counterstories are needed that portray nurses as knowledgeable, skilled, and powerful (Peter et al. 2013). The aim of counterstories is to re-identify persons (i.e. nurses) as competent members of a moral community and in doing so enable their moral agency. *Being “less distracted by nursing while nursing”* is a counter-narrative wherein participants described preserving their moral integrity during task-based care by using their tasks as opportunities to engage personhood. This counter-narrative was revealed as a way in which participants created opportunities to engage personhood despite working in an environment that prioritizes task- and efficiency-based care. Counterstories can be created in conversations between colleagues and management, they can be written (e.g. professional nursing magazines/blogs and personal journaling) and they can be co-authored in constructivist qualitative research. In the end, narratives of nursing care are essential not only for the well-being of nurses’ moral agency; they are also valuable for the well-being of healthcare institutions, whose moral integrity is challenged by values of corporatism. With this study, the master narrative that acute care nurses do not have time to engage personhood at the end-of-life is challenged here with a counter-narrative that acute care nurses should, can, and do engage personhood in their everyday practice.

Implications for Nursing Practice, Education, and Research

Although the tensions revealed in these study findings raise concern for experiences of moral distress and damaged moral identities in acute care nurses, they can also act as springboards for action. In a call for action to challenge the dominating biomedical culture of

care that is often present in healthcare institutions where priorities can conflict with patient care and damage nurses' identities and agency, I propose a need for moral communities in contemporary healthcare wherein the ethical concerns of acute care nurses are taken seriously. According to Borgstrom (2014), "relationships are at the heart of good care" (p. 100); Therefore, acute care nurses and nursing leaders need to work together to create moral communities in acute care wherein ethical relationships can flourish.

The findings generated from this research study have implications for nursing practice, education, and research. Although changing the culture in healthcare seems challenging and daunting, acute care nurses must strive for change. Take the following quote by a nurse in Rodney et al.'s (2009) study which explored the meaning of ethics and the enactment of ethical practice:

"Well, we have to have some hope. And so that's how I look at it ...I am in no way thinking that there's not more work to be done (to improve ethical nursing practice). There definitely is. But I have seen successes, and so I think it is possible" (p. 310).

As previously mentioned, nurses are the people that work the closest with patients and their families, therefore, nurses have the capability to instigate change at the practice level. Thus, improving the moral habitability of everyday work environments is dependent on the development of strong narratives of moral identity that can then be supported through moral communities, not only for nurses and nursing leaders, but also for nursing students, physicians, administrators, and policymakers too. Nursing takes place almost entirely within institutions: hospitals, home-care agencies, public health departments, and schools. How these institutions are structured and the organizational values they embrace directly affect the practice of nursing (Weiss et al., 2002). According to Nussbaum (2001):

“The relationship between compassion and social institutions is and should be a two-way street: compassionate individuals construct institutions that embody what they imagine; and institutions, in turn, influence the development of compassion in individuals” (p. 405).

Here Nussbaum refers to the shape of a moral ecology, calling attention to the reciprocal relationship nurses have with the institutional leaders with whom they work. It is this reciprocity between individual nurses and their institutional contexts – between structure and agency (Musto et al., 2018) – that the potential for change exists.

Practice. According to MacIntyre (1981), “No practices can survive for any length of time unsustained by institutions” (p.194). Therefore, engaging personhood behind the scenes needs to be brought to the forefront and recognized by healthcare leaders as an important part of acute care nursing. I propose the need for building moral communities in acute care so that ethical end-of-life nursing practice is consistently promoted. In spite of the task- and efficiency-based priorities that prevail in contemporary healthcare, Liaschenko et al. (2016) argue that hospitals and other health care facilities have the potential to be moral communities that develop and nurture moral agency and respond well to their members, thereby having the potential to sustain positive moral identities. Furthermore, healthcare environments that function as moral communities and that foster the moral agency of its nurses, have been shown to be ‘antidotes’ to moral distress in critical care nurses (Traudt et al., 2016). Traudt et al. (2016) used narrative analysis to explore the reported practices of experienced critical care nurses who were skilled at and comfortable working with families and physicians regarding the withdrawal of aggressive treatment (Traudt et al., 2016). In their findings, the authors describe that, in spite of the frequent

