

**NURSES' MORAL EXPERIENCES OF
ETHICALLY MEANINGFUL SITUATIONS IN END-OF-LIFE CARE**

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Abstract

Nursing ethics in end-of-life care is often framed in reference to dramatic moral dilemmas and resulting moral distress that nurses experience in practice. While important, this framing obscures the moral significance of nurses' everyday practice. The purpose of this study was to explore nurses' moral experiences of palliative and end-of-life care, including situations that are enriching. The research question was: *What are the moral experiences of nurses engaged in ethically meaningful situations in end-of-life care?* Semi-structured interviews were conducted with five nurses from across Canada who practice in settings where palliative and/or end-of-life care are an important part of their role. Informed by interpretive description and a theoretical scaffold about nurses' moral practice, a descriptive and thematic analysis of the data was performed. The participants described ethical challenges relating to patient autonomy, futility, prognostication, and navigating requests for medical assistance in dying. Experiences that were ethically enriching involved situations where the nurse, patient, and family worked together to create a peaceful and dignified death. Taken together, the participants' narratives revealed them as morally engaged in their everyday practice, where such moral engagement is both reflective and relational. This study expands understanding about how nurses' stories of end-of-life care reveal their capacity for moral sensitivity. This study also contributes to the articulation of a theoretical lens for examining the moral dimensions of nursing work. By explicating the relational dimensions of ethically meaningful experiences, including relationships with wider structures that facilitate and constrain the possibility for ethical action, this theoretical lens can support researchers to think creatively about palliative and end-of-life nursing from an explicitly ethical perspective.

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Glossary

This glossary reviews some ethical terminology that I use throughout this thesis. The definitions presented below represent basic and succinct conceptualizations of some key terms relevant to the research study – their full meanings, however, are more complex and nuanced than what can be described here. I hope to demonstrate this complexity and nuance throughout the thesis. Importantly, conceptual understandings in nursing ethics are continuing to evolve with emerging research and scholarship. I also use the terms ‘moral’ and ‘ethical’ interchangeably, which is consistent with the use of these terms in the Canadian Nurses Association Code of Ethics (CNA, 2017).

Moral (ethical) agency: Nurses’ capacity to direct their motives or actions to some ethical end (CNA, 2017; Holt & Convey, 2012; Rodney, 2017).

Moral (ethical) community: A moral community is “a workplace where values are made clear and are shared, where these values direct ethical action” (CNA, 2017, p. 24). Coherence between the professed values and lived reality is essential for a genuine moral community to be developed and sustained, and where individual members of the community feel safe and heard (CNA, 2017).

Moral (ethical) dilemma: According to the CNA (2017), moral dilemmas “arise when there are equally compelling reasons for and against two or more possible courses of action, and where choosing one course of action means that something else is relinquished or let go” (p. 6).

Moral (ethical) distress: A phenomenon in which the nurse makes a moral judgement about the right or best course of action to take, but is unable to realize this ethical choice (CNA, 2017; Jameton, 1984).

Moral (ethical) residue: The leftover and long-term effect of morally distressing situations that, by the nurses' own assessment, caused their integrity to be compromised (Rodney, 2017).

Moral (ethical) resilience: The capacity to sustain or restore moral integrity in response to complexity, confusion, distress, or setbacks (Rushton, 2016).

Moral (ethical) sensitivity: Discernment of ethical dimensions and/or the recognition of values at stake in a given situation (Lützén & Kvist, 2012).

Normative: How the actions that nurses undertake, or the outcomes that they seek, are oriented around ideas about what is *good* for those in their care, where this notion of 'good' is based on values and assumptions about how things 'should' or 'ought' to be (Gastmans et al., 1998; Jonasson et al., 2011)

Chapter 1: Introduction

The everyday practice of nurses is rife with moral implications (Hunt & Carnevale, 2011; D. K. Wright & Brajtman, 2011; D. K. Wright, Brajtman, & Bitzas, 2009). This is because day-to-day nursing work is concerned with morally relevant concepts, such as trust, dignity, choice, integrity, and personhood (D. K. Wright & Brajtman, 2011; D. K. Wright et al., 2009). Nursing practice is essentially normative in that nurses' actions are guided by values and aspirations to bring about what is *good* for the patient (Gastmans, 2013; Gastmans, Dierckx de Casterlé, & Schotsmans, 1998; D. K. Wright & Brajtman, 2011). While inherent to all of nursing practice, these values are particularly salient in the context of end-of-life (EOL) care (i.e. the broad practice of providing care to people prior to and immediately following death) and palliative care (care that seeks to promote an individual's quality of life once a life-limiting diagnosis is established). Nursing values are closely tied to palliative care values – all nurses value the right to quality of life and the importance of individual autonomy, dignity, and respect (CNA, CHPCA, & CHPC-NG, 2015).

Sustained and growing scholarship of moral distress in the context of EOL care and palliative care suggests that much is at stake for nurses when providing care to dying patients (Rodney, 2013). First conceptualized by Jameton in 1984, moral distress is a phenomenon in which the nurse believes she knows the right course of action to take, but is constrained in acting on her ethical choice. Despite over three decades of scholarship in this area, Jameton's original definition continues to be influential; according to the Canadian Nurses Association (CNA, 2017), moral distress arises when nurses make a moral judgement, but systemic structures or personal limitations make it nearly impossible for nurses to do what they think is right. As the concept of moral distress became part of nursing's disciplinary lexicon, researchers have

increasingly sought to understand the phenomenon of nurses being inhibited from “translating moral choice into moral action”, often in the context of EOL care (Rodney, 2017, p. S7).

Issues around the initiation of palliative sedation, the provision of invasive or aggressive care, and conflict about perceived medical futility are frequent sources of ethical challenge and moral distress for nurses providing care to those at the EOL (Johnson & Gray, 2013; Peter, Mohammed, & Simmonds, 2013; Wilkinson, Truog, & Savulescu, 2016; D. K. Wright et al., 2009). In Canada, ethical challenges related to medical assistance in dying (MAiD) are particularly salient, where recent changes to Canadian law grant competent and terminally ill adults with grievous and irremediable suffering the possibility of seeking a deliberately hastened death (Carter v Canada, 2015; Bill C-14, 2016). While issues relating to MAiD, withdrawal of care, and futility have undeniable moral implications, discourse about the ethics of nursing care, particularly in the context of EOL, are often conflated with dramatic ethical dilemmas, eclipsing the moral significance of nurses’ *everyday* practice (D. K. Wright et al., 2009). Also overlooked is the idea that the experience of moral distress is not entirely negative, as at the very least it reminds us that nurses have a keen awareness of the ethical dimensions of their practice.

According to D. K. Wright (2017):

Moral distress, the emotional destabilization we face when we feel prevented from doing what is right for our patients, is painful. But the upside to moral distress is that it reveals a moral engagement in our practice. If we are distressed, it is a sign that our patients, and their vulnerabilities, matter to us. (p. 44)

McCarthy and Deady (2008) argue that understanding moral engagement solely through a lens of moral distress can be limiting, and “it seems fair to say that being involved in moral decision making can elicit a range of different responses, both positive and negative” (p. 260).

Furthermore, focusing on dramatic situations of distress and dilemma alone, has the potential to

perpetuate a reductionist narrative that “implies that nurses are powerless to do anything about their own stress or the situations that give rise to moral distress” (McCarthy & Deady, 2008, p. 260). Without ignoring the pain and suffering caused by moral distress, there is need for a broader reflection and study of nurses’ moral engagement in EOL care, to more fully explore the many diverse responses of nurses faced with ethically meaningful situations. Here, *ethically meaningful* refers to situations that are ethically challenging, as well as situations that are ethically enriching (Barlem & Ramos, 2014; Johnstone & Hutchinson, 2015; Rushton, 2017).

By shifting how we think about and engage with the moral dimensions of nursing practice, we have the opportunity to transform our disciplinary narrative regarding ethics from one of powerlessness, to one of possibility and empowerment (Rushton, 2017). Moral resilience in nursing, conceptualized by Cynda Rushton, a contemporary nursing and bioethics scholar, is “the capacity of an individual to sustain or restore their integrity in response to moral complexity, confusion, distress, or setbacks” (2016, p. 112). The articulation and development of concepts like moral resilience shift the focus away from powerlessness and offer the possibility of imagining solutions that can help transform the conditions that produce moral distress and help cultivate moral communities (Liaschenko & Peter, 2016; Rushton, 2017). A moral community is understood as a workplace where values are made clear, are shared, and direct moral action, and where individuals feel safe and heard (CNA, 2017). Moral experience, a concept introduced by Hunt and Carnevale (2011), offers another lens by which we can consider moral engagement in its broader sense, i.e., as experienced in everyday life, not only in distressing circumstances. Hunt and Carnevale (2011) offer the following definition of moral experience:

Moral experience encompasses a person’s sense that values that he or she deems important are being realised or thwarted in everyday life. This includes a person’s

interpretations of a lived encounter, or a set of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust. (p. 659)

By understanding moral engagement more broadly, such as through concepts of moral experience and moral resilience, we can consider this engagement as an opportunity, rather than a hindrance; an opportunity for growth, self-reflection, and the evolution of moral communities that foster recognition, cooperation, and that promote constructive ethical discourse (Peter & Liaschenko, 2013; Rodney, 2017). Without overlooking the anguish experienced by nurses as a result of moral distress, there is a need to broaden our understandings of nursing ethics and consider the many diverse experiences associated with nurses' moral engagement in their practice (Rushton, 2017).

My interest in this topic is personal as well as academic. I am a registered nurse, with many personal experiences of facing ethically meaningful situations when providing EOL care. During my time as an intensive care unit nurse, I found myself in several patient encounters where my values were being challenged, particularly in the face of EOL care situations. There have been numerous moments where I felt morally destabilized, such as when it felt as though our invasive care was promoting suffering, instead of alleviating it, or when the physician seemed unwilling to discuss futility or goals of care. While certain EOL care nursing experiences have left me haunted, others have created beautiful memories – I have had the privilege of witnessing – and promoting – moments of love, laughter, comfort, and dignity in the lives of dying patients and their loved ones. Through these unforgettable and enriching EOL care experiences, I was able to re-establish my personal 'moral order' and find value and meaning in my work. The idea that there are connections to be made between deeply damaging or disturbing moral experiences and experiences that inspire, motivate, and create meaning for nurses became my motivating curiosity to do this research.

Problem Statement

The narrative of powerlessness associated with moral distress conceals the vast range of responses moral practice can elicit, and may be hindering our ability to appreciate the spectrum of experiences that manifest when nurses engage in the moral dimensions of their practice (Rushton, 2017; Johnstone & Hutchinson, 2015). There is a need to explore and examine other moral experiences brought forth through nurses' moral engagement in their everyday practice, particularly in the context of EOL care, as our knowledge in this area is often eclipsed by moral distress. This study offers a shift in perspective to one that is not limited by a lens of moral distress, and instead changes the focus from victimhood to empowered agency. The phenomena of interest are the moral experiences of nurses engaged in ethically meaningful situations in EOL care, where 'ethically meaningful' refers to the situations that nurses themselves deem ethically challenging and/or ethically enriching. Ethically challenging and ethically enriching experiences are not dichotomous and, in the context of this study, 'ethically challenging' serves as a way to capture experiences where values at stake are thwarted or at risk, whereas 'ethically enriching' serves to capture experiences where values at stake are actualized. Both types of experience are meaningful, and therefore, 'ethically meaningful' serves as an umbrella term to capture the range of morally relevant experiences that nurses encounter. As such, the research question is: *What are the moral experiences of nurses engaged in ethically meaningful situations in end-of-life care?* Informed by Thorne's (2016) interpretive description design, the following two aims will serve as guiding questions for this study:

1. How do nurses describe ethically meaningful situations in the provision of EOL care?
2. What do these descriptions reveal about nurses as moral agents?

Outline of Chapters

The following two chapters (Chapter 2: Pertinent Literature and Chapter 3: Theoretical and Methodological Considerations), create a foundation for understanding the moral experiences of nurses faced with ethically meaningful situations in EOL care. Chapter 2 explores terminology related to EOL care, as well as literature related to nurses' roles and moral engagement in the provision of care at the EOL. Chapter 3 presents a theoretical scaffold, 'nursing as moral practice', that uses relational ethics to weave together the contemporary nursing ethics concepts of moral identity, moral agency, and moral experience in nursing. This scaffold then serves as the framework I use to orient my exploration of nurses' moral experiences in EOL care. Also in Chapter 3 is a review of my study design, including the epistemological, ontological, methodological, and procedural details of my research. In Chapter 4 (Findings), I present the results of a descriptive and thematic analysis of the stories of five nurses whom I interviewed about their ethically meaningful experiences of EOL care. These nurses were drawn from across the country, and all occupied nursing positions in which palliative and end-of-life care was a major aspect of their role. Finally, in Chapter 5 (Discussion) I discuss the research findings as they relate to the theoretical scaffold first presented in Chapter 3, together with extant literature. Chapter 5 also presents the research limitations and implications for practice, education, and research.

Chapter 2: Pertinent Literature

The following chapter, along with the theoretical considerations presented in Chapter 3 (Theoretical and Methodological Considerations), serves as the foundation for my exploration of the moral experiences of nurses faced with ethically meaningful situations in EOL care. The literature review is a valuable component of the research study as it demonstrates what is understood, from published literature, about the most important topics relevant to the phenomena of interest (in this study, ethically meaningful situations in EOL nursing). Beyond that, the literature review generates insights that help situate the research study within a logical frame. For me, the literature review also helps sensitize me to concepts or perspectives that might be missed without a broad engagement with the literature. This literature review is dynamic in that my engagement with the literature was iterative and exploratory. Although I provide a breakdown of some of the approaches I used to begin exploring the literature (see Appendix A), my literature search was not restricted to searches using a fixed set of keywords run at singular moments in time. Rather, as certain topics or ideas were revealed as important to the research study, a renewed and continuous engagement with the literature (through expanding a previous literature search or carrying out a new search) was necessary to develop a conceptual foundation. Without a broad engagement with the literature, the researcher risks overlooking insights that are unexpected or divergent. By undertaking an iterative and flexible approach to the literature review, I am attempting to foster a sensitivity for the diversity of nurses' moral experiences.

This review will present the literature related to the phenomena of interest, focusing first on what is meant by the terms 'palliative care', 'palliation', and 'end-of-life', followed by the pertinent literature on role of nurses in the care of dying patients, across settings, and throughout the trajectory of EOL care (including the transition from curative to palliative and/or EOL care, and up until bereavement and post-mortem care). Then, the literature about the ethical issues

encountered by nurses in the provision of EOL care will be reviewed. Finally, the last section of this review will critique the literature about nurses' moral engagement in the provision of EOL care. The body of evidence synthesized in this chapter reveals that the everyday work of nurses caring for dying patients and their loved ones encompasses a host of duties and responsibilities, and that this care is morally complex and fundamentally relational and normative. Note that when I use the term 'normative' throughout this thesis in relation to nursing care, I am referring to how the actions that nurses undertake, or the outcomes that they seek, are oriented around ideas about what is *good* for those in their care, where this notion of 'good' is based on values and assumptions about how things 'should' or 'ought' to be (Gastmans et al., 1998; Jonasson et al., 2011). I am not necessarily referring to notions of social norms or standards.

The literature also reveals two principal gaps: first, several articles explore nurses' role in EOL care and describe the various normative aspects of this care, yet few articles take an explicit ethical perspective when describing these aspects. Second, while there is ample literature on moral distress and the ethical challenges nurses face in the context of EOL care, fewer articles explore the positive or enriching outcomes associated with moral engagement, or the constructive ways in which nurses can address the ethical challenges they face. Furthermore, few empirical sources acknowledge the potential for moral resilience or other constructive outcomes in nurses who face moral distress and/or ethical challenges in the provision of EOL care.