and intense end-of-life situations that nurses experience, their participants did not verbalize moral distress, nor did they demonstrate any of the aspects of moral distress described in the literature. Instead, they demonstrated a strong sense of moral agency that was supported by and contributed to the moral community of their units (Traudt et al., 2016). For example, a frequent source of nurses' moral distress as cited in the literature is a lack of input on end-of-life decision making (Oliveira et al., 2016; Thompson et al., 2006). The participants in Traudt et al.'s (2016) study, however, saw themselves as active participants with not just a key role but also a responsibility to facilitate end-of-life discussions. They reported practices that demonstrated skill in moral communication – the verbal and non-verbal social interaction that enhance understanding of moral situations and informs moral decision-making (Traudt et al., 2016). They also indicated strong awareness of the importance of moral community and saw themselves as critical to the team process of decision-making regarding the withdrawal of aggressive treatment.

A promising initiative at the care level for persons at the end of life is advanced care planning (Thorne et al., 2016). Advanced care planning is both a relational process and a means of engaging personhood at the end of life. According to Heyland et al. (2013), advance care planning is an “on-going process of reflection and communication in which a person who has decision-making capacity makes decisions regarding future health and personal care” (p. 778). This process ideally involves discussions with health care providers, family members, and close friends regarding the person's values and wishes regarding the type of care they want to receive – and do not want to receive – at the end of life (Heyland et al., 2013).

The idea of advanced care planning derives directly from the palliative approach to care in which meaningful conversations about both disease trajectory and the patient's wishes with respect to quality of life are valued (Thorne et al., 2016). According to Thorne et al. (2016), conversations about advanced care planning are meaningful encounters between nurses, patients

and families that are often captured in the moment, rather than scheduled and structured. As previously mentioned, nurses are the clinicians that work the closest with patients and families and, thus, are well-positioned to engage in these meaningful conversations. However, nurses working in acute hospital settings are more likely to wait for physicians to initiate end-of-life care conversations before engaging in these conversations themselves (Thorne et al., 2016). Thus, the biomedical culture of acute care may not only serve to limit what can be said but it can often strip away the capacity of nurses to engage in these important conversations (Thorne et al., 2016). Thorne et al. (2016) critically reflects that nurses' inability to engage in these conversations results in a "paradox of those that are most present often being the ones that are most silenced" (p. 98). I argue here that nurse-patient relationships built on trust and mutual respect can foster meaningful end-of-life care discussions that focus on personhood. Therefore, nurses and physicians share the responsibility to engage in advanced care planning with patients and families.

According to Heyland et al. (2013), advanced care planning is essential to providing person-centered care. Thus, advanced care planning that accurately represents the person's values and wishes is not possible without engaging personhood. End-of-life care planning would also reinforce nurses' moral identity of helping patients feel "human" at the end of life and facilitating a 'good death' for patients and a 'quality bereavement' for families; advanced care planning is associated with better quality of life for patients, better outcomes for family caregivers, improved communication between patients, family and clinicians, and less invasive treatment at the end of life (Heyland et al., 2013). Subsequently, one could argue that if end-of-life care planning was done consistently in acute care then the final theme of this study, "*The things we do to patients here are not nice*" – where nurses described feeling distressed about actively participating in subjecting patients to painful interventions at the end of life – may cease

to exist. Advanced care planning has also shown to improve communication between interdisciplinary staff, which could ease some of the nurse-physician conflict often associated with end-of-life care planning. Nurses need to advocate for models of care that accommodate and foster thoughtful, relational engagement between nurses, patients, and families and support decision-making around the human aspects of quality of life (Thorne et al., 2016). One way to advocate for this change is through moral communities.

As previously discussed in the section on theoretical assumptions, moral communities are described by nurses and clinical ethicists as ethically sensitive and responsive environments (Pavlish, 2014) where members engage in relationships built on trust, mutual respect, and shared understanding of care goals between patients, families, healthcare providers, and administrators. According to nursing ethics researcher Janet Storch (2007), a few essentials are required to develop moral communities. These include having time to be together and to reflect, sharing experiences (e.g. formal meetings *and* informal meetings over coffee and lunch breaks) and having managers who understand and support ethics in practice. Within moral communities, relationships are enhanced, moral problems are named, and organizational supports are built (Storch, 2007). Furthermore, moral spaces are necessary for institutional leaders to understand the needs of all of its members, including all healthcare professionals, patients and families, because all people require care. Walker (2003) also uses the term “space” to refer to actual places and times where there can be meetings, discussions, classes, and rounds “that animate and propel the moral life of that institution and link it to the larger communities of moral discourse in which it nests and to which it must account” (p.20). These conversations require a dialogue that addresses questions such as: What is your understanding of the situation? What counts as a good outcome? What is at stake for you? How do you view your responsibilities in the situation? What is most important to you? What is your view of yourself and others? (Walker, 2003). Therefore,

moral communities can be understood as a place where members are encouraged to bring ethical concerns to light and to deal with these in a manner that promotes shared understanding and mutual respect. This relates to a model of relational ethics for nursing that emphasizes mutual respect as a central theme (Leung, 2010).

The basic premise of relational ethics is that ethical issues, decisions, and actions occur within the context of relationships. The theme of mutual respect is particularly relevant to moral communities as relational because it is the attitude of others towards us and our attitude towards others that fundamentally connect us and reveal how we help and are helped by others (Bergum 2004). Thus, a lens of relational ethics is useful to consider moral communities in healthcare. According to Rodgers (2009), a thoughtful relational ethical stance offers a way to improve practice and policy across all levels for the benefit of health and healthcare as well as society and the environment. A lens of relational ethics sees individuals (whether patients, family members, health care providers, or policy-makers) as “nested” within layers of relationships of power and influence; from the individual through to the organization and beyond. The ideal of moral community is relevant across the entire spectrum of the healthcare system, from individual units to the boardroom, and from interactions between colleagues, patients, and families to issues of policy (such as nurse staffing levels and management philosophies); Nurses and organizational leaders ought to work together as connected moral agents across all levels of the healthcare system (Rodgers, 2009). Three key ideas embedded in a ‘functioning’ moral community are that healthcare workers *think and talk* about the ethics of their practice; that they are *encouraged* by colleagues and management to learn, reflect and share their ethical challenges; and that they are supported and provided with *resources* by managers and senior administrators in doing so (Austin, 2007). Dialogues amongst colleagues about the ethics of their practice can help prevent or diminish ethical conflicts and the moral distress that often follows (Austin, 2007).

The Canadian Nurses Association (CNA, 2017) incorporates the concept of a moral community into its code of ethics. The CNA (2017) code of ethics defines moral community as “a workplace where values are made clear and are shared, where these values direct ethical action and where individuals feel safe to be heard” (p.16). Furthermore, the CNA (2017) states that “coherence between publicly professed values and the lived reality is necessary for there to be a genuine moral community” (p.16). As part of nurses’ ethical responsibilities, the Code states: 1. Nurses foster a moral community in which ethical values and challenges can be openly discussed and supported; 2. Nurses work collaboratively to develop a moral community and, as part of this community, all nurses acknowledge their responsibility to contribute to positive and healthy practice environments; 3. Nurses support a climate of trust that sponsors openness, encourages the act of questioning the status quo and supports those who speak out in good faith to address concerns. According to the CNA (2017), building moral communities can lead to better quality of care for patients and families, health professionals’ freedom to practice safe, competent and ethical care, and the potential for health professionals to experience more meaningful work, which in turn could help with nurse recruitment and retention.

Building moral communities in acute care is an exciting prospect because it will provide channels and forums in which acute care nurses can share and dialogue about the moral experience of providing ethical end-of-life care while simultaneously juggling the many care responsibilities of their acute care unit. Moral communities would allow for the meaningful work described by participants in this study to be brought out from ‘behind the scenes’ and provide space for nurses and other healthcare professionals to speak openly and comfortably about their ethical concerns. Over time, moral communities would enhance the quality of relationships between nurses and their healthcare colleagues, as well as relationships between nurses, patients

and their families. It is also a space where discussions about the importance of advanced care planning and nurses' roles in initiating end-of-life care conversations can begin.