End-of-Life Care: Terminology and Definitions

Nurses are essential providers of health care across the lifespan of individuals, from birth to death (CNA et al., 2015). The central aim of palliative care, and nursing more broadly, is to help individuals live well until death, across the lifespan, and across all practice settings (CNA et al., 2015). 'End-of-life care' refers to care that starts in the final stage of dying, and continues until death and into bereavement and care of the body (CNA et al., 2015). 'Palliative care' is care

that seeks to improve an individual's quality of life once a chronic, life-limiting diagnosis is received (CNA et al., 2015). Nurses have a duty to provide and advocate for safe, competent, compassionate and ethical palliative and EOL care (CNA et al., 2015). Palliative and EOL care are provided in all practice settings, including primary care settings (such as in the home and community) and acute care settings (such as hospitals, hospices and long-term care settings) (Canadian Hospice Palliative Care Association, 2015; CNA et al., 2015).

All nurses have an essential role in the advancement and provision of a palliative approach to care (CNA et al., 2015). The palliative approach to care refers to the application of palliative care principles, such as dignity, hope, comfort, quality of life, and relief of suffering, to any individual facing chronic and/or life-limiting conditions at all stages, not just at the EOL (Canadian Hospice Palliative Care Association, 2015; CNA et al., 2015). A palliative approach is underpinned by person-centered care, which honours a person's values and wishes, promotes autonomy, and supports informed decision-making in all health-related decisions (Canadian Hospice Palliative Care Association, 2015; CNA et al., 2015). In Canada, the Canadian Hospice Palliative Care Association (CHPCA) has developed a framework detailing the integration of the palliative approach to care – their vision is to help Canadians benefit from the principles of palliative care throughout their illness trajectory (2015). The palliative approach to care is underpinned by holistic care, that respects the individual's wishes and values in all care settings, provides greater access to high quality palliative care services that reflect their goals, and helps individuals achieve greater quality of life and autonomy (Canadian Hospice Palliative Care Association, 2015). The role of Canadian nurses in the palliative approach to care is outlined by a Joint Position Statement put forth by the CNA, CHPCA, and the Canadian Hospice Palliative Care Nurses Group (CHPC-NG) (2015). Nurses play an essential role in the provision of care that reflects the values of a palliative approach to care. Symptom management and pain relief are

inherent to providing quality care, and responding to suffering has the potential to improve quality of life and dignity in life until death (CNA et al., 2015).

The term ‘end-of-life’ is inconsistently defined, despite its common use across practice, research, and policy. In a 2014 systematic review undertaken to understand the concepts and definitions of terms such as ‘actively dying’, ‘end of life’, and ‘terminally ill’, Hui and colleagues (2014) found that only three of 134 articles retrieved conceptualized or defined the term ‘end of life’. According to their findings, EOL can be understood in two ways: first, according to a disease-centered perspective that is defined by a period of irreversible functional decline before death; and second, a temporal perspective that relates to an individual’s limited life expectancy (Hui et al., 2014). Hui and colleagues’ (2014) systematic review also included 12 palliative care and oncology organization websites – according to their findings, only the International Association for Hospice and Palliative Care defined ‘end of life’, which they described as, “That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown” (p. 84).

In the New Zealand Ministry of Health’s Palliative Care Glossary, ‘end of life’ is explained as a period of time prior to death, the duration of which cannot be precisely defined in advance (Ministry of Health, 2015). According to the authors, the EOL period is often triggered by a change or transition in the place of care, level of care, and/or goals of care (Ministry of Health, 2015). This transition can be understood as a change in focus from curative or restorative measures, toward palliative care (Ministry of Health, 2015). In the same Palliative Care Glossary (2015), the term ‘palliation’ is defined as the “alleviation of symptoms when the underlying medical condition or pathological process cannot be cured” and the goal is to improve comfort and quality of life for the patient (p. 12).

Few empirical studies have explicitly sought to understand how nurses themselves define EOL and palliation. In a qualitative study exploring the factors that influence clinicians' recognition of dying in end-stage cancer and heart failure patients, Taylor, Dowding, and Johnson (2017) found that clinicians had difficulty describing in detail how they recognized a patient might be dying, and would often draw on previous experiences to identify patterns which informed their reasoning. Clinicians also described recognizing a patient as approaching death through more intuitive ways of knowing, rather than through standard criteria. One participant, an experienced oncology nurse, stated, "I do have, I don't know, a sixth sense, it'd be silly to say that, but I do kind of know when somebody's dying" (Taylor et al., 2017, p. 6). The findings of the papers just reviewed suggest that EOL is an ambiguous construct.

Nursing Care at the End-of-Life

In order to obtain literature about the role of nurses in the context of EOL care, an initial literature search was conducted using multiple databases and search terms. This initial search strategy is detailed in Appendix A. The findings of my literature review are thematically organized into three sections: first, the role of nurses in the transition to EOL care; second, the nurses' role in the provision of care to dying people; and finally, nurses' role in bereavement support and care of the body.

Nurses' role in transitioning to end-of-life care. While conversations and subsequent decisions around moving from curative care to palliative EOL care are often seen as the responsibility of the physician, nurses play a pivotal role in this transition (Kirby, Broom, & Good, 2014; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). As the primary providers of care who typically spend the most time with patients, nurses are well situated to be proactive in identifying psychological, emotional, and physiological issues that may warrant the initiation of conversations about palliative and/or EOL care (Arbour & Wiegand, 2014; Izumi, 2017; Kirby et

al., 2014). Nurses who care for patients transitioning to EOL care advocate for the patient and family to ensure their wishes are heard and honoured, and to ensure they are receiving the appropriate treatment for their pain and/or suffering (Arbour & Wiegand, 2014; Izumi, 2017; Raymond, Lee, & Bloomer, 2017). In a study by Kirby and colleagues (2014), nurses revealed that maintaining a caring relationship with the patient and family, at this transitioning stage of the illness trajectory, was important to the nurses' role – nurses viewed it as their role to reassure and provide emotional support to the patient and family, to incorporate considerations about pain and symptom management and psychosocial well-being, and to listen and help address their needs and concerns. The authors of this study found that maintaining a trusting, caring, and positive relationship with patients was highly valued by nurses and a core tenet of nursing practice (Kirby et al., 2014).

Nurses provide emotional support and build their relational dynamic with patients and families by being physically present and spending time at the bedside (Arbour & Wiegand, 2014; Ferguson, 2018; Kirby et al., 2014; Noome, Beneken genaamd Kolmer, van Leeuwen, Dijkstra, & Vloet, 2016). By being present, nurses engage in conversations about mortality and futility, listen to concerns and beliefs about the transition to EOL care, and identify care needs and preferences (Kirby et al., 2014; Wittenberg-Lyles et al., 2011). According to Kirby and colleagues (2014), nurses perceived effective transitions to be ones where nurses were given the opportunity to communicate with patients throughout the transitional period. It is through regular contact and dialogue during this time, that nurses are well-positioned to help patients and families understand their situation (Arbour & Wiegand, 2014; Kirby et al., 2014; Wittenberg-Lyles et al., 2011). According to Arbour and Wiegand (2014), “nursing is essential in that patients and their families frequently look towards the nurse attending to their loved one to provide honest information regarding what to expect as death approaches” (p. 216).

Unfortunately, a biomedical model of care that privileges task-oriented nursing, and associated time constraints, impede nurses' ability to prioritize spending time with the patient and/or family and providing emotional support (Kirby et al., 2014; Mahon & McAuley, 2010; Molina-Mula, Gallo-Estrada, & Perelló-Campaner, 2017). Nurses have identified that regular interaction with the patient and family enable nurses to optimize the transition to EOL care – despite this, day-to-day nursing tasks, time constraints, and patient loads impede nurses' ability to ensure adequate communication and supports are in place (Kirby et al., 2014; Wittenberg-Lyles et al., 2011). These barriers reveal that an organizational culture that privileges biomedicine and task-based efficiencies is fundamentally flawed, and creates missed opportunities for nurses to participate in care that is considered meaningful, for both the patient and the nurse (Molina-Mula et al., 2017). For example, nurses must often prioritize tasks and efficiencies, which makes it difficult for them to regularly attend family meetings held by the physician. The scheduling of family meetings outside of how nurses must necessarily organize their work is only made possible by a culture that values instrumental tasks over nursing care. As such, this creates a missed opportunity for nurses to communicate with the patient, family, and physician about the transition to EOL care, to clarify information provided by the physician, to advocate for the wishes of the patient and family, and to ensure that everyone is 'on the same page' (Arbour & Wiegand, 2014; Kirby et al., 2014; Wittenberg-Lyles et al., 2011). While the intimate knowledge about the patient and family is beneficial to the delivery of optimal care during the transition from curative to palliative care, it is of limited value if communication with the physician is irregular or the nursing voice (and nursing 'work') is under-valued (Kirby et al., 2014).

Caring for patients and families during the transition from life-prolonging treatment to EOL care requires intimate involvement of the nurse. Nurses must manage information and

expectations, balance narratives of hope and futility, as well as respond to the emotions of the patient, family, and themselves (Arbour & Wiegand, 2014; Kirby et al., 2014). The responsibility on nurses to communicate with patients and families during the transition to and throughout EOL care is enormous, and nurses perceive that they must maintain their emotional composure when providing support and compassion to others (Barnard, Hollingum, & Hartfiel, 2006; Georges, Grypdonck, & Dierckx de Casterlé, 2002; Kirby et al., 2014; Wittenberg-Lyles et al., 2011). Moreover, nurses have deep consideration for the extent to which they are (or should be) emotionally involved with the patient and family transitioning to EOL care (Arbour & Wiegand, 2014; Kirby et al., 2014). Managing caring relationships with patients and families can be challenging for nurses in this context, and given the emotional weight of their work during the transition period, nurses also require emotional and clinical support during this time (Barnard et al., 2006; Kirby et al., 2014).

Nurses' role in the provision of palliative and end-of-life care. The ideology of a good death has been shown to serve the interests of dying patients and those caring for them – across the literature, authors identify that nurses aspire to provide their patients with quality EOL care, with a good death being the ultimate goal (Barnard et al., 2006; Forster & Windsor, 2014; Fridh, Forsberg, & Bergbom, 2009; Kaasalainen et al., 2013; Kehl, 2006; Robinson, Gott, Gardiner, & Ingleton, 2017). A good death is understood as a death experience with dignity, awareness, peace, adjustment, closure, and acceptance (Kehl, 2006; Robinson et al., 2017). A good death is a uniquely subjective experience, underpinned by a person's values, beliefs, and experiences (Hold, 2017; Kehl, 2006; Robinson et al., 2017). Furthermore, relational, sociological, spiritual, and cultural dimensions influence an individual's perception of a good death, and the ways in which they are cared for at the EOL (Hold, 2017; Robinson et al., 2017). The following section

of this literature review will describe nurses' various roles and experiences in the provision of EOL care, all of which contribute to their ability to actualize a good death.

Building and maintaining relationships. Human beings are relational beings (Kane, Hellsten, & Coldsmith, 2004). It is a fundamental need of people to experience intimate relationships and to have a sense of belonging (Kane et al., 2004). In health care, illness and suffering is a shared experience, not only between the ill individual and their family, but also between the social network of nurses, physicians, social workers, and other providers of care throughout the illness trajectory (Kane et al., 2004; Noome et al., 2016). All individuals live within the context of their social environment, and the role that relationships play in the dying experience is becoming increasingly accepted as an essential facet of compassionate, competent and ethical EOL care (Kane et al., 2004; D. K. Wright et al., 2009).

An individual's experience at the EOL is greatly influenced by their community, culture and family (D. K. Wright et al., 2009). Optimizing family relationships is considered a key component to the achievement of a good death (Arbour & Wiegand, 2014; Kehl, 2006; D. K. Wright et al., 2009). Nurses promote relationships between family members and the patient by encouraging family presence at the bedside and encouraging relatives to talk to the patient and touch the patient, even when they are unconscious or unresponsive (Arbour & Wiegand, 2014; Fridh et al., 2009). Care providers have a duty to learn about the dying individual's perceptions, expectations, and preferences regarding their care and how these affect the social relationships that surround the individual (Kane et al., 2004; Robinson et al., 2017; Sekse, Hunskaar, & Ellingsen, 2017). This task must be carefully balanced by also learning about the family's perceptions, expectations, and wishes and how these influence the family bonds and decision-making (Kane et al., 2004; K. Wright, 2002). In addition, as nurses and other health care providers support the dying individual and their family, they often become significantly invested

in their experience – as such, clinicians are bound to have influence on the experience of patients and families in EOL care (Kane et al., 2004).

Among all health care providers, nurses typically spend the most time with individuals who are receiving care at the EOL (Schroeder & Lorenz, 2017). Much like when the patient is transitioning to EOL care, regular and frequent contact provides the opportunity for nurses to build intimate, caring relationships with patients and families. Nurses identify that building a relationship is essential in providing quality palliative and EOL care across settings (Calvin, Kite-Powell, & Hickey, 2007; Ferguson, 2018; Georges et al., 2002; King, Melvin, Ashby, & Firth, 2010; Kirby et al., 2014; McMillen, 2008; Noome et al., 2016; Offren, 2015; Sekse et al., 2017; K. Wright, 2002). These relationships are underpinned by values of trust, compassion, respect, empathy, and authenticity, and provide the foundation for which EOL care can be provided (Calvin et al., 2007; Georges et al., 2002; Kane et al., 2004; Kehl, 2006; Puchalski et al., 2009; Robinson et al., 2017; Sekse et al., 2017; D. K. Wright, Brajtman, Cragg, & Macdonald, 2015). Without the opportunity to create a therapeutic relational space, nurses believe they are unable to provide optimal EOL care (Fridh et al., 2009; Sekse et al., 2017). Building a trusting relationship with the family is just as important as the relationship with the patient, particularly when the nurse did not have the opportunity to establish a relationship with the patient before they became unconscious – nurses gain insights about the patient through the family's narratives about who the patient is and what their needs and preferences are (Fridh et al., 2009; Noome et al., 2016). Establishing contact early in the trajectory of care, possibly even before the transition to EOL care, is seen as an important aspect of providing quality care at the EOL, particularly among nurses providing palliative care in the community and/or home care setting (Sekse et al., 2017; K. Wright, 2002). Moreover, nurses who care for the patient over an extended period of time and know the family well, or provide care in the intimate setting of the

patient's home, often become emotionally involved; the caring relationship can also turn into one of reciprocity and equality, often similar to a friendship (McMillen, 2008; Offren, 2015). It is important for nurses to be present and spend time with the patient and family at the EOL, in order to build a caring relationship and ensure the patient and family feel supported (Fridh et al., 2009; Kirby et al., 2014; Noome et al., 2016).

Nurses as advocates. Nurses providing EOL care across contexts (i.e. in homes, clinics, hospices, and hospitals) frequently identify advocacy as part of their role (Arbour & Wiegand, 2014; Calvin, Lindy, & Clingon, 2009; Georges et al., 2002; Sekse et al., 2017). According to the CNA (2017), advocacy is, “the act of supporting or recommending a cause or course of action, undertaken on behalf of persons or issues” (p. 5). As part of their ethical responsibilities, nurses must advocate for their patients if they believe their health or their care is being compromised by factors beyond the patient's control, such as the decision-making of others (CNA, 2017). Nurses advocate for their patient's autonomy at the EOL by assisting them to maintain their independence and control of their life, and supporting the decisions they make about their care (Barnard et al., 2006; CNA, 2017; CNA et al., 2015; Kehl, 2006). As advocates, nurses ensure the quality and continuity of care – nurses ensure that the patient and family are well informed, that the information provided by the physician and/or other health care providers is understood, and facilitate conversations about the EOL (Arbour & Wiegand, 2014; Calvin et al., 2009; Dierckx de Casterlé, Denier, De Bal, & Gastmans, 2010; Sekse et al., 2017). In addition, nurses providing care at the EOL advocate for adequate relief of pain and suffering, as well as for the patient and family's goals and preferences of care (CNA, 2017). Patients are, and should be autonomous agents; however, within a biomedical model of care, patients are subordinate to treatments, tests, and protocols established by the organization and/or managing bodies, and their role is too often that of a passive subject (Molina-Mula et al., 2017). As such, the role of nurses

as advocates is relevant and necessary. As stated by a nurse in a study by Calvin and colleagues (2009), “We [nurses] are the eyes and ears for the patient” (p. 146).