At an organizational level, the presence of moral communities may sensitize managers and policy makers to the ethical experiences of frontline nurses. Thus, through deliberate efforts to develop moral communities, nurses will better articulate — and subsequently defend — the day-to-day relational processes that influence the moral climate of nursing practice and interdisciplinary team functioning. Furthermore, in relation to my theoretical assumption on empty discourse in healthcare, a moral community is “a community in which there is coherence between what a healthcare organization publicly professes to be, and what employees, patients and others both witness and participate in” (Webster et al., 2000, p. 228). Thus, moral communities that ‘hold’ and preserve the moral identity of their nurses can foster a culture where engaging personhood and biomedicine are valued equally, eventually challenging the existence of ‘empty discourses’ in contemporary healthcare.

Education. Several nursing researchers have advocated for the ‘language of nursing ethics’ to be taught to nurses and nursing students in order to better prepare them for the ethical experiences of everyday nursing practice; from ‘typical’ ethically challenging situations to day-to-day micro-ethical moments (Kelly, 1998; McMillian, 2018; Rodney et al., 2009). According to Rodney (2009), helping nurses to use the ‘language of nursing ethics’ is a way to help nurses verbalize their ethical experiences. In Rodney’s (2009) study on nurses as moral agents, nursing participants said their voices were seldom heard when they tried talking about ethically challenging situations. Rodney suspected that this was, in part, due to nurses not explicitly verbalizing a problem as ethical. However, participants’ failure to use ethical language is no indication that they are not living moral experiences. This resonates with my study in that participants did not explicitly use ‘ethical language’, despite describing ethical moments in their

stories. Formal education in ethics and education about the ‘language of ethics’ may help nurses find and express their voices.

There is a need for formal and informal nursing education in ethics (Storch et al., 2002; Rodney, 2009) as well as education preparing nursing students for their work as nurses. The participants in my study described how knowledge they learned in school was inadequate in preparing them for end-of-life care in acute care. For instance, when I asked Kim how she goes about addressing end-of-life suffering in practice, she said: *“Yeah, well it isn’t something they teach you in school. It takes experience”*. Therefore, there is a need for education on end-of-life care with a specific focus on acute hospital settings and the potential barriers that nurses may encounter.

It is important for nursing educators to have open and honest conversations with students about the realities of practice and the importance of voicing any ethical concerns they may experience. Benner (1991) recommends storytelling as an effective way to explore the moral experiences of nurses. But this can start at the level of nursing education whereby nursing students are encouraged to tell stories about ethical experiences they encounter or anticipate encountering. Nursing students, especially, are intensely aware of the discrepancy between what they experienced in hospital practice and what they were taught in schools of nursing (Kelly, 1993; Kelly, 1998). And while undergraduate nursing students are not naïve about the reality of practice, they do view themselves as powerless upon entering the practice of nursing. Thus, through teaching the ‘language of ethics’ as well as engaging in open, honest, and constructive conversations with nursing students, we can empower them with the necessary knowledge and tools to use upon entering the ‘working life’ of nursing and to advocate for moral communities as described above. Indeed, the classroom is a space where discussions about *moral distress as springboards for action* can begin. In nursing education, students need to learn how to deal with

the unexpected and learn from it. They also need to learn that, under the best of circumstances, things go wrong. They need to forgive themselves when they are unable or incapable of doing all that they would like to do. Of equal importance, experienced nurses need to realize the significance of providing a supportive environment for new graduate nurses.

Lastly, discussions about ‘empty discourse’ in healthcare and the risk of using buzzwords such as ‘person-centered care’ need to be initiated in nursing education. Nursing students, practicing nurses, and nurse leaders need to be aware of the consequences of using such terms as ‘tokenism’ (McCance et al., 2011). By spending the time talking about the philosophical underpinnings of these buzzwords, nurses and nursing students can reconnect with the values of the nursing profession and how they can enact these in practice (i.e. personhood, dignity, compassion). It was not until doing this master’s thesis that I was able to put language to my own moral experience as an acute care nurse. My hope is that future nursing students will not have to wait until graduate school to engage with such ideas.

Research. The acute care environment presents many challenges to consistency, communication, and teamwork. Healthcare restructuring is often focused on achieving efficiencies that do not always support effective communication between interprofessional teams (Arford, 2005). Therefore, more research is needed on how to support and structure healthcare environments so that they are conducive to interprofessional communication and collaboration. An interesting study for future research could look at ‘functioning’ moral communities in healthcare and their influence on nursing care as there is an explicit lack of inquiry into acute care units as moral communities. Ethical leadership is an important aspect of creating an ethical climate in which both nurse and patient outcomes are enhanced, therefore more research is needed on the ethical leadership of formal nursing leaders (i.e. clinical nurse managers, charge nurses, clinical care leaders and advanced practice nurses) in acute care and their ability to assist

and foster the development of moral communities on their units. According to Makaroff et al. (2014), formal nursing leaders are often caught in the tension between enacting ethical obligations of the profession and working within the priorities and needs of their healthcare organizations and governments. However, in the current context that emphasizes business and market values, it is not surprising that the ability of nurse leaders to enact ethical leadership based on values related to compassionate and competent care can easily be dismissed or devalued (Makaroff et al., 2014). Thus, formal nursing leaders require support and resources to enact their ethical commitments as well.

This study sheds light on the moral identity of acute care nurses in end-of-life care specifically. Therefore, more research could be done on the moral identity of acute care nursing taking into account their entire scope of practice and the ways in which their moral identity is shaped in this context. Another interesting study for future research could look at the ways in which new graduate nurses working in acute care units with less than two years of experience engage, or fail to engage, personhood at the end of life. This would offer interesting insights as ‘years of experience’ was revealed in the study findings as a potential facilitator to engaging personhood at the end-of-life, while at the same time, one of my most novice participants was deeply reflective and offered insightful ideas about engaging personhood. Such a study might challenge the simplistic idea that relational skill in nursing depends entirely on length of experience. Finally, my decision to re-orient the research question speaks to the potential value of pilot interviews. Therefore, researchers doing similar qualitative research in the future may want to consider conducting pilot interviews prior to initiating data collection.

Limitations

The purpose of this study was to better understand how acute care nurses recognize, engage with, and promote patients' personhood in a way that responds to, and sometimes alleviates, peoples' suffering at the end of life with the greater intention of inspiring a cultural shift in acute care, in which the needs of dying patients are taken seriously. Interpretive descriptive qualitative research allows for knowledge related to human experience to be generated with depth and attention to, without creating findings that are generalizable to a population (Thorne, 2016). Therefore, the findings of this study are not necessarily reflective of all acute care nurses and their experiences of end-of-life care. However, in providing a thorough description of the study setting and participants, the reader should be able to evaluate the extent to which the conclusions drawn are transferable to other settings, situations, and people. For instance, when I presented my preliminary study findings to the members of the palliative care research and education unit of my university, I received feedback that the findings resonated with others' own nursing experiences (both acute care nurses and nurses working in palliative care settings).

Limitations related to sampling may have impacted the study findings. The specific topic of suffering and end-of-life care may have led nurses with a particular interest in these phenomena to volunteer for this study. Similarly, nurses who may be uncomfortable with these topics may have avoided participating in this study, therefore their experiences may not be reflected in the study findings. Another potential limitation is that all participants were women. Although the participants reflected the majority of potential participants for the study, there is a lack of stories from nurses of different cultural backgrounds. According to McClendon et al. (2007), morals are influenced by an individual's personal and professional experiences, religion, family, life experiences and cultural background. Therefore, participants with different cultural backgrounds may possess different moral values. There was also a lack of input from other gender identities. Insight from participants who do not identify as female would have provided interesting insight on the phenomenon of study – especially with nursing's history of being a 'woman's profession'

where a caring identity is often misrepresented as being feminine and sentimental. Thus, further research is needed on whether gender influences nurses' experiences of engaging personhood at the end of life in acute care. There was, however, a wide range in years of experience amongst the study participants, which proved to be relevant to the study findings (i.e. participants described 'newer' nurses as being more task-based in end-of-life care).