Nurses as coordinators of care. The accessibility of nurses compared to other members of the health care team allow them to be a central point of contact for patients and families (Ferguson, 2018; Sekse et al., 2017). As a result, nurses often coordinate services and facilitate communications between other professionals and the patient and family (Allen, 2014; Ferguson, 2018; Holms, Milligan, & Kydd, 2014; Sekse et al., 2017). Nurses consistently identify that good communication within the interdisciplinary team is vital to the provision of EOL care (Ferguson, 2018; Holms et al., 2014). In addition, nurses are liaisons within the care network for patients, aligning and connecting different services or health care providers to ensure the patient receives optimal care (Allen, 2014; Sekse et al., 2017). In order to be effective coordinators of care, nurses build partnerships with other services at various levels of a complex health care system (Sekse et al., 2017). According to Allen (2014), “nursing is relational and not just of people” (p. xi). As formal or informal coordinators of care, nurses are tasked with managing complex relationships with and between people and systems (Allen, 2014). This role requires an ability to be effective communicators, as communication among all key stakeholders in the circle of care is essential to the provision of optimal EOL care (Ferguson, 2018; Holms et al., 2014).

Providing comfort and dignity. Care activities at the EOL are often described as comfort measures or comfort care. Comfort as a concept is difficult to characterize, implement, and evaluate – across the literature, it appears as a noun, a verb (i.e. to comfort), an adjective (i.e. comfortable), as well as a state, process, and/or outcome (Pinto, Caldeira, & Martins, 2016). According to the International Classification of Nursing Practice, comfort is a, “sensation of physical ease and bodily well-being” (International Council of Nurses, 2017). However, this

definition may be reductionist, as it does not account for the environmental, social, psychological, or spiritual dimensions of comfort (Pinto et al., 2016).

Comfort measures are defined as interventions or actions directed to promote the comfort of patients (Oliveira, 2013). The literature reveals that nurses view keeping patients comfortable as an important part of their role (Fridh et al., 2009; Kehl, 2006; Sekse et al., 2017). In a concept analysis on comfort measures, Oliveira (2013) found that nurses enact comfort measures by *stepping in* or *stepping back*, where stepping in refers to the clinician engaging in an action or providing an intervention, and stepping back refers to the clinician making a decision not to act, for the purpose of enhancing comfort. Stepping in might include interventions aimed at relieving pain, coaching (e.g. reassuring and being with the patient), and caring actions that strengthen patients against discomfort, such as hand holding (Oliveira, 2013). Stepping back most often involves withdrawing or withholding one or more treatments to improve comfort and/or prevent future discomforts (Oliveira, 2013). Oliveira (2013) identifies withdrawing and/or withholding enteral or parenteral nutrition and hydration as a common example of stepping back in palliative and EOL care. More subtle acts, such as ensuring patients and families have space to be alone together during intimate moments at EOL, are also instances of stepping back (Andersson, Salickiene, & Rosengren, 2015). Importantly, decisions around action or inaction are not mutually exclusive, and decisions are made largely around patient and family care preferences – nurses may be required to “step in” and provide pain relieving interventions, while simultaneously stepping back, by minimizing interventions or treatments that are considered burdensome for the patient and family (Oliveira, 2013). Nurses identify that comfort care can also include emotional, psychosocial, and existential care (Sekse et al., 2017).

Physical aspects of comfort measures at the EOL include hygiene, pain and symptom management, and positioning (Barnard et al., 2006; Fridh et al., 2009; Pinto et al., 2016; Searle

& Mcinerney, 2008). Across settings, nurses consistently identify that optimizing pain control and symptom management are integral to their role in EOL care (Arbour & Wiegand, 2014; Kaasalainen et al., 2013; Noome et al., 2016; Robinson et al., 2017; Wittenberg-Lyles et al., 2011). In a study of the role of nurse practitioners in the provision of care to residents in long-term care homes, all members of the health care team (including nurses, nurse practitioners, physicians, and other allied health care providers) revealed that they must always be acutely aware of pain and symptom management needs (Kaasalainen et al., 2013). In some studies, pain and symptom management are described in terms of administering analgesics, sedatives, and other treatments to relieve pain, nausea, dyspnea, and other symptoms (Barnard et al., 2006; Kisorio & Langley, 2016; Noome et al., 2016). In other studies, the ability to manage pain and symptoms is understood from a more holistic perspective, where nurses believe that pain management allows relational trust to be established, open conversation to occur, and future needs to be voiced and addressed (Wittenberg-Lyles et al., 2011). Other interventions nurses provide at the EOL include passive range of motion exercises, removal of technology (such as an endotracheal tube, oxygen mask, or monitoring equipment), mouth care, hair care, and bathing (Noome et al., 2016).

The nursing role in creating comfort involves more than a micro-focus on the pain and symptoms associated with dying, but also caring for the broader well-being of the patient and family (Kirby et al., 2014). Taking into account the emotional and psychosocial aspects of pain is important to the overall care of the patient, a notion that is described by the concept of “total pain”, articulated by Dame Cicely Saunders (1978, p. 148). A nurse turned social worker and physician, Saunders founded the modern hospice movement and emphasized that the ongoing development of palliative care is in response to the diverse unmet needs of those facing death (Mehta & Chan, 2008; Saunders, 2000). Total pain is the notion that pain and suffering at the

EOL do not only exist in the physical dimension of an individual's being, but also in the emotional, social and spiritual dimensions (Georges et al., 2002; Mehta & Chan, 2008; Robinson et al., 2017; Saunders, 2000; Sekse et al., 2017). As total pain is subjective and multidimensional, treatments for pain and suffering must also be multidimensional, not limited to only pharmacological interventions, and tailored to meet the specific needs of the individual (Georges et al., 2002; Kehl, 2006). In Mehta and Chan's (2008) article highlighting how total pain can be a useful concept for the assessment and management of pain for cancer patients, the authors provide the example of a man's pain that could not be controlled until he was reassured that his son would be looked after following his death. This example describes how a patient's lack of response to pain medication may be related to unrelieved existential and spiritual concerns, which are real and significant aspects of his pain (Mehta & Chan, 2008). Mehta and Chan (2008) argue that considering pain as total pain is a necessary prerequisite for optimal pain management at the EOL – without properly exploring the other dimensions of the patient's experience, treatments will remain incomplete or ineffectual. In order to meet the needs of dying patients, from a total pain perspective, nurses strive to maintain open communication, ensure patients feel emotionally supported and secure, assist them in maintaining independence and self-worth, support them in leaving a legacy, and assist them in optimizing relationships and achieving a sense of closure (Georges et al., 2002; Kehl, 2006; Mehta & Chan, 2008; Saunders, 2000).

Building on the concept of total pain, spiritual care is increasingly being seen as an essential domain in the provision of EOL care, and refers to care that attends to both religious and existential issues experienced by patients and families at the EOL (Robinson et al., 2017; Wittenberg, Ragan, & Ferrell, 2017). The following definition for spirituality is offered by Puchalski and colleagues (2009):

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (p. 887).

Spiritual support is defined as, “a process through which the sufferer finds order and transcendent meaning” (Kane et al., 2004, p. 181). Spiritual support is beneficial for patients, families, and clinicians at the EOL, as it is associated with improved quality of life, coping, and EOL decision-making (Puchalski et al., 2009; Wittenberg et al., 2017). In a study by Wittenberg and colleagues (2017), nurses identified that discussions about spirituality include the patient’s and family’s spiritual beliefs, anger (such as anger at God about their diagnosis), fears, and regrets. Nurses in this study identified that being able to engage in conversations about spirituality was necessary for the delivery of optimal EOL care (Wittenberg et al., 2017). Importantly, nurses must remain non-judgemental and encourage the expression of the patient’s and family’s beliefs, even if they do not align with the nurse’s own beliefs (CNA, 2017; Wittenberg et al., 2017). Engaging in spiritual care can be meaningful for nurses, it can strengthen the nurse’s own spiritual beliefs, and personal faith can sometimes extend into nursing care (such as through prayer), particularly when nurses face emotionally burdensome EOL cases (Calvin et al., 2009; Olausson & Ferrell, 2013; Wittenberg et al., 2017).

Although the provision of spiritual care is understood as beneficial at the EOL and is part of nurses’ overarching ethical responsibilities, spiritual care is infrequently or inconsistently provided (Kisorio & Langley, 2016; Wittenberg et al., 2017). Nurses often feel unprepared to effectively communicate with patients about spiritual matters (Kisorio & Langley, 2016; Wittenberg et al., 2017). Nurses’ feelings of inadequacy in initiating conversations about spirituality, along with lack of time and/or privacy to have these conversations are barriers to the provision of spiritual care (Kisorio & Langley, 2016; Wittenberg et al., 2017). Furthermore,

Wittenberg and colleagues (2017) identify that the unclear and nebulous definition of spirituality, coupled with confusion around how and by whom spiritual care should be delivered, are major obstacles to the provision of spiritual care.

The overall experience of nurses providing care at the EOL is often described as an experience of privilege (Calvin et al., 2007; Fridh et al., 2009; Kehl, 2006; Offren, 2015). As the primary providers of EOL care, nurses are in a unique position to accompany the patient on their final journey through life, together with their loved ones (Fridh et al., 2009). By integrating the aforementioned experiences and skills into their care, nurses shape the potential for a good death to be achieved. The impact of a good death on nurses can be significant – professional satisfaction, learning and growth from the experience, improved self-awareness and awareness of others, and feeling greater comfort with one's own mortality are potential outcomes of achieving a good death (Hold, 2017; Kehl, 2006). The reciprocity and mutuality experienced by nurses providing EOL care affirms the deeply relational dimensions of caring for the dying (D. K. Wright et al., 2009).

Nurses' role in post-mortem and bereavement care. The nursing role in EOL care continues through family bereavement and care of the body after death (CNA, 2017; CNA et al., 2015; Forster & Windsor, 2014; Raymond et al., 2017). Bereavement care is the provision of nursing care to address the needs of families experiencing grief and bereavement (Raymond et al., 2017). Bereavement care may include addressing psychosocial and emotional needs, and referral to interdisciplinary services to aid in the bereavement process; but, it also begins before death, by maintaining the needs of the dying patient, ensuring adequate pain and symptom control, and preparing the family for death (Raymond et al., 2017). In addition, honest communication about treatment options throughout the trajectory of care can improve the bereavement experiences of the family (Wittenberg-Lyles et al., 2011). According to D. K.

Wright and colleagues (2009), families pay attention to and construct meanings about dignity and quality of life from the care that is delivered to their loved ones at the EOL – these meanings leave a lasting impression at the time of death and into the bereavement experience.

Bereavement care requires nurses to provide emotional support to patients and families, by being present, spending time with patients, and by facilitating and supporting traditional, cultural, or religious practices (Olausson & Ferrell, 2013; Raymond et al., 2017). Nurses have a positive impact on the bereavement experiences of the family by being actively involved in the patient and family's EOL planning, and facilitating means of emotional support and comfort for the dying patient, such as supporting family to stay or sleep at the bedside (Raymond et al., 2017). Moreover, nurses facilitate the fostering of family connections by ensuring that the family is given ample opportunity to spend time at the bedside, and attempt to construct positive memories by ensuring the patient appears clean, comfortable, and while minimizing technology around the dying person (Arbour & Wiegand, 2014; Raymond et al., 2017). Nurses also sometimes connect with the bereaved family in the period following death – depending on their relationships with the family, institutional policy, and their personal character, nurses will sometimes make contact with the family either formally (e.g. formal telephone follow-up, organizing a memorial service) or informally (e.g. attending the funeral) (Dierckx de Casterlé et al., 2010; Macdonald et al., 2005).

Nurses' ability to provide optimal bereavement care is relative to their workload and physical environment (Hogan, Fothergill-Bourbonnais, Brajtman, Phillips, & Wilson, 2016; Kirby et al., 2014; Raymond et al., 2017). Lack of spiritual support after hours, such as little access to chaplaincy services, is a barrier to the provision of quality bereavement care and supports for the family after death (Raymond et al., 2017). In addition, lack of training or education about bereavement care and grief is another barrier to the provision of optimal

bereavement care (Raymond et al., 2017). In a systematic review on the bereavement care roles of nurses in acute care, Raymond and colleagues (2017) found that many nurses had not received sufficient formal education or experience in caring for newly bereaved families. Nurses report seeking guidance from more senior colleagues in order to navigate family bereavement, and there is a need for increased professional development, direction, and support for nurses in the area of bereavement care (Raymond et al., 2017).

In addition to bereavement care, EOL care extends to care of the body after death. In nursing, after-death care is understood as the thoughtful preparation of the body, consistent with patient and family preferences, and ensuring the family can spend time with the deceased (Olausson & Ferrell, 2013). Care of the body after death is an opportunity for nurses to honour and advocate for the cultural, religious, and/or spiritual practices important to the patient and family and participate in post-mortem care rituals that help families accept death, cope with loss, and facilitate grief (Olausson & Ferrell, 2013). Nurses can also facilitate the bereavement process by supporting the family to be involved in care of the deceased, such as cleaning and washing the body (Olausson & Ferrell, 2013). In some instances, the care nurses provide to the deceased can help with their own coping and bereavement needs (Olausson & Ferrell, 2013; Williams, 2016). For example, in Olausson and Ferrell's (2013) qualitative description study of nurses' perceptions of care of the body after death, one nurse stated: "As we cleaned, her daughter talked about what her mom liked and didn't like. We continued care while reminiscing. I believe this time was very healing for both of us" (p. 649).

A biomedical ontological position about death might assume a "cessation view", where death is the end of an individual's existence and where personhood no longer coexists with their physical body (Williams, 2016, p. 136). However, nurses identify that they continue to care for the patient who has died via their remains, often referring to them by name (Forster & Windsor,

2014) – this relational state of being is described by Williams (2016) as “dead personhood”, whereby the nurse considers the deceased as a person, whilst simultaneously recognizing their status as deceased (p. 136). Williams (2016) argues that dead personhood is enacted by nurses through post-mortem care rituals, such as talking to the deceased, cleaning the body, and positioning the body (such as placing the deceased person’s hands together over their abdomen).

By taking controlled care of the body, nurses undertake the practice of assisting the once living into death (Williams, 2016). While biomedical death exists as a single moment or event, the deceased body continues to function socially – as such, the deceased person does not fit into the neat, cultural categories of alive or dead (Forster & Windsor, 2014; Williams, 2016). Nurses’ interaction with the body following death can help make death real, by transforming the body from an embodied person to a disembodied object (Williams, 2016). Nursing care changes following death, where the need to take one’s time, handle the body gently, and speak softly have been identified as important aspects of post-mortem care – the care of the body involves actions aimed at de-medicalizing, cleaning, and positioning the body (Forster & Windsor, 2014; Williams, 2016). Nurses also explain what they are doing to the deceased person, offering apologies or reassurances when the body is being rolled, positioned awkwardly, or when invasive medical devices are being removed (Williams, 2016). This conduct is typically kept up until the face of the deceased is covered and the body is shrouded – it is at this stage that nurses typically cease communication with the deceased via the body (Williams, 2016).

Nurses’ deliberate handling of the deceased body aligns with the ontological position of dead personhood, where nurses are acutely aware of the person’s humanness, even after death (Forster & Windsor, 2014; Williams, 2016). In a study by Forster and Windsor (2014) about the experiences of health professionals in providing pediatric EOL care, the authors found that talking to a child after death was a socially symbolic process, which “(...) was humanising, gave

recognition to a child's spirit, was a sign of respect for a child and a way of de-medicalising the experience" (p. 503). Through these interactions, nurses display the importance of treating the patient with respect and veneration – by managing the care of the body and enacting dead personhood, nurses are maintaining the personal integrity and dignity of the deceased (Williams, 2016).