A third limitation could be my position as an 'insider researcher'. I worked on the unit of study for two years prior to conducting this study, therefore, it is possible that nurses on this unit may have felt obligated to support me in my endeavors. I was mindful of this limitation, therefore, I purposefully stressed during the recruitment process that participation in this study would be strictly voluntary. According to McMillan (2018), being an insider may also increase the risk of the insider researcher taking things for granted or introducing bias. I mitigated these risks by maintaining transparency in openly positioning myself in the research as well as through reflexive journaling (discussed in the rigour section of chapter 3). Reflexive journaling allowed me to be mindful of the influence of my past experiences, beliefs and values about end-of-life care in acute care on this study. I also mitigated risks of bias through the use of member reflections, which prompted authentic portrayals of participants' experiences. Lastly, collaborating with my academic supervisor and thesis committee resulted in both challenging and inspiring conversations that pushed me to explore beyond the boundaries of my own perspective.

Being an insider also has its advantages in qualitative research. According to Evered et al. (1981), it is the insider researcher who, through lived experiences within an organization is aware of the complexities and human components of organizational life. For instance, knowing the study participants allowed for rich, honest, in-depth conversations that would otherwise not have been possible if I was a stranger to these nurses. Furthermore, in the process of writing this

thesis I came to realize that my own moral identity had been damaged in acute care and that the moral distress that I experienced was the catalyst for this research project. Insider researchers also seek not only to describe the reality of their work lives but strive to change aspects of their work or restructure their workplace in ways that promote supportive environments for its members. Therefore, the discussion around acute care nurses' risk of moral distress is relevant because, as a nurse who has cared for many patients who were dying in acute care, I have experienced moral distress firsthand and I still feel it today. I believe my own experience of moral distress provides credibility and authenticity to this work. In writing this thesis, I engaged in ethical reflections about my experiences of engaging personhood or failing to engage personhood in end-of-life care which led me to clarify some of my own moral understandings surrounding experiences of moral distress.

Conclusion

The findings of this study contribute to a disciplinary understanding of how acute care nurses engage, and sometimes fail to engage, personhood in end-of-life care. Participants' stories about end-of-life care, with a focus on suffering, came to challenge the current discourse in healthcare literature wherein acute care nurses are perceived as being unable to engage personhood due to the biomedical culture of care in these units. In contrast, the study findings revealed that acute care nurses have moral identities oriented towards caring for patients-as-persons, which guide them in helping patients to "feel human" at the end of life. It was revealed, however, that participants were not always engaging personhood fully and were, instead, caught oscillating between ethical end-of-life care that reflects their values and the contextual constraints of working in a biomedical culture of care. The influence of biomedicine was evident across participants' stories which led to a reflection on the effects of constrained moral agency in these nurses. With moral distress and damaged moral identities seemingly on the rise in today's

highly technical healthcare environments (Liaschenko et al., 2016; Thompson et al., 2006), it is important that we focus not only on preserving the identities of our patients but on preserving the moral identities of nurses too. Thus, in writing this thesis I have come to see my nursing colleagues in a new light as persons living profound moral experiences whose moral identities need to be preserved, held, and fostered through the creation of moral communities.

This study demonstrates how a theoretical lens of nursing ethics underpinned by the specific concepts of personhood, moral identity, moral agency, moral community and relational ethics can be a useful frame in better understanding the experiences of nurses providing end-of-life care in acute care units. In conclusion, I would like to offer a personal reflection on the impact this research has had on my own identity as an acute care nurse. In the process of doing this thesis, I have come to better understand the experiences of the participants in delivering ethical end-of-life care in acute care, as well as my own. Upon entering this master's program, I was unable to make sense of the anger and frustration that I felt upon quitting my job after working as an acute care nurse for six years. With some time and space, and many meaningful conversations with friends, family, colleagues, and teachers, I found the courage to embark on this work. Listening and engaging with the stories told by the participants prompted memories of my own experience providing end-of-life care in acute care and provided me with the ethical language and insight that I needed to begin to understand my own experience of moral distress. While I am still working to make sense of my own identity as a nurse, I genuinely hope insights from this study will reach other nurses who may be experiencing similar feelings and inspire them to advocate for change in hopes of moving toward a moral community in acute care that values personhood and biomedicine equally.