Ethical Challenges in End-of-Life Care

Providing care to dying patients at the EOL has unequivocal ethical implications. The aspiration to achieve a "good death" for patients is underpinned by nurses' values and ethical standards (Kehl, 2006). The nursing values of promoting well-being, promoting and respecting patient autonomy, honouring dignity, and promoting justice and accountability are all implicated when a nurse is faced with providing EOL care (CNA, 2017). Furthermore, there has been sustained academic interest in the study of moral distress, particularly in the context of nurses who provide EOL care, suggesting that caring for dying patients is ethically challenging for nurses.

Despite ample literature about the experiences of nurses providing care at the EOL, and despite authors often acknowledging value-laden aspects related to caring for the dying, the initial literature search revealed that nurses' role in EOL care is seldom discussed from an explicitly ethical perspective. The following section will describe the pertinent literature about the ethical issues nurses face when providing EOL care.

Relational tensions. As described in an earlier section of this literature review (see pages 15-17) nursing practice is deeply relational – nurses pride themselves on the ability to form caring relationships with patients and families at the EOL, must collaborate and communicate with other members of the health care team, and are culturally embedded within their unit or place of work, organization, and broader societal contexts. As nurses navigate these relational

contexts, they must manage numerous accountabilities, which can be described in terms of fidelity, the moral obligation that one should uphold their commitments and promises (Hamric, 2001). Nurses are faced with multiple fidelities that influence their professional and ethical practice – commitment to the patient and family, although the obvious and precedent responsibility, is not the only fidelity nurses must manage. Nurses are also tasked with remaining faithful to the institution that employs them, their nursing colleagues, and the health care team (Hamric, 2001; Liaschenko & Peter, 2016). Importantly, nurses must also balance these accountabilities with their personal fidelities and remain faithful to their own values, beliefs, and commitments, or they risk compromising their own moral integrity (LeBaron, Beck, Black, & Palat, 2014; Liaschenko & Peter, 2016). Moral integrity is defined as a virtue that relates to one's soundness, reliability, integration of character, and fidelity in relation to their moral norms, standards, and principles, and the preservation of these virtues over time (Burkhardt et al., 2017; Lasala, 2009). In short, moral integrity means having a strong sense of self and acting in ways that are consistent with one's character and values.

In an article on the ethical decision-making of nephrology nurses providing care at the EOL, Cooper (1998) describes that nurses have a primary commitment to the patient's interests, even when this conflicts with the interests of families, colleagues, or the organization they work in. Cooper (1998) goes on to describe that nephrology nurses providing ethical care at the EOL must remain faithful to the patient's identity and values, and support the integrity of their personhood. Ultimately, the values that guide how the patient experienced life are maintained to guide their experience of dying (Cooper, 1998). Pavlish and colleagues (2011), in their study examining the descriptions of ethically difficult situations encountered by nurses across care settings, found that concerns about the patient's quality of life and autonomy were the most

frequently encountered ethical issues, and nurses indicated that the patient's wishes should be prioritized over that of the family and health care team.

However, remaining committed to the interests of the patient (above all else) is not always without challenge. Hold's (2017) study on hospice nurses' day to day encounters with ethical dilemmas revealed that palliative care nurses often encounter other forces that interfere with their commitment to the patient. For example, one nurse in the study felt as though the patient's needs were overshadowed by the family's desire to have "everything done" (Hold, 2017, p. 12). When close relatives disagree with the patient's wishes, are distressed, and/or fear the death of their loved one, nurses have trouble establishing a trusting relationship and their ability to provide optimal care at the EOL can be challenged, requiring nurses to approach the issue with a different set of skills, knowledge, and/or with support from others or their organization (Calvin et al., 2007; Fridh et al., 2009). The role of the nurse in caring for the family can sometimes be more ambiguous than their role in the care of the actual patient at the EOL, despite practice standards that emphasize the importance of patient- and family-centered care (Association of Registered Nurses of British Columbia, 2016; Hamric, 2001; Hold, 2017; Registered Nurses' Association of Ontario, 2015; D. K. Wright et al., 2009). While nurses have a primary responsibility to the well-being of the patient, family members who accompany a loved one in dying have much at stake and often look to nurses for care and support (Hamric, 2001; D. K. Wright et al., 2009). As optimizing relationships is considered an attribute of a good death, managing conflicts within the family can raise ethical challenges for nurses seeking to create and support meaningful connections between the dying patient and their family (Hold, 2017; Kehl, 2006; D. K. Wright et al., 2009). Furthermore, caring for unaccompanied patients through death has moral significance for nurses who wish to ensure a dignified death, particularly because a

good death is often understood as one where the dying patient is not alone (Fridh et al., 2009; Kehl, 2006; Stokes, 2017).

Considerations about the extent to which nurses are (or should be) emotionally or personally involved with patients and families at the EOL can present as a moral challenge for nurses (Arbour & Wiegand, 2014; Erikson & Davies, 2017; Kirby et al., 2014; D. K. Wright et al., 2009). These considerations are often described through the notion of ‘professional boundaries’, which are understood as what delineates appropriate actions from what is inappropriate or ‘out of bounds’, in the context of a relationship between a professional and a patient (Austin, Bergum, Nuttgens, & Peternelj-Taylor, 2006). According to Austin and colleagues (2006), “boundaries emphasize the limits of what the participants should or should not do to preserve the ethical sanctity of the relationship” (p. 81). While boundaries are intended to protect both the client and the professional engaged in a caring relationship, the boundary metaphor is problematic, as its rigidity undermines the possibility for meaningful engagement with the other (Austin et al., 2006; D. K. Wright et al., 2009). D. K. Wright and colleagues (2009) argue that in the context of palliative care, relational engagement is the crux of compassion – decisions to disclose personal experience or personal beliefs can allow for dialogical connections between the nurse and patient/family. However, within biomedical models of care nurses are expected to ‘care for’ patients (through instrumental tasks and checklists), without necessarily ‘caring about’ them (Borgstrom & Walter, 2015). When nurses do perform their instrumental tasks with compassion and commitment to the wellbeing of others, this ‘caring about’ is often unrecognized and unrewarded (Borgstrom & Walter, 2015). Prescriptive rules about what is appropriate and what is not create moral challenges for nurses who feel they must behave professionally, at the expense of connecting personally (Erikson & Davies, 2017; D. K. Wright et al., 2009). Strict professional boundaries promote clinician

detachment and disengagement, rather than allowing consideration for the human relationships at the center of nursing practice, and the human responses to giving and receiving nursing care (Austin et al., 2006; Erikson & Davies, 2017; D. K. Wright et al., 2009).

Another type of relational conflict that can prove ethically difficult for nurses is conflict among health care team members. In their day-to-day interactions, nurses often occupy a position ‘in the middle’ of the patient and the physician (Calvin et al., 2007, 2009; Hamric, 2001). While this is not always morally problematic, it has the potential to give rise to ethical challenges for nurses, particularly when the physician makes unilateral decisions, when nurses are not involved in decision-making processes, and/or when there is a lack of collaboration and communication about the plan of care (Calvin et al., 2009; Fridh et al., 2009; Hamric, 2001; Hamric & Blackhall, 2007; Sekse et al., 2017). The position nurses hold as primary providers of care is an ethical opportunity to advocate for the needs of the patient and family – when tensions between health care providers exist, or when the nursing voice is unheard, the agency of nurses is constrained and their ability to enact their role at the EOL life is challenged (Hamric, 2001; Hamric & Blackhall, 2007; Johnson & Gray, 2013; Searle & Mcinerney, 2008; Sekse et al., 2017). Furthermore, nurses identify that physicians’ reluctance to discuss EOL care options, or suggest the transition from curative care to palliative care, is an ethical challenge in provision of good EOL care (Calvin et al., 2009; Pavlish, Brown-Saltzman, Fine, & Jakel, 2015).

Nurses exist within the relational context of the organization and systems they practice in (Musto & Rodney, 2016; Rodney, 2013, 2017). Nurses must work within complex and often disempowering organizational structures, where power dynamics and organizational priorities that misalign with nurses’ ethical standards create an environment that often produces ethical issues for nurses (Hold, 2017; Rodney, 2013, 2017; Searle & Mcinerney, 2008). For instance, in Hold’s (2017) study about the ethical dilemmas encountered by hospice nurses, a nurse describes

a time when a particular medication (that was effective and appropriate) would not be paid for by a patient's private insurance. The nurse received resistance from her organization about supplying the medication, prompting her to ask whether she is to care for the patient or the company's bottom line (Hold, 2017). In this scenario, the nurse felt conflict as the organization's goals were incongruent with her desire to provide adequate patient care (Hold, 2017). While nurses have a duty to act on moral issues, examples like this reveal that nurses as agents and advocates can only enact these qualities if their broader relational contexts support, encourage, and create channels for them to do so (Carnevale, 2013b; Musto & Rodney, 2016; Rodney, 2013; Searle & Mcinerney, 2008).

Nurses' moral engagement and ability to act according to their ethical standards is further challenged by staffing shortages, cutbacks, increasing patient acuity, team conflict, and organizational decision-making – all factors which affect the moral climate of their workplace (Rodney, Doane, Storch, & Varcoe, 2006). The term moral climate is defined by Rodney and colleagues (2006) as the “implicit and explicit values that drive health care delivery and shape the workplaces in which care is delivered” (p. 24). A positive moral climate is one where nurses' moral sensitivity (one's awareness of the ethical dimensions of their practice) is encouraged and safe channels exist for nurses to voice – and act on – their moral concerns (Carnevale, 2013b; Rodney, 2013; Rodney et al., 2006). Organizations share responsibilities with individual nurses to respond to ethical issues so that, at all levels, the process of navigating these challenges is one of support and collaboration.

Medicalization of dying. The literature reveals that the medicalization and routinization of the dying process is an ethical challenge for nurses (Floriani & Schramm, 2012; Robinson et al., 2017). As advances in technology provide the opportunity for medicine to extend life, nurses are faced with conflict around determinations of futility and the degree to which medicine is

prolonging life and, in consequence, prolonging suffering (Dierckx de Casterlé, Izumi, Godfrey, & Denhaerynck, 2008; Shepard, 2010; Wilkinson et al., 2016). The medicalization of the dying process (or the need to treat and control), as opposed to caring for emotional, spiritual, and social needs at the EOL, create moral conflict for nurses who practice in a context that privileges biomedical care over more holistic models care (Floriani & Schramm, 2012; James & Field, 1996; Robinson et al., 2017). Furthermore, environments underpinned by a biomedical model of care tend to privilege efficiency and task-oriented nursing care, which leave little room for addressing existential concerns and to spend time “being with” the patient and family at the EOL (Barnard et al., 2006; Georges et al., 2002; Kirby et al., 2014; Sekse et al., 2017). An environment that is overly technological and that does not provide space for nurses to engage in the emotional, social, and spiritual aspects of care at the EOL is perceived by nurses as depersonalizing, as violating the patient’s quality of life, and as interfering with the achievement of a good death for the patient (Calvin et al., 2009; Fridh et al., 2009; Kehl, 2006; Robinson et al., 2017).

Perceived or actual inability to provide “good” care. Nurses’ pursuit of a good death for their patients carries significant moral weight – it is a deeply important part of the nursing role at the EOL to relieve suffering and provide comfort. As such, nurses feel a sense of failure or powerlessness when they are unable to adequately attend to their patients’ pain or suffering (Calvin et al., 2007; Georges et al., 2002; Karlsson, Karlsson, Barbosa da Silva, Berggren, & Söderlund, 2013; Wiegand & Funk, 2012; D. K. Wright et al., 2009). In a study to understand the perceptions of ICU nurses about EOL care, Calvin and colleagues (2009) found that when nurses witnessed a patient or family’s pain or suffering at the EOL, they felt pain alongside them. Moreover, nurses across contexts feel morally distressed when they must witness or implement care that causes pain or suffering – examples of this from the literature include overly aggressive

medical treatments, unnecessary tests or procedures, and even basic bodily care such as re-positioning (Browning, 2013; Cheon, Coyle, Wiegand, & Welsh, 2015; Erikson & Davies, 2017; Eriksson, Andersson, Olsson, Milberg, & Friedrichsen, 2014; Johnson & Gray, 2013; Karlsson et al., 2013; Peter et al., 2013; Pugh, 2014; Searle & Mcinerney, 2008). Re-positioning, for instance, can be a source of moral uncertainty for nurses, as performing this action can facilitate the relief of discomfort or pressure on the body, but may in fact disturb the patient or introduce pain (Searle & Mcinerney, 2008). This example reveals that even the most basic and everyday nursing actions are morally complex.

Organizational barriers (perceived or actual) to the provision of EOL care are a source of ethical distress for nurses. The literature reveals that inadequate staffing and resources, along with increases in workload or patient acuity impede nurses' ability to spend time with patients and develop meaningful relationships, across contexts and throughout the entire trajectory of EOL care (including when the patient is first transitioning to EOL care and during the provision of bereavement care) (Fernandes & Moreira, 2012; Hogan et al., 2016; Kirby et al., 2014; LeBaron et al., 2014; Peter et al., 2013; Raymond et al., 2017; Searle & Mcinerney, 2008; Sekse et al., 2017). In acute care, workload is a major indicator of the amount of time nurses can spend with dying patients, and physical environment, such as lack of space or privacy, impacts nurses' ability to provide good EOL care (Hogan et al., 2016; Raymond et al., 2017). Furthermore, insufficient support from nurses' workplaces or organizations when faced with ethical challenges, distress, and grief may perpetuate and/or heighten experiences of moral unease and jeopardize the nurses' ability to cope with stress (Fridh et al., 2009; Kirby et al., 2014; Kisorio & Langley, 2016). When organizational priorities are inconsistent with nurses' core values, such as the desire to form close relationships with patients and "be present", the outcome is often ethically significant for nurses, as nurses are forced to prioritize activities that they may not

perceive as the most important in achieving the patient's goals or needs (Hold, 2017; Kirby et al., 2014; Molina-Mula et al., 2017; Searle & Mcinerney, 2008).

Nursing Moral Engagement in the Provision of End-of-Life Care

As introduced in Chapter 1 (Introduction), nursing moral engagement, in the context of EOL care, is often understood through a lens of moral distress. Ethical issues related to the provision of nursing care at the EOL, such as those described in the previous section, suggest that there is much at stake for nurses when caring for dying patients. The following section will present a critical reflection of the literature around moral distress and moral resilience in the context of EOL care, in order to achieve an understanding of how moral engagement has been conceptualized in the literature. Despite ample literature on nurses' moral distress in EOL care, there remains few sources offering a broader reflection on nurses' moral engagement in this context. Many articles examining moral engagement explicitly focus on the pain and suffering associated with moral distress, rather than seeking to understand the broad range of responses that might result when nurses are engaged in the ethics of their practice. Moral resilience and similar concepts are relatively novel within the nursing literature. There is a need to further examine these concepts as they apply to nursing care at the EOL.

Moral distress. Moral distress is prevalent in the nursing literature, and many nursing researchers have applied Jameton's (1984) conception of moral distress to their scholarly work in many settings, including palliative care, medical-surgical, oncology, critical care, mental health, and geriatrics. Since Jameton's (1984) conceptualization, many nursing scholars have sought to understand, elaborate upon, and at times redefine the concept of moral distress. In more recent conceptualizations, Nathaniel (2006) defines moral distress as, "pain affecting the mind, the body, or relationships" that results from making a moral judgement, but due to perceived or actual constraints, one is unable to act on this judgement (p. 421). McCarthy and Deady (2008),

who critique the lack of conceptual clarity around moral distress, describe the term as “an umbrella concept that captures the range of experiences of individuals who are morally constrained” (p. 254). For McCarthy and Deady (2008), if moral distress is considered as an umbrella term, its conceptual ambiguity is less concerning, as it provides a unified lens to capture different sets of phenomena.

Some authors see specific problems with the discourse of moral distress (Fourie, 2015; Johnstone & Hutchinson, 2015; McCarthy & Gastmans, 2015). Johnstone and Hutchinson (2015) argue that moral distress assumes that nurses ‘know’ the right course of action to take (and are constrained from doing so), but without a critical focus on the soundness of nurses’ ethical judgements that result in this ‘knowledge’. For Fourie (2015), the focus on constraint in prevailing definitions of moral distress is too narrow, and she suggests a broader understanding of moral distress, that results from any kind of moral challenge or moral conflict. Other nursing scholars take issue with the individualized framing of moral distress, and these authors point to the important relationship between nurses and the organizations within which they are embedded – sociopolitical structures impact nurses’ ability to take action in situations of moral distress, and stakeholders at all levels have a responsibility to foster moral communities and address ethical issues (Carnevale, 2013b; Liaschenko & Peter, 2016; Rodney, 2013, 2017).

The antecedents of moral distress are varied; however, issues pertaining to the provision of EOL care are consistently cited as a cause of moral distress, suggesting that there is a lot at stake for nurses caring for dying patients. Nurses caring for patients at the EOL are faced with conflict regarding differing views about futility, prolonging life, and what palliative care options are permissible and when they should be initiated (McCarthy & Deady, 2008; Wilkinson, Truog, & Savulescu, 2016). Nurses can experience moral distress when conflicts arise about decision-making at the EOL – this conflict can manifest within the family, between the family and the

health care team, or among health care providers (such as disagreement between the nurse and physician) (Johnson & Gray, 2013; Karlsson, Karlsson, Barbosa da Silva, Berggren, & Söderlund, 2012; Peter, Mohammed, & Simmonds, 2013). Furthermore, nurses report feeling moral distress when they perceive pain and symptom management as inadequate or inappropriate, and when they feel the patient and family are deceived or not given important information (such as prognosis) (Cheon, Coyle, Wiegand, & Welsh, 2012; Hold, 2017; Karlsson et al., 2012; Piers, Van den Eynde, Steeman, Vlerick, Benoit, & Noortgate, 2012; Wiegand & Funk, 2012).

Organizational and social structures can also generate the conditions that allow moral distress to occur (Hold, 2017; Johnson & Gray, 2013; LeBaron, Beck, Black, & Palat, 2015). Responsibilities to provide safe and ethical patient care are hindered when nurses have a lack of time, resources, staffing, or a poor workplace culture (Lachman, 2016; Mason et al., 2014; Rice, Rady, Hamrick, Verheijde, & Pendergast, 2008). Power dynamics and oppressive environments can prevent nurses from acting on their moral judgments, leading to moral distress and compromised quality of patient care (Johnson & Gray, 2013; LeBaron et al., 2014; Peter, Simmonds, & Liaschenko, 2016; Rodney, 2013; Rushton, 2017).

The consequences of nurses' moral distress when faced with ethical challenges in EOL care are not to be overlooked. Direct consequences on the nurse include negative emotions, such as anger, frustration, and guilt, and feelings of powerlessness and burnout, which can lead to avoidance or disengagement (Arbour & Wiegand, 2014; Barnard et al., 2006; Carnevale, 2013b; Johnson & Gray, 2013; Rushton, 2017). Lachman (2016) also describes moral injury as a consequence of moral distress, where the nurse's individual beliefs about meaning and purpose are shattered. If nurses become disengaged or avoidant of ethically difficult situations, their moral sensitivity (one's awareness of the ethical dimensions of their practice) and ability to care

for patients with integrity are undermined (Georges et al., 2002; LeBaron et al., 2014; Rushton, 2017). The indirect consequences related to these manifestations include compromised quality of patient care, as some nurses choose to avoid situations that might provoke distress, and greater staff turnover, with some nurses leaving their position or profession altogether (Arbour & Wiegand, 2014; Johnson & Gray, 2013; LeBaron et al., 2014; Rushton, 2017).

Moral resilience. Observations of moral distress as a catalyst for constructive outcomes in nurses are scant, and as described in Chapter 1, there is a call for a broader reflection on how nurses are morally engaged in their practice. The articulation and development of concepts like moral resilience are helpful in addressing this need, as they provide language for nurses to describe the enriching and/or constructive outcomes of facing ethically challenging situations (Rodney, 2017; Young & Rushton, 2017). The concept of moral resilience provides an opportunity to reframe how we think about moral distress, provides a means to engage in broader discourse about moral adversity, and provides a novel conceptual lens to engage in nursing scholarship that may reveal a broader understanding of the scope of nurses' ethical engagement.

A concept analysis on moral resilience revealed that only 17 peer-reviewed sources used the terms 'moral resilience', 'morally resilient', or 'moral resiliency', and only few authors attempted to define the concept – even in those who did define the term, there is a lack of unifying definition of moral resilience (Young & Rushton, 2017). Young and Rushton (2017) describe that moral resilience can be understood through its antecedents, which describe the conditions that allow moral resilience to be fostered, and its attributes, which elaborate upon the positive outcomes of moral distress and adversity. In their analysis, Young and Rushton (2017) found that education (ethics education or education more generally), understanding that diversity exists in core human values, and reducing moral stressors (by naming, assessing, and analyzing ethical issues) can all promote the development of moral resilience in nurses. Although this

concept analysis is helpful in beginning a conceptual exploration about moral resilience, more studies need to be undertaken to further elaborate on this concept and to deepen understanding about what it means to be morally engaged in nursing practice.

There is a significant lack of literature explicitly relating to nurses' moral resilience in the context of EOL care. While discussion about the constructive ways in which nurses engage with ethical issues in nursing practice exist, they are few and far between, and seldom articulated through the use of ethical concepts like moral resilience. Furthermore, within the moral distress literature, studies might allude to experiences of growth in the face of ethical challenges, but these experiences often receive only cursory attention, with authors instead focusing predominantly on moral distress.

In a theoretical article aimed at expanding a social psychology model of empathy and compassion in response to suffering to include an ethical dimension, Rushton, Kaszniak, and Halifax (2013) propose four dimensions that should characterize clinician responses to distressing events in EOL care: empathy, perspective taking, memory, and moral sensitivity. Citing Singer and Lamm, Rushton and colleagues (2013) describe empathy (or emotional attunement) as “an affective response to the directly perceived, imagined, or inferred feeling state of another being” (p. 1075). In other words, it is the ability to imagine the emotional experience of another, while maintaining the distinction of self from other. Perspective taking (or cognitive attunement) is the moral analysis clinicians undertake in response to ethically challenging situations – clinicians must “simultaneously evaluate the possible impact of various actions from multiple perspectives” (Rushton et al., 2013, p. 1075). Memory refers to how personal experiences can inform one's response to ethically difficult situations; for instance, past experiences might provide ethical knowledge on how to address a similar issue in the future, or, in the case of unresolved moral distress, might create the conditions for memories to exacerbate

one's distress. Lastly, moral sensitivity is conceptualized by the authors as the "ability to recognize the presence of moral issues in real-world situations" and "that aspect of oneself that evaluates one's own actions" (Rushton et al., 2013, p. 1075-1076).

The authors suggest that when these four dimensions are aligned, clinicians providing EOL care are able to appraise and engage in a robust view of ethical issues, and are able to seek possible solutions, take action, and foster moral resilience. It is argued that although moral distress is an unavoidable reality of nursing practice, clinicians can draw from meaningful experiences to find ways to address it. While Rushton and colleagues (2013) offer a unique theoretical approach to understanding moral resilience in clinicians who provide EOL care, it is somewhat abstract and does not provide specific examples from nurses themselves who respond to ethically significant situations in EOL care every day. As such, there is a critical need for primary, empirical research that explore nurses' moral engagement, including the potential for resilience, in the face of ethical issues in EOL care.

Summary of the Literature Review

Overall, this literature review provides a foundation for understanding the moral experiences of nurses faced with ethically meaningful situations in EOL care. Through the analysis and development of the literature review, I can conclude that nurses' roles in EOL care encompass a broad array of duties and responsibilities, that are predominantly underpinned by relationships and the normative aspiration to achieve a "good death". Furthermore, nursing practice in EOL care is morally complex, revealing many ethical challenges faced by nurses in their everyday work. Finally, moral distress is a deeply important and disturbing issue in nursing, and our sustained and growing scholarship of moral distress in the context of EOL care reveals that there is much at stake when nurses undertake the care of dying patients.

Nonetheless, this literature review also revealed that critical gaps remain in our understanding of nurses' engagement in the ethics of providing care at the EOL. First, the body of knowledge around the role of nurses in EOL care reveals that nurses provide care that is at once value-laden and fundamentally relational in their everyday practice, yet few articles take an explicit relational ethics perspective to understand these experiences. Second, while empirical and theoretical sources about moral distress and the ethical issues nurses face when providing EOL care are abundant, there are few primary research studies that offer broader reflections of nurses' moral engagement with ethically meaningful situations in EOL care.

Chapter 3: Theoretical and Methodological Considerations

To deepen my understanding about the moral experiences of nurses providing care at the EOL, this study drew on techniques from Thorne's (2016) interpretive description qualitative design. This chapter provides a detailed overview of the theoretical considerations that underpinned the study, as well as the study design, including the sample, setting, and procedures for data collection and analysis.

Interpretive Description

According to Thorne (2016), qualitative inquiry seeks to generate empirical knowledge about human phenomena for which depth and contextual understandings of individual human experiences are useful. Interpretive description builds findings around what can be seen or understood by examining a phenomenon, relying on inductive reasoning to build on specific observations that will lend themselves to broader conceptualizations or theoretical constructions through the analytic process (Thorne, 2016). As a qualitative research study, this study was designed in the constructivist paradigm of nursing research. Constructivism offers a worldview that allows researchers to study the meaning of human experiences (Appleton & King, 1997). Constructivist research is underpinned by a relativist ontology, whereby truth is understood as multiple, context-bound constructions that are socially and experientially based (Guba & Lincoln, 1994). Constructivism holds a transactional and subjective epistemology, whereby the researcher and the participants of the investigation are inextricably linked (Guba & Lincoln, 1994). In speaking to the transactional nature of constructivist research, Appleton and King (1997) state, "the researcher must interact with study participants throughout the research process to access the multiple views of reality that may exist" (p. 1). Through this interactive relationship, findings are co-created as the investigation proceeds (Guba & Lincoln, 1994).

Interpretive description was developed to provide qualitative researchers in nursing with a study design set in nursing's disciplinary logic (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997). Thorne (2016) claims that traditional qualitative methodologies of grounded theory, phenomenology, and ethnography have limitations when applied to the nursing context, as these designs have complex relationships between methodological standards and the larger objectives of the discipline from which they were derived (Thorne et al., 1997). Thorne and colleagues (1997) recognized that nurses may be faced with structuring their research around or within these study designs that may not entirely meet their needs. In response to these tensions and the need for qualitative methods aligned with our own disciplinary logic, Thorne and colleagues (1997) developed a descriptive qualitative method built upon nursing's epistemological foundations. The result was interpretive description, which offers a coherent and defensible manner for conducting qualitative research in nursing, that legitimizes nursing's distinct disciplinary reasoning, with the goal of producing empirical knowledge relevant to nursing practice (Thorne et al., 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004).

What drew me to interpretive description is that it offers a disciplinary orientation that is grounded in the realities of nursing practice (Thorne, 2011; Thorne et al., 2004). Furthermore, interpretive description provides a coherent logic and structure for the research study (Hunt, 2009) that is accessible to a novice researcher. Interpretive description studies are underpinned by the assumption that individuals have multiple, unique experiences (Thorne, 2016; Thorne et al., 1997). These experiences are understood to be dependent on context and are socially constructed (Thorne, 2016). Interpretive description studies acknowledge human commonalities, as well as individual variance within a shared phenomenon of interest (Thorne, 2016). Interpretive description is a research approach that is transactional, in that, this study involved the researcher and the participants as active partners in discovering what can be known about the

moral experiences of nurses faced with ethically meaningful situations in EOL care (Thorne, 2016). Interpretive description is consistent with the constructivist paradigm of research and congruent with the focus of my inquiry, in that the disciplinary orientation and analytic approach of interpretive description make it well-suited to answer questions about nursing experience, where such experiences are socially-constructed and unique in their own right.

In order to enhance credibility in interpretive description research, Thorne (2016) has put forth several standards that are to be embedded throughout the research process. These standards include epistemological integrity, analytic logic, representative credibility, and interpretive authority (Thorne, 2016). Epistemological integrity refers to a defensible line of reasoning from the assumptions made regarding the nature of knowledge throughout the study. Analytic logic makes explicit how the researcher is oriented from their theoretical forestructure, and is maintained through to the interpretation of the claims about the results of the research. Representative credibility means the researcher only makes theoretical claims that are consistent with the context under which the study was sampled. Finally, interpretive authority refers to the assurance that the researcher's interpretations are trustworthy. The ways in which I have engaged with Thorne's standards of credibility will be presented throughout this chapter, with a final reflection on credibility in Chapter 5 (Discussion). Importantly, representative credibility and interpretive authority will be judged by the reader based on how the findings of this study are articulated in Chapter 4 (Findings).

An important aspect of interpretive description is the development of a theoretical scaffold, which describes the researcher's theoretical and analytical positioning, and the assumptions, values, and beliefs with which they enter the study (Thorne, 2016). There are two elements to the scaffolding of a study: the literature review, as described in Chapter 2, and the theoretical forestructure (Thorne, 2016). The theoretical forestructure elaborates on the

positioning of the researcher within the field of study and the theoretical world that surrounds it (Thorne, 2016). Developing and maintaining a theoretical forestructure is essential to preserving the epistemological integrity and analytic logic of the study. It is imperative that if the researcher locates themselves within particular theoretical understandings, they must explain their theoretical allegiances and use their theoretical scaffold consistently throughout the study (Thorne, 2016). In constructivist inquiry, the researcher is considered an instrument, and as such he or she plays a meaningful role in shaping the nature and outcome of the research (Thorne, 2016). Thus, it is important to thoughtfully account for the researcher's actions and thinking when entering the study, and throughout the research process (Thorne, 2016). To further enhance epistemological integrity in this research study, a reflective journal was used to track my personal beliefs or assumptions, to track updates and changes to theoretical allegiances as new ideas emerged, and to document how decisions were made throughout the study (Thorne, 2016). As constructivist epistemology assumes that the researcher and the participants are partners in co-constructing the research findings, a reflective journal was a useful space to record the reflections and thoughts that, ultimately, shaped the construction of this study and the research findings.

Theoretical forestructure. While social science disciplines typically undertake research with the aim to generate theory, Thorne (2011) speaks to the applied nature of nursing research when she states, "Nurses study phenomena because we need to understand them in a way that will be applicable to the diversity of context and complexity within the actual realtime setting, and not because they exemplify something that is theoretically interesting" (p. 449). However, I would argue that advancing theoretically 'interesting' phenomena is important in nursing – theory generates concepts and ideas that inform how we practice, how we understand who we are, and what our role is, and helps drive the development of nursing by advancing our

discipline's unique contribution to health care literature (Colley, 2003). Eakin (2016) claims that practice-based research, and interpretive description specifically, has been used to justify atheoretical qualitative research. Eakin (2016) argues, "Such de-theorizing of [qualitative research] may be contributing to the methodological 'simplification' of qualitative inquiry" (p. 110). Therefore, although the methodological approach for this study is informed by interpretive description, I have been thoughtful in conducting it in a way that is not atheoretical.

In this section, I articulate the theoretical knowledge that influenced the construction of this study. As I am particularly interested in a broader understanding of the moral experiences of nurses, beyond moral distress, in the provision of EOL care, I have developed a specific theoretical orientation toward the notion of 'nursing as moral practice'. Inspired by Gastmans, Dierckx de Casterle, and Schotsmans' (1998) philosophical interpretation of nursing as moral practice, the theoretical underpinnings that I bring to this study are built around contemporary concepts in nursing ethics as we understand them today, that I believe relate to and strengthen Gastmans and colleagues' original notion of nursing as moral practice. These ethical concepts, inclusive of moral identity, moral agency, and moral experience, are underpinned by relational ethics, which has emerged as an important framework for understanding moral practice and ethical issues in nursing. In the following sections, I will elaborate on 'nursing as moral practice', the contemporary ethical concepts relevant to the study, and describe in detail how this theoretical forestructure informs my research study.