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Appendix A: Interview Guide

Interview Guide

1. My first question is very broad. What is it like to be a nurse on this acute care unit?

Prompts: *What does a typical day look like for you? Can you describe a 'day in the life of an acute care nurse'? What are your priorities? With whom do you work most closely, and what are those relationships like? What do you like most about this work? What do you like the least?*

2. As you know, this project is about suffering. This word means different things to different people. To start things off, what does suffering mean to you?

Prompts: *What about in an end-of-life context? What does it mean to suffer at the end-of-life? You've made some [personal/professional] references. I'm wondering if you have any [other: personal/professional] experiences that also influence how you understand suffering at the end-of-life?*

3. Considering what you've said about suffering, in what ways do your ideas about suffering at the end-of-life influence the way that you provide care to people on this unit?

4. Can you think about a specific patient whom you felt was suffering at the end of their life? Talk to me about that case.

Prompts: *How is it that you came to recognize that this patient was suffering? What were the issues the patient was dealing with? How were they responding to their situation? What did they say to you?*

5. Thinking still about this same patient that you've just spoken about, talk to me about the nursing care you provided to this person.

Prompts: *What assessments did you make? What strategies or interventions did you put in place? What was most important to you, as her/his nurse? Do you feel your nursing care of this person was helpful? Why or why not? How do you know?*

6. We began this interview talking about your work as a nurse on this unit. You spoke about how on this unit, [paraphrase some responses from Question 1]. I'm wondering, in what ways does what you've described influence the way that you care for people who are suffering at the end-of-life?

Prompts: *Time to care; Inter-professional relationships; Relational or task-based vision for nursing care on this unit, etc...*

7. Is there anything else that we haven't talked about that you would like to discuss?

Appendix B: Participant Informed Consent Form



PARTICIPANT INFORMED CONSENT FORM

Title of Study:

End-of-Life Nursing Practice in Acute Care Settings: Caring for the Suffering Patient

Principal Investigator (PI):

Lisa Robinson

Master's student at the University of Ottawa School of Nursing

xxx-xxx-xxxx

Principal Investigator's Supervisor:

David K Wright

Assistant Professor at the University of Ottawa School of Nursing

xxx-xxx-xxxx extension xxxx

Participation in this study is voluntary. Please read this Participant Informed Consent Form carefully before you decide if you would like to participate. Ask the PI and study team as many questions as you like.

Why am I being given this form?

You are being asked to participate in this research study because you are a nurse working on an acute care unit who has experience caring for patients at the end-of-life.

Why is this study being done?

Witnessing suffering is part of the everyday work of nurses in all settings, across diseases, and in people of all ages. When suffering is present, it has important effects on the quality of life of patients, families, and nurses. The majority of research on end-of-life nursing practice of suffering patients takes place within palliative care. Therefore, this study will uniquely address how nurses on acute care units care for patients who suffer at the end-of-life. We estimate that 10 to 12 participants will be enrolled in the study.

How is the study designed?

This study involves one-on-one interviews lasting approximately 45 to 75 minutes in length at a location chosen by the participant. The interviews will be audio taped and transcribed word for word. The researcher will also be taking notes during the interviews.

What is expected of me?

You will be asked to meet with the researcher one time for a 45 to 75 minute interview at a place that is convenient for you. A debriefing session will be offered at the end of the interview. Once the data is analyzed, the researcher can contact the participants by telephone to share the findings from the study and provide opportunities for questions, critique, and feedback. You will be asked below whether or not you would like a follow-up phone call.

You will be asked several open-ended questions during the interview. Your answers to these questions will enable a stronger understanding of how nurses care for patients who suffer at the end-of-life. You may skip any questions that make you uncomfortable or that you do not wish to answer.

Will my research data be used in future research?