Nursing as moral practice. In 1998, Gastmans and colleagues published an article that articulated a fundamental ethical view of nursing considered as moral practice. This philosophical-ethical interpretation proposes that the essence of nursing is the virtue of care, a normative ideal that "accepts a goal or ultimate value in which the patient's well-being is represented" (p. 57). The authors propose that nurses achieve the virtue of care through the

relationships they build and the caring actions they perform in their day-to-day practice.

The caring relationship is described by Gastmans and colleagues (1998) as the foundation of nursing moral practice. Caring for another requires the nurse to enter a relational space with the person receiving their care – each encounter is situated in time and place, where nursing care presupposes a reciprocal interaction between the nurse and the patient as two unique human persons (Gastmans et al., 1998). Within this relationship, nurses have an opportunity to engage with and promote the patient's personhood in all of his or her dimensions (i.e. physical, emotional, ethical, social, spiritual) (Gastmans et al., 1998). When a nurse enters into a relation of care with a patient, the nurse becomes part of the patient's social world, and vice-versa (Gastmans et al., 1998). It is in this relational space that the goals and the appropriate means of providing care are negotiated (Gastmans et al., 1998).

The caring behavior is the integration of the nursing virtue of care and the delivery of expert activity that nurses commit themselves to. Gastmans and colleagues (1998) write “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 other words, nurses establish their commitment to patients in *how* they perform the various actions required of them. It is here that the authors distinguish technique and practice – according to Gastmans and colleagues (1998), a technique is appraised by its efficiency, whereas a practice is evaluated by the good that is sought through its delivery. Importantly, the authors state that it is not sufficient to simply itemize the various technical activities and cognitive skills required for nursing. Although many of these skills are required for the adequate delivery of nursing care, “care may not be reduced to its instrumental context” (Gastmans et al., 1998, p. 3).

Take the following hypothetical example, inspired by my own practice: critical care settings are often dominated by a culture that values intrusive physical care and instrumental

tasks. In my own clinical experience, the complexity and number of these tasks are often a measure of how we evaluate the acuity of care – patient situations that require the nurse to perform many instrumental tasks are deemed more complex, and thus require more attention. This can become problematic if, for example, the goals of care change from curative to palliative care and the existential and emotional needs of the patient and family are seen as less complex or less worthy of attention. In my experience, nurses with palliative patients in the ICU are often given additional patients to care for, as patients receiving palliative care are often seen as ‘easier’ – this is morally significant, because it prevents nurses from actualizing what they perceive as good care at EOL, such as working through existential concerns and ‘being with’ the patient and family. When nursing care becomes reduced to its instrumental context (i.e. technical skills and tasks), there are missed opportunities for nurses to participate in care that is considered meaningful (and not always readily measureable) for both the patient and the nurse. This example demonstrates that an instrumental view of nursing is insufficient – nursing is a practice, not a technique.

Gastmans and colleagues’ (1998) foundational claim that nursing practice is moral practice provides a framework for understanding nurses and their experiences more broadly. Nurses have a disposition toward doing what is good or right in a particular situation, and the everyday, locally contextualized relational spaces nurses occupy are also moral spaces (Benner, Tanner, & Chesla, 2009a; Frank, 2004). In the last two decades, since Gastmans and colleagues published their paper, nursing scholars have elaborated and unpacked related concepts important to nursing ethics, including relational ethics, moral identity, moral agency, and moral experience. In the following section, these contemporary concepts will be described, as they inform my theoretical understanding of nursing as moral practice.

Relational ethics. Relational ethics has emerged as an important framework for

understanding moral practice and ethical issues in nursing. Relational ethics is a philosophy that assumes all relationships have a moral dimension, and asks the question “what is the right thing to do”, in the here and now, both for others and for one’s self (Bergum, 2013). Gastmans and colleagues (1998) speak to the importance of relationships throughout their work, going so far as to claim that the caring relationship is the essential condition and foundation of all nursing practice. Other researchers have theorized the importance of relationships as the ethical lens by which we can better understand what nursing is and can be (Carnevale, Teachman, & Bogossian, 2017; Musto, Rodney, & Vanderheide, 2015; D. K. Wright et al., 2009).

By taking on the responsibility to care for others, nurses enter into a relational space as one human responding to another (Frank, 2004; Gastmans et al., 1998). This relationship is ideally one of reciprocity – each nursing encounter involves a continuous flow of ethical decisions and a certain degree of openness exists from one toward the other (Frank, 2004). The nurse enters the relationship acknowledging the other as a whole person, where care is most meaningful when the nurse promotes the patient’s personhood in all of his or her dimensions (Gastmans, 2013).

This construct of understanding the patient in all of his or her dimensions is reflected in Gastmans’ work around vulnerability and dignity-enhancing nursing care. While Gastmans (2013) claims that vulnerability is an essential aspect of being human, he argues that there are certain people who are “extraordinarily vulnerable”, such as patients with dementia (p. 146). On how the vulnerability of those with dementia is situated in all dimensions of their personhood, Gastmans (2013) writes:

Persons with dementia are vulnerable not only with respect to their frail bodies but also with regard to the psychological, relational, social, moral, and spiritual dimensions of their being human, regardless of whether they are cognitively aware of their

vulnerability” (p.146).

Nurses enter a relationship with the other as a person who needs care, but must also recognize this person is unique and has unique values in his or her own right (Gastmans, 2013). Relational ethics posits that all relationships have moral weight – in connecting with others, nurses try to enact what is good, just or right for themselves and for (or with) others (Bergum, 2013). Through a lens of relational ethics, Carnevale, Teachman, and Bogossian (2017) state: “What is ethically right is understood through meaningful dialogue regarding interdependence and connectedness of persons” (p. 274). Through dialogical and interpretive engagement with the other, nurses occupy a relational space where their moral practice manifests in the day-to-day, locally contextualized moments that are experienced as one human voice responds to another (Carnevale et al., 2017; Frank, 2004; Hunt & Carnevale, 2011; Rodney et al., 2009; D. K. Wright & Brajtman, 2011). If the relational space is where morality is understood, examined, and enacted, then nursing ethics can be considered in every encounter and with every patient (Bergum, 2013; Carnevale et al., 2017).

A relational ethics view of nursing moral practice holds that nurses’ moral understandings are based on their experiences, history, and context (D. K. Wright & Brajtman, 2011). As described in Chapter 2, positivist and objective ideas about ‘boundaries’ and professional detachment deny the contextual realities of what it means to enter into a relation of care with another (D. K. Wright & Brajtman, 2011; D. K. Wright et al., 2009). When human relationships are considered at the center of nursing practice, there is an opportunity to promote meaningful engagement, which is the “capacity to connect and be with another in an intersubjective, mutual, and authentic way, all while honoring complexity and ambiguity” (D. K. Wright & Brajtman, 2011). Nurses and their patients do not exist in isolation from one another – a lens of relational ethics provides an opportunity to move beyond an individualist focus on

ethics to one that is contextually rich and acknowledges the inexorable connections nurses make with those in their care (D. K. Wright et al., 2009).

According to Rodney (2017), “people and systems don’t exist in isolation from one another” (p. S9). Relational ethics offers a lens that allows for a deeper appreciation of the relationship between nurses and the social, political, and organizational structures they practice within (Rodney, 2017; Rodney, Kadyschuk, et al., 2013). Organizational structures dictate how care is organized (i.e. day-to-day nursing tasks and nurse to patient ratios), that create missed opportunities for nurses to participate in care that considered meaningful, for both the nurse and the patient (Kirby et al., 2014; Molina-Mula, Gallo-Estrada, & Perelló-Campaner, 2018; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). For example, an organizational culture that privileges nursing tasks over relational engagement can leave little time for nurses to address existential concerns and/or engage in meaningful relationships with those in their care (Barnard et al., 2006; Georges et al., 2002; Kirby et al., 2014; Sekse et al., 2017). This example demonstrates how certain structures can disempower nurses striving to provide good care at the EOL; however, according to Rodney, Kadyschuk, and colleagues (2013), sociopolitical and organizational structures also have the potential to empower nurses. For instance, relationships between nurses and their colleagues and/or organizational leaders that are built on trust and mutual respect, and where all participants in the relationship are knowledgeable and approachable, can help support nurses in addressing their moral concerns. As such, recognition of and reflection on moral issues must not only be enacted by nurses, but also at a collective level (Rodney, Kadyschuk, et al., 2013).

Moral identity. Identity is the product of an individual’s sense of self with other’s understanding of who the individual is (Peter et al., 2016). Moreover, moral identity is described by Walker (2007) as an ongoing account of, “(...) where we stand and what we stand for” (p.

119). How we understand, communicate, and fulfill our responsibilities, defines our moral identities. The importance of responsibility to moral identity is exemplified by Peter and colleagues (2016) when they write that moral identities “reflect our ongoing moral histories of what we take responsibility for, respond to, are concerned about, care for and value” (p. 3). Moral identities are socially constructed and relational, as they are created by the relational histories, practices, and characteristics of a particular way of life, much like the identity of a ‘nurse’ is a social construction (Peter & Liaschenko, 2013; Peter et al., 2016). Furthermore, relationships have implications for how nurses conceive of moral issues, and how they understand and enact their moral responsibilities (D. K. Wright & Brajtman, 2011). Our moral identities are inevitably intertwined with the relationships we hold, in that the connections we share with others are expressions of our values (Walker, 2007).

In an ethnographic study to explore ethical conflicts in oncology, and what aspects of the health care environment averted or mitigated these occurrences, Pavlish and colleagues (2015) conducted focus groups and individual interviews with nurses, ethicists, nurse administrators, and oncologists. These authors found that differing moral perspectives are built on diverse moral identities that are informed by conceptions of “what it means to be a good nurse, oncologist, parent, or patient” (Pavlish et al., 2015, p.133). This is consistent with Peter and colleagues’ (2016) findings when examining the narrative stories of nurses, in that the socially constructed identity of a good or virtuous nurse operates as a normative expectation of who nurses are or should be. Moreover, these narrative stories revealed that the nursing profession cannot be simply reduced to a means of employment – often, the values and commitments of nursing as a discipline are infused in one’s sense of self (Peter et al., 2016). According to Sekhon (as cited in Peter et al., 2016), “Life – and nursing – is not about being the ‘bigger person,’ it’s about bettering yourself and the ones around you, connecting and co-creating a meaningful life” (p. 5).

Moral agency. In recent years, moral agency has emerged as an important component to nursing moral practice, as it directly relates to the capacity of nurses to direct their motives or actions to some ethical end (CNA, 2017). Moral agency implies a capacity to make choices about the right course of action based on an evaluation and judgement of a particular ethical encounter (Holt & Convey, 2012). According to Rodney and colleagues (2013), “nurses are not disengaged thinkers” (p.160). Moral agency is enacted from nursing knowledge (we act in accordance with what we believe or what we know about a particular case or context) and through the commitments we hold (our actions arise from the ethical commitments we have, which are informed by the relationships we enter into with those in our care) (Rodney, Kadyschuk, et al., 2013).

Importantly, nurses as moral agents must be capable of justifying the choices they make – Holt and Convey (2012) argue that following a morally defensible course of action, as opposed to simply following the law or a code of ethics, is a much more meaningful form of accountability. Reducing nursing moral agency to simply following a set of duties and principles does not give credit to the commitment nurses have as moral agents and their horizon of accountability (Holt & Convey, 2012; Peter et al., 2016). Codes of ethics, while valuable and necessary, tend to list the ethical standards and obligations that must be met in nursing (Carnevale, 2013b; Snelling, 2016). In some jurisdictions, these codes are used as a regulatory framework which outline the minimum expectations of ethical nursing care that nurses can be evaluated against (Carnevale, 2013b; Snelling, 2016). When codes are used as a regulatory framework, they promote a minimalist view of what ethical nursing is and the capacity nurses have as moral agents (Carnevale, 2013b; Snelling, 2016). According to Carnevale (2013), “following codes of ethics is *necessary* but not *sufficient* for defining moral agency in nursing” (p. 36). Moral agency is a useful frame to move beyond deontological rules of what it means to

be an ethical nurse, towards a richer conception of the deliberate and morally relevant actions nurses take to ensure their patients receive care that is good, right, and just (Carnevale, 2013).

That being said, it is important to recognize nurses in relation to their sociopolitical and organizational contexts, as power dynamics and oppressive environments may constrain nurses from enacting their moral agency, which can lead to moral distress and unsafe or poor quality of care for patients (McCarthy & Gastmans, 2015; Peter et al., 2016; Rodney, 2013). According to Musto and Rodney (2016), a relational view of moral agency holds that an “individual agent’s actions [are] nested within layers of structural contexts that are infused with complex power dynamics” (p. 77) – nurses, as moral agents, are relationally embedded within their sociopolitical contexts that shape the courses of action that are available to them (Carnevale, 2013b; McCarthy & Gastmans, 2015; Rodney, 2013). Nurses, along with their colleagues and organizational leaders, share the responsibility of confronting ethical issues. In order for progress to be made, nurses must be recognized as moral agents and must be supported in voicing concerns and enacting change (Carnevale, 2013b). By fostering moral communities within their respective organizational contexts, nurses and leaders can transform morally restrictive environments to ones that nurture moral agency and strengthen moral identities (Peter et al., 2016).

Moral experience. The concept of moral experience has emerged as a framework for bioethics research that allows ethical issues to be assessed more broadly. The conceptualization of moral experience offered by Hunt and Carnevale (2011) is as follows:

Moral experience encompasses a person’s sense that values that he or she deems important are being realised or thwarted in everyday life. This includes a person’s interpretations of a lived encounter, or a set of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust (p. 659).

Inquiry into moral experience does not seek to identify universals, but rather understand real life

experiences and the meaning that individuals ascribe to a particular encounter (Hunt & Carnevale, 2011). Research around moral experience seeks to understand the values the individual deems important, and how these values are enacted and impeded – situations where values are actualized are just as worthy of consideration as those where values are in jeopardy (Hunt & Carnevale, 2011). As such, moral experience does not focus on strictly negative lived encounters, but instead considers encounters on a spectrum; individuals may ascribe a particular event as anywhere from good to bad, right to wrong, or just to unjust (Hunt & Carnevale, 2011). Ultimately, moral experience provides a lens to explore how individuals engage with the moral dimensions of their everyday life (Hunt & Carnevale, 2011).

Rashotte's (2005) reflective article on pediatric critical care nurses' experience of grief focuses on the meaning of the stories that "haunt" nurses following the death of a child. This particular article is an example how moral experience can be a useful concept to engage when trying to uncover the deeply-rooted moral nature of nursing experiences. Rashotte's (2005) articulation lends itself well to the idea that the day-to-day, ethically relevant EOL experiences faced by pediatric critical care nurses cannot be reduced to simply negative encounters. Instead, Rashotte (2005) describes how nurses survive and find meaning in the face of grief, and how encountering the death of a child touches the nurse in a way that effects their moral identity – who they are as a person and as a nurse. Although anguishing, these encounters create and reinforce the ongoing moral responsibilities nurses hold themselves accountable to, and by reconstructing them into a more productive form, nurses can implement the ethical knowledge gained from these encounters in the care of other dying children. In the following passage, Rashotte (2005) explains how nurses reframe the meaning(s) created from grief following the death of child (p. 39-40):

It is my belief that nurses' grief causes a reflection upon their practice, questions of doubt

about how it could be better. Their doubt becomes a good attribute. It becomes a *knowing*; it becomes a critic. The nurses ask what it is that is ugly in the care that has been provided. Storytelling becomes the means of demanding proof of it and testing it, sometimes because they are perplexed and confused, but sometimes in protest. But they don't give in. They demand arguments (either within themselves or of others). They act with alertness and responsibility, each and every time, and the day comes when doubt that came from grief becomes one of their wisest fellow-workers.

Rashotte's work provides an example of the rich moral nature of nursing experiences, and uncovers how we can arrive at a more thoughtful understanding of moral experience by considering it in relation to moral identity (i.e. moral experiences leave a lasting impact on nurses by reinforcing their moral responsibilities) and moral agency (i.e. moral experiences are a source of ethical knowledge that nurses can implement in the care of others).