It is possible that members of the research team (including the PI's supervisors and/or their future students) may want to re-read your interview to answer a different nursing research question. This is referred to as secondary analysis of qualitative data. In the event that your data is used in a secondary analysis, all of the conditions specified here with respect to protection of your personal information will apply. You will be asked below whether you give permission to the research team to use your data in potential future secondary analyses. This permission is separate from your consent to participate in this study.

How long will I be involved in the study?

Your participation in the study will last approximately 45 to 75 minutes. If you choose to have a follow-up phone call, it will last approximately 15 to 30 minutes.

What are the potential risks I may experience?

It is possible that the interview questions may be upsetting as they pose questions related to your experiences caring for patients who are suffering at the end-of-life. You do not have to answer any questions that make you uncomfortable. The interview will be stopped at any point if you feel unable to continue.

Can I expect to benefit from participating in this research study?

There is no anticipated direct benefit to you as a study participant, although some people do find it helpful to talk about their experiences. More generally, your participation will enable a stronger understanding of nursing practice with people who suffer, which can be used to influence education and practice in end-of-life care.

Do I have to participate? What alternatives do I have?

Your participation in this study is voluntary. You may decide not to be in this study. Your decision will not affect your current or future employment at this hospital.

Can I change my mind and withdraw later?

You may withdraw from the study at any time without any impact on your current or future career at this institution.

- You may choose to discontinue your participation in the study.
- If you withdraw your consent, the study team will no longer collect information from you for research purposes.
- You will have the choice of having your data withdrawn from the study completely.

Will I be paid for my participation or will there be any additional costs to me?

There is no compensation for this study. There are no costs to you.

How is my personal information being protected?

- All information collected during your participation in this study will be identified with a unique study number (for example participant #1, 2, 3, ...), and will not contain information that identifies you.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records and will be stored on a secure server.
- All hardcopy study documents will be brought from the interview location to the University of Ottawa, where they will be stored. Any documents leaving the University of Ottawa will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- Research records will be kept for a minimum of 10 years, as required by the Research Ethics Board.
- If records are deleted at the end of the storage time, this will be done securely.

Do the investigators have any conflicts of interest?

There are no conflicts of interest to declare related to this study.

Whom do I contact if I have any further questions?

If you have any questions about this study, please contact the PI, Lisa Robinson, at xxx-xxx-xxxx or the PI's supervisor David Wright at xxx-xxx-xxxx, extension xxxx.

The hospital research ethics board and the research ethics board of the University of Ottawa have reviewed the plans for this research study. If you have any questions about your rights as a study participant, you may contact the Chairperson at xxx-xxx-xxxx, extension xxxxx or the Protocol Officer for Ethics in Research at the University of Ottawa at xxx-xxx-xxxx



End-of-Life Nursing Practice in Acute Care Settings:
Caring for the Suffering Patient

Consent to Participate in Research

- I understand that I am being asked to participate in a research study about how acute care nurses care for patients who are suffering at the end-of-life.
- This study was explained to me by _____.
- I have read, each page of this Participant Informed Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Informed Consent Form.

If interested, please tick one or both of the boxes below:

- ☐ I give permission to the research team to use my data in potential future secondary analyses.
- ☐ I consent to a follow-up phone call from the Primary Investigator to discuss the study findings.

Participant's Printed Name

Participant's Signature

Date

Investigator or Delegate Statement

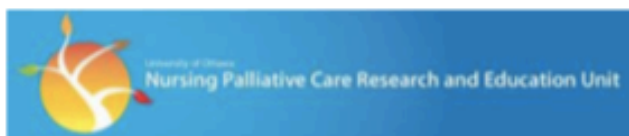
I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Appendix C: Recruitment Poster



INTERVIEW PARTICIPANTS WANTED

RESEARCH STUDY ABOUT PATIENT SUFFERING AND END-OF-LIFE NURSING CARE



Tell us your stories! To participate, you must:

- **Work on either** [redacted]
[redacted]
- **Work full or part time as a Registered Nurse**
- **Have provided end-of-life care to someone you felt was suffering**

Contact Lisa Robinson at:

[redacted]

This study is being conducted by researchers at the University of Ottawa School of Nursing, and has been approved by the [redacted]

PARTICIPATION IN THIS STUDY IS STRICTLY VOLUNTARY

INTERVIEW

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