Importantly, nurses not only *have* moral experiences, but are *affecting* moral experiences. By caring for people in all of their dimensions, by seeing beyond the technical aspects of nursing work, and by entering a relation of care with intention, nurses demonstrate that they care about the sort of moral person the patient (or family) will become through their experience of illness (Frank, 2004; Gastmans, 2013; Rashotte, King, Thomas, & Cragg, 2011). Nurses are deeply committed to those receiving their care and strive to create a legitimate space where the patient and family's voices are welcomed and heard (Rashotte et al., 2011). In decision making, the nurse's role is not to push the patient towards what the nurse believes is most desirable, nor is the nurse to enter the encounter knowing what values apply and how – instead, he or she meets the patient in a relational space where values are learned and clarified, and where the nurse helps the patient find meaning in their experience (Frank, 2004; Gastmans et al., 1998). The person for which the nurse cares must be understood and respected as a moral subject (Gastmans et al.,

1998).

The theoretical forestructure presented in this chapter serves several purposes. First, this theoretical worldview informs the questions asked of the participants, as the interview guide (Appendix B) was developed with an orientation to the notion of nursing as moral practice. As a researcher, I bring with me my theoretical assumption that nurses' practice in EOL care is a moral practice, defined as a coming together of moral identity, moral agency, and moral experience. My task during interviews was to encourage nurses to reflect on and speak to each of these dimensions as they relate to their everyday work.

In addition, this theoretical forestructure informed how the data was analyzed. A theoretical position oriented around nursing as moral practice provided an analytic lens that brought to light the rich, nuanced, and value-laden foundation of nursing – by applying this theoretical lens, I looked for a spectrum of moral experiences, not only those that were damaging, and sought to understand how the participants were engaged in values-based actions or reasoning in their everyday practice.

Methodological Considerations

Sample. Participants were chosen using purposive sampling. Purposive sampling refers to a sampling technique where the researcher chooses participants that will benefit the study (Polit & Beck, 2007; Thorne, 2016). According to Sandelowski (1995), sample sizes in qualitative research should focus on quality of data collected – an adequate sample size is one that is small enough to allow for a deep, comprehensive analysis, yet large enough to result in a rich array of experiences, understanding, and meaning. According to Thorne (2016), sample size is determined based on the collection of qualitative data until only redundant information is found and no new categories have emerged (Thorne, 2016). The sample of this study consisted of five participants. When the study was initially proposed, the desired sample was

approximately ten participants; however, recruitment was stopped at five participants to allow for timely completion of the thesis. In the context of a national study with participants from different practice settings, the sample size of five participants prevents me from making broad, transversal claims from the research findings. However, through the participants' accounts and varied backgrounds and experiences, I am able to make inferences about certain theoretical notions of nursing as moral practice and demonstrate how the theoretical considerations presented above may provide a useful lens for exploring nurses' moral experiences. As the recruitment strategy was broad, spanning across Canada, the goal was to achieve some sense of representation from nurses across the country. Representation in this sense is not referring to the sample being large and diverse enough to represent or speak to a whole, but instead refers to the idea of meaningfully thinking about the sample, the subsets created for the purpose of answering the research question, and the rationale for what groups are worth attending to and how this angle might privilege or silence particular individuals (Thorne, 2016).

Two recruitment strategies were employed in the initial round of recruitment: 1) through collaboration with the CNA who distributed the information letter electronically to a mailing list of specialty certified nurses who expressed interest in supporting the CNA's specialty certification program; and 2) through key informants on the research committee, who identified potential participants and distributed the information letter (Appendix C), followed by a snowball approach to recruit additional participants. Nurses certified in CNA specialities that have specific competencies related to EOL care were sought; these specialities include critical care nursing (adult), critical care nursing (pediatrics), hospice palliative care nursing, nephrology nursing, and oncology nursing. Specialty certified nurses were chosen as the purpose of the study was to gain a deeper understanding of nurses' moral engagement – it was expected that nurses who have recently engaged with specific competencies related to EOL care and who have deeply

reflected upon their practice, as required by their chosen specialty to become certified or maintain certification, would be able to speak to their moral engagement in EOL care. According to Thorne, the expert practitioner's "perspective will have been formulated on the basis of seeing many 'cases' over time, and who may well be able to spot potential variations and diversities that are beyond the reach of most qualitative studies" (2016, p. 85). Furthermore, in an article exploring the benefits of specialty certifications for nursing, Williams, Lopez and Lewis (2013) claim, "A culture of excellence begins with the power of knowledge. Nurses who have sought certification have demonstrated a desire for excellence for themselves and their healthcare community" (p. 252). In this way, specialty certified nurses have the potential to provide insights that reflect a deep commitment to excellent nursing practice, and may inspire ideas that are beyond our present conceptualization of moral practice in EOL care.

That being said, several nurses who were not specialty certified contacted me wishing to participate – given that these nurses reached out wanting to participate in a study about moral experiences in EOL care suggested a degree of engagement in the moral dimensions of their work. As I already had perspectives from specialty certified nurses, I amended the recruitment criteria to include all RN's with the following eligibility criteria: 1) Be a registered nurse in Canada; 2) Be currently practicing in a clinical setting where palliative and EOL care is part of their role; 3) Be able to speak, read, and understand English. An amended information letter (Appendix D) reflective of these changes was approved by the Research Ethics Board of the University of Ottawa. Data was explicitly analyzed with a focus on the level of moral engagement of the specialty certified participants, followed by the same analysis for the non-specialty certified participant. This analysis revealed that the non-specialty participant appeared to be as morally engaged in her practice as the other participants.

Nurses who were interested in the study contacted me by email – at this stage, potential

participants were given another copy of the information letter and a copy of the consent form (Appendix E). If the potential participant chose to proceed with an interview, verbal consent was received and audio recorded at the time of the interview. Interviews were scheduled at a convenient time for the participant.

Participants. Participants were asked to confirm that palliative and EOL care was part of their nursing role. The participants identified as currently practicing in the following care settings: palliative home care (n=1), residential hospice palliative care (n=1), palliative care unit within an acute care hospital (n=1), intensive care (n=1), and geriatrics/continuing care (n=1). Across all settings, the participants were involved in providing direct patient care. Four of five participants were specialty certified from the CNA. Participants identified as being from the following provinces and territories: Nova Scotia (n=1), Ontario (n=2), Alberta (n=1), and the Yukon (n=1). Four participants identified their region as urban, while one identified their region as rural. Years of clinical experience ranged from 15 to 39 years. The highest level of education among three participants was a bachelor's degree, while two participants had achieved a master's degree and were practicing as advanced practice nurses. All of the participants were female, within the age range of 37 to 59 years. Three out of five participants practiced full time, one participant practiced part time, and one participant practiced casually.

Procedures for data collection. Semi-structured individual interviews were conducted with each participant, using open-ended questions. Participants were given the first question in advance of the interview, to allow them the opportunity to reflect on their practice and recall personal experiences related to the phenomena of interest. This broad question was: *can you tell me about a situation (or situations) you have faced, when providing end-of-life care, that you found ethically challenging and/or ethically meaningful in your practice?* Note that the decision to frame the phenomena of interest as 'ethically meaningful situations' came after the interviews

were completed – at the time of the interviews, ‘ethically meaningful’ was used more restrictively, in that it served as a dichotomy to ethically challenging. However, while analyzing the participants’ interviews, I realized that ethically challenging experiences were also ethically meaningful, and the dichotomy did not reflect what I was seeing in the data. This led to conceptualizing ‘ethically meaningful’ as a broader construct, encompassing both ethically challenging and ethically enriching, after the interviews were completed. In addition to the question above, for nurses practicing in settings that were not explicitly palliative or hospice EOL care, the following question was given in advance of the interview and served as a way for nurses to self-identify as appropriate candidates for the study: *How is palliative and/or EOL care part of your role?*

As participants were located across Canada, telephone interviews were conducted using Skype technology (using only the audio function). Interviews were audio recorded using a software called Audacity. To maintain confidentiality, participants were assigned a numerical code. Prior to starting the interview, the consent form was verbally reviewed and any questions that arose were answered. The consenting process was audio recorded.

Within the interview, participants were asked to describe their practice setting and the types of patients they encounter. They were then asked to answer the initial broad question (which was given in advance of the interview, as stated above), and were asked to elaborate on certain aspects of the situation or situations they chose to share. Prompts included asking the participants “What went well?”, “What didn’t go well?”, and “In what ways did this situation affect you? How has it affected your day to day practice?”. Demographic information was collected at the end of each interview, and was not audio recorded to maintain as much anonymity in the recordings as possible. Interviews were completed in English and lasted from 50 to 70 minutes (approximately 60 minutes on average). Interviews were transcribed verbatim,

by me, within 48 hours of each interview, and all identifiers were removed to maintain confidentiality. Upon completion, the transcripts were verified against the audio recordings to ensure accuracy. Pseudonyms were incorporated, instead of numerical codes, when writing the findings (Chapter 4). Recordings and transcripts were stored on my personal password-protected computer, in digitally-protected formats (i.e. encrypted folders for the audio recordings and password-protected documents for the transcripts).

Following the interview, a brief, unrecorded debriefing conversation was undertaken with each participant, lasting from 5 to 10 minutes. During this time, participants shared that the interview offered the opportunity to reflect on their practice and past experiences. One participant voiced that participating in the interview and recounting her experiences was a better opportunity to debrief than she had been given when the situation occurred.

Data analysis. The following section describes the overall analytic logic of my engagement with the data, and makes explicit the role of the theoretical forestructure in the analysis process. In the following section, I will first describe my overall approach to data analysis, followed by specific phases of analysis that sought to answer the research question.

The initial, preliminary analysis was done by immersing myself in the data, by re-listening to the interviews and re-reading the transcripts, to get a sense of the overall message(s) conveyed by participants. In this initial phase, I considered the phrases within the interview that took prominence and seemed to demand consideration, and began to reflect on why these particular parts of the interview caught my attention right away (Thorne, 2016). This was followed by a line-by-line analysis of each individual transcript, where I reflected on the participants' specific words, phrases, and pauses, and the nuances in the language they chose to use – Thorne (2016) states that much can be learned when reflecting on the nuanced aspects of the interview, rather than simply the storyline. It was during this stage of the analysis that

specific questions were asked of the data, such as, “What does this mean?”, “What is going on here?”, and “How does this speak to the phenomenon of interest and the research question?” As potentially similar ideas were identified across transcripts, specific quotes that exemplified these ideas were grouped together, allowing for the data from across interviews to be compared and contrasted.

In an attempt to answer the research question, further analysis was done in two phases and guided by the questions that are the underlying aims of the study. These questions are: 1) How do nurses describe ethically meaningful situations in the provision of EOL care?; and 2) What do these experiences reveal about nurses as moral agents? In order to address the first question, the transcripts were analyzed with an eye towards how nurses describe the situations they face and what constitutes an ethically meaningful encounter to them. In order to address the second question, the analysis involved a thematic interpretation of what the participants’ experiences with these ethically meaningful situations reveal about their moral agency.

The thematic analysis involved grouping common ideas together, and as patterns and relationships were identified through these groupings, I was able to generate constructions out of the data. Once these initial constructions were created, they were considered explicitly through a lens of nursing as moral practice, identified earlier in this chapter as the theoretical scaffolding for the study. At this stage, any patterns and relationships were identified between the analytical construction and the specific concepts that make up the theoretical scaffolding – a great deal of caution was used during this stage of the analysis, as to not impose an artificial narrative on the data based around the theoretical scaffolding. This was done by starting with a line-by-line method for data analysis to maintain focus on the data itself, and by considering ideas against the theoretical scaffolding only once the initial constructions emerged from the data.

Ethical considerations. This study received Research Ethics Board approval (Appendix F) through the University of Ottawa. Prior to data collection, interested participants who were eligible for the study were given a standardized letter of information, which included the purpose of the study, eligibility information, and details on what will be asked of those recruited. Participants were also given a consent form that outlined methods for data collection, associated risks of participating, and how participant confidentiality and anonymity was maintained. To protect the privacy of participants, all identifiers were removed from interview transcripts and participants were assigned a numeric code to maintain confidentiality. Pseudonyms were used when quoting participants. Electronic records, such as transcripts and audio recordings, were stored in a password-secured folder on a password-secured computer. In accordance with the approved University of Ottawa Research Ethics Board application, data will be conserved indefinitely, on the encrypted and password-protected laptop computer, issued by the University of Ottawa, of the research supervisor, to provide the opportunity for secondary analysis in the future. If at any point in the future the research team does not wish to perform any further analysis of the data, electronic files will be securely deleted. The contact information of myself, the research supervisor, and the University of Ottawa Research Ethics Board was made readily available to the participants should that have any questions or concerns throughout or following the study.

Chapter 4: Findings

This chapter presents the descriptive and interpretive meanings that were generated as a result of the data analysis. Organized into two sections, the first part of this chapter presents a description of the participants' own accounts of ethically meaningful situations – ethically challenging situations are presented first, followed by a description of the participants' ethically enriching experiences. While separated for the purpose of maintaining clarity when presenting the findings, it is important to note that ethically challenging and ethically enriching experiences are not dichotomous, as ethically challenging situations might also be ethically enriching and vice versa. The second part of the findings will present a thematic interpretation of what the participants' experiences reveal about nurses' moral agency.

Part 1: How do nurses describe ethically meaningful situations in the provision of end-of-life care?

The following section of the findings aims to answer one of the study's guiding questions: How do nurses describe ethically meaningful situations in the provision of end-of-life care? This section is explicitly descriptive – the goal is to present the participants' voices and viewpoints, while providing a description of the nurses' own accounts of their experiences with ethically meaningful situations. Ethically challenging situations will be presented first, followed by ethically enriching situations. This section provides the narrative detail and context necessary for the thematic interpretation of the participants' capacity for moral agency (Part 2: What do the participants experiences reveal about nurses' moral agency?).

Ethically challenging situations.

“I felt like we failed him somehow.” Dana was the first participant interviewed for this study. As a palliative care consult nurse with over 20 years of nursing experience, Dana provides care at the EOL to individuals in their homes. She describes her work as particularly

autonomous, as she spends most of her time either alone in the car or in her patients' homes.

Dana explained that although she is called a 'consult' nurse, she does not practice in a consultant capacity whereby "you go and make some recommendations and step out". Instead, once consulted, Dana often sees patients over the course of their entire EOL trajectory.

Prior to the legalization of MAiD in Canada, Dana stated that a common ethical issue she encountered was navigating requests for MAiD in the community palliative care setting. In her description of an ethically challenging situation, she told a story about a patient with whom she "had developed a really good relationship along the way." Dana described this man as having significant chronic obstructive pulmonary disease (COPD) and recounts coming into his home for a visit one day when, amidst their casual conversation, he stated, "I just want this over now" and "I just want to die now. So I want you to give me something to die now." Dana described feeling caught off guard by his statement and probed him for more information to better understand why he felt this way. She elaborated:

Because you always have to go back to why the request comes in, and so, long before it was ever legal we were still going back to the why are you asking me that, what symptom is bothering you so much, what is bothering you so much about your life that you feel like you want that right now?

Through their conversation, Dana was able to determine that the source of the man's distress was the shortness of breath he was experiencing. According to Dana, his position on the matter was that he was satisfied with his life up until now, and he did not want to "go through this process" of losing "control" of his body and his family having to care for him. Together, Dana and the patient came to the decision that if and when his shortness of breath became too distressing for him, palliative sedation would be an option they could consider. She stated, "But, obviously ending his life sooner than it was gonna end wasn't an option that we could go

through.” In the following passage, Dana explained how this case was particularly challenging for her:

I found that case really hard because, I think we had developed a really good relationship, and so I felt like what did we do wrong that he wanted to die instead of just finish living his life. I felt like we failed him somehow.

Dana’s feeling that she “failed him” or did something “wrong” reveals the ethical dimension to her narrative account.

Dana explained that in the end, the patient died at home, surrounded by his family. She stated, “he was asleep, but he was comfortable. It’s what he wanted.” She also stated everyone “worked together” to honour his wish to die at home, and his family was “grateful” and “didn’t feel like anything was lacking.”

Despite the patient dying comfortably and surrounded by family, Dana said that she still had to find a way “to work through” her sense of failure. She did this by framing his dying as “that man’s life and that man’s experience”. She further stated, “One of the strongest parts of my education was that this isn’t about us, this is about our patients, and our personal values don’t count” and “it [his dying] had to be right *for him*”. When asked to elaborate on how putting her values and beliefs aside affects her practice, Dana stated:

But I think it’s only in the moments when we put ourselves aside and be that person that our patients need, not... And I mean, of course it’s part of ourselves as well, we give ourselves, but there has to be that... Patients aren’t going to open up to us if they don’t trust us, is the long and short of it. So, I think, that I’ve probably over the years grown to be a better person; a better person or better nurse that keeps my judgments to myself, like I should. Because I think nurses should keep their judgements to themselves and I think

sometimes your patient needs you to say, kind of, make you look at their situations from their point of view and maybe reflect on that.

In speaking about how she had to work through her sense of failure, she described recognizing that despite doing their “best”, the reality was that “sometimes our best is not quite good enough” for the distress the patient is experiencing.

At the time of the interview, Dana stated that this situation occurred 7 years ago. When asked what she would do differently now, she explained that she lives in a “different world now” because MAiD is a legal option for individuals at the EOL. When the laws around MAiD initially changed, Dana described wanting “nothing to do” with the practice – she would support her patients in other ways, but she did not want to be involved in the practice of MAiD. However, she has since changed her position on this, which she explained when she stated:

We support our patients and advocate for our patients for any other kind of care. (...) If I need to advocate for them to get the contacts they need to have that process done, then I’m advocating. Like I would advocate for radiation therapy [something offered only exceptionally within palliative care] if that’s what they wanted or needed.

According to Dana, “it is the values and needs of the person you’re caring for that ultimately count, and not necessarily the nurse’s.” Dana stated that she was not sure whether or not this patient was fully committed to ending his life through MAiD, and given that MAiD was not a legal option at the time, it was never fully explored with him. Regardless, Dana explained that she would have supported her patient in any way that he articulated.

“Do you realize we’re putting her to sleep today?” In the 10-bed residential hospice where Julie practices, patients are typically only accepted when they are expected to die within two weeks. In her account of an ethically challenging situation she faced in her practice, Julie described a time when a patient with leukemia was admitted to the hospice and initially appeared

to be declining quickly, but remained stable for several months. Julie described the patient as “getting weaker, but so slowly”. Julie explained that because the patient had been in hospice for many months, she came to know her very well. She stated, “I mean, when a patient is there that long, and I mean we only have ten patients, so we get to know these people very well, and their families, and their whole history.” Julie described that on top providing physical care for this patient, they were also managing some “long-standing” emotional issues that existed previous to her diagnosis of cancer. Julie felt as though, with the help of the spiritual care worker, they were making a “breakthrough” in working through these issues with her.

In the midst of the progress they were making in her care, Julie explained that the family abruptly asked a nurse if they could receive MAiD (now legal) for the patient. In this hospice, Julie stated that they do not practice “euthanasia”. When the family made this request, the physician was called – Julie explained that the physician’s position on the matter was essentially, “I can’t do that [MAiD] but I can do palliative sedation.”

For Julie, this was morally problematic “for a few reasons”. The problem was “saying that you’re doing one thing but doing another.” In other words, Julie felt that this was not truly palliative sedation and that, since this patient was relatively stable and had been for months, initiating palliative sedation would be no different than MAiD, in terms of intent to hasten death. Julie also described feeling not only ethically conflicted but legally conflicted as well. In addition, Julie described her beliefs and values as oriented around her religious ideals, and as such, she is firmly against the practice of MAiD on the basis of “thou shall not kill.” For Julie, the practice of palliative care is about allowing the “natural time of death” to occur.

Julie explained that she found out about the situation when she came into work the next day and was assigned this patient. She walked into the patient’s room and the family said, “Do

you realize that we're putting her to sleep today?" When I asked her to describe how she reacted to this, she stated:

As I'm looking into Jane's¹ eyes, I felt like I couldn't breathe, I was conflicted about what I should say to the family, to the patient. I mean, I'm sure my facial expression spoke volumes to them. (...) But the patient, as I was leaving the room, is saying, "Julie, what's the matter? What's the matter?" So I mean, here I am thinking I'm covering up my emotion in that and just trying to get out of the room.

In explaining the emotions she felt, Julie explained that she was "shocked", "angry", and "sad". She explained further:

As I'm leaving the room, the husband very loudly was saying to her, "This is a good idea, we're doing this... this is really good, it's good. And Jane... don't worry Jane, this is a good idea." So I was like really conflicted about that too because I'm like, whose idea was this? And then, a lot of anger and frustration at the system and directed toward the physician who made that decision. Quite independently from the staff, I must say.

According to Julie, it is uncommon for the nurses and physicians in the hospice to experience conflict like this; however, this particular physician, to her, has "no personal ethic, except what is law." She explained that since the MAiD legislation has been passed, "he's strongly protective of the rights of patients that now are invoked with the new law"; whereas prior to the amendment of the Criminal Code of Canada, he was "strongly protective" of the law preventing access to MAiD. In the following passage, Julie refers to a communist regime as an analogy for the physician's ethical standards. She stated:

¹Pseudonym provided by the participant.

So his bottom line for decision-making is whatever the law is. So, um, I mean, we have to function within the law, but you know, if he was in a communist country or let's say Nazi Germany, would that be the same thing? He's just, whatever the law is, that's what he wants to fulfill. So there's nothing greater than what his government is providing for him. Which seems very shallow.

Julie explained that she refused to care for this patient and her supervisor supported her in that, which was a great relief to her. When her colleagues stepped in to take her place in the care of the patient, she stated that it was not just a "nice" gesture for them to do, it was imperative – she said, "I would have quit if they had made me care for that patient. I considered quitting anyway." Julie described later on in the interview that she loves her job, so it was "hugely disturbing" to her that she had considered resigning as a result of being "so deeply conflicted" from this encounter.

When I asked Julie how the phrase 'We're putting her to sleep today' made her feel, she stated, "Well the first thing I thought was like, wow, it's like putting a dog down. So it dehumanized her." Julie also explained that there were only hours between when the decision to pursue palliative sedation was made and then implemented – the "suddenness" of the situation was "horrifying" to her. According to Julie, the guidelines that underpin the practice of palliative sedation in her hospice require that the patient is within two weeks of dying for the initiation of palliative sedation. Julie stated it was a "violation" to offer and initiate palliative sedation when "she was nowhere near dying in two weeks". According to Julie, the patient died 48 hours after the initiation of palliative sedation.

At the time of the interview, Julie said that this situation had happened three months prior and was so significant that "discussion and debriefing" were still continuing to go on at the hospice. Julie explained that her manager was "genuinely concerned" for the conflict she felt as

a result of this situation and that she has since participated in an “entire ethical review.”

Furthermore, Julie described that change occurred at the hospice as a result of how vocal she was about this situation; she explained, “Now, all physicians, when they decide to do palliative sedation, it has to be approved by at least one other physician within the hospice” and “that they need to talk with the staff”. Julie described speaking with her manager, the director of medical care, and consulting the ethics support committee at her organization. In communicating her concerns through a number of channels, she influenced change within the hospice. As such, Julie said she would “speak up again” in the future.

“The bad news wasn’t that the child had died, the bad news was that the child was still living.” Michelle is an advanced practice nurse with over 25 years of experience in nursing, most of which spent in palliative care. Several years ago, while working as a nurse practitioner for a pediatric palliative care program, a role which largely involved supporting the transition of pediatric patients in and out of the hospital, Michelle described a time where she was providing care to a dying infant at home in the community. Michelle explained that a member of her team (consisting of herself, a palliative care physician, a medical resident, and a clinical nurse specialist) would see the family on a daily basis to ensure that, on top of the community healthcare team, the family had support from the hospital team as well.

Michelle recounted that the decision to proceed with palliative care was made while the infant was in the hospital, and the reason they chose to send the patient home for care at the EOL was so that the family “could experience a certain degree of living with this child until he died.” Michelle described the parents as a “very young, unmarried couple”, with this infant being their first child. She explained that they did not have a close relationship with their family, and so Michelle described taking on a “maternal role” when caring for them. Michelle explained that she was able to “work through” the ethics of withholding and withdrawing nutrition and

hydration with the parents in the hospital and that she supported them in this by giving them guidance about how to comfort an infant that is not being fed.

In this situation, what became ethically challenging for Michelle was that the course of this infant's EOL care did not progress as expected – she explained that the team had anticipated that the child would die within a few days, when in fact, he did not die for 25 days. Michelle said the ethical challenge was “the idea that perhaps we made an error in our prognosis and counselling of the family around proceeding this way.” The intentions around sending the family home to experience some sense of normalcy with the infant before his death were thwarted because the parents “started to feel like they were stuck in their home” for fear of being judged, “because their child started to look very sick.”

Michelle explained that the distress she felt from this situation stemmed from her feeling unable to adequately support the family through this or explain why this was happening. She stated:

I think what became ethically challenging for me was that the distress that the parents were feeling and more importantly, was my inability, or my feeling of inability to support them through that distress because I was so distressed. Because they were... I wasn't able to explain or feel like I could support them, because I didn't understand why or how this was happening.

After each daily visit, the clinician who visited the family would call each of the other members of the team to give an update on the situation. Michelle described waiting on “baited breath” for the call, and in the following passage, described what it was like to find out the child was still alive. She added:

(...) The bad news wasn't that the child had died, the bad news was that the child was still living. And when it becomes that news, the child is still living, you just start to feel,

like, you know, this is awful. I can't believe I am wishing for this poor child to be gone, because I just, I don't know that I can witness this anymore.

Michelle described the “dread” she felt upon seeing the family because she could not explain “why or how this was happening”, and it was distressing for her to not have answers for them. Despite the child not appearing to be suffering physically, to Michelle, everyone was feeling a sense of “emotional anguish”.

This experience was extremely destabilizing for Michelle, which she herself characterized as “moral distress”. She felt that questions began emerging (either from within herself or externally from other stakeholders) as a result of this situation, which she explained in the following passage:

And then further to the ethical challenge, I think for me it was the questions that came because I started questioning myself internally, so that inner voice. At the time, we worked very closely with a team, both in the community and in the hospital, and my colleagues in the hospital started questioning our decision, and then as a whole team were questioning our prognostication. And then, the community partners were also questioning us. And it was spilling over into other things and other decisions we were making for other clients, and patients, and their families.

This idea that Michelle began questioning herself “internally” also came up as she explained how she began to question her role and what “good, evidence-based” care at the EOL looks like when everyone around her was “feeling so distressed”. In spite of being a palliative care nurse for nearly 15 years, Michelle explained that she began to question the “value proposition” that she had “always put forth for palliative care”, which was “the idea that it's not about the length of time, it's about the quality of that time.” Even though she felt as though the team had done

everything they were supposed to do for this child, Michelle explained that she could not say she had “done anything to improve the quality of this time” for the family.

This case left a lasting impression on Michelle, which she described as “moral residue”. To her, moral residue was the “leftover feeling” that she “hadn’t been able to come to some resolution to all the distress.” Michelle explained that in other cases, she had been able to achieve resolution by looking at the evidence, being supported by her team, and by spending time reflecting on her practice. In other situations, she “had been able to find a way to make sense of the framework” within which she practices. But in this circumstance, Michelle felt as though she could not “make sense of this”, even though she knew that as a practitioner and as a team they had done everything they could when making decisions about this infant’s care.

Michelle also explained how the moral residue (her term) had lasting implications for her practice, even though she is no longer working in pediatric palliative care. She stated, “Whenever I’m counselling a family or counselling an individual about what this might look like, I hesitate a little bit. I always hesitate a little bit.” To her, this hesitation is a reflection of the lasting impact of this case on her practice, to the point where she will sometimes “defer to someone else” when facilitating decisions to withdraw or withhold treatments at the EOL. That being said, Michelle recognized an opportunity to learn from her experience and adapt her practice for the better, which she explained in the following passage:

I think what the learning that has happened in a positive way, is that that hesitation always makes me make sure that I reflect to say, “What we would expect to happen is the following, however, there are those that lie in and out, and that if this becomes too much or too hard, there are other options for us to consider.” And so that’s what I think I’ve learned from it. And also, I feel like I’ve become much more open to considering alternatives. So, maybe if we, you know, just let the I.V. run a little bit longer [in

palliative care, artificial hydration is considered a medical intervention; long-standing controversy exists about whether artificial hydration prolongs dying or is in the best interest of the patient].

Michelle explained through “experience and time spent in self-reflection” she has also come to learn that sometimes suffering cannot be eliminated “despite the best evidence in the world”, and that her role “has got to be just to witness it”. By understanding “bearing witness” as “what the role is really meant to have been”, Michelle has been able to reconcile that the moral distress she felt from this case was her “not recognizing or not understanding” that bearing witness was her role all along, and has since learned to “understand that, embrace that, and accept it”. Michelle says she has since been able to integrate this learning and growth into the care of other patients.

“Their voice seemed to be louder than the voice of the patient.” Renée, an ICU nurse, described that the provision of care at the EOL is an “expected” part of her role as a critical care nurse because patients in the ICU die on a “fairly regular basis”. Renée explained that care in the ICU is often one-on-one as the patients often have many complex physiological needs, such as requiring dialysis or pacemakers. She described that she and her colleagues often work short staffed and that they have a “really good working relationship” with the physicians on their unit. When asked to describe an ethically challenging and/or ethically meaningful situation she has faced in the provision of care at the EOL (recall, ethically meaningful had a more restrictive conceptualization during the interviews, as described in Chapter 3 [see pages 60-61]), Renée stated that there are “many ethical challenges in the ICU environment”. For her, one that often arises is when the patient’s family is unable to accept that “death is a part of life”. Renée explained that “we tend to overlook the wishes of the people that are actually in the bed” when the family does not accept that their loved one is dying.

To illustrate this, Renée gave the example of an 86-year old patient with end-stage COPD who made it clear that “she wished her care to be palliative”. Renée described this woman as someone who knew her disease process very well and understood her prognosis. According to Renée, this woman had stressed to all of the healthcare staff what her wishes were – the patient was not interested in being intubated and she was not interested in wearing a bilevel positive airway pressure (BiPAP) breathing mask, and she understood and accepted the consequences of that.

Renée explained that the “ethical dilemma” occurred when the patient's wishes were overruled by her family. According to Renée, the patient had two sons who came into the unit and claimed that their mother “doesn’t know what she is talking about” and they wanted everything done for her. This resulted in the physician ordering the patient to be placed on BiPAP against her wishes. In the following passage, Renée describes what it was like when they placed the BiPAP mask on the patient:

(...) We tied her down to the bed and strapped a BiPAP mask to her face, while she screamed the entire time, “Why are you doing this to me? Help me, help me. I know what I’m saying, I’m not crazy. I want to die. Why can’t you listen to me? Why won’t you help me?”

Renée described her experience of this situation as “moral distress”, stemming from the fact that the family’s “voice seemed to be louder than the voice of the patient”. When describing her experience of moral distress in this situation and what it felt like to her, she stated:

Honestly, it’s a physical reaction, first off. You *actually* feel nauseated; you *actually* feel dizzy. You... It’s almost like a fight or flight reaction, because you know what you are doing at that point is not correct, it’s not the right thing to do, and so your body actually has that visceral reaction to that. And then of course you get emotional on top of it. We

had people going off on stress leave because you could hear this woman screaming across the unit, “why are you doing this to me?” I knew that it wasn’t because she was delirious, or you know, because that happens. But she was of sound mind, and so you have that emotional reaction, you link that to, “oh God, what if that was my grandmother.” And tears come. Like, there... absolutely tears come. And then there’s anger.

Renée described that her moral distress in this situation was also exacerbated by the fact that, to her, she was constrained in enacting her nursing role. For example, Renée described that her role involves using critical thinking and knowledge to assess the cognition of the patient, and that part of her role requires “teasing out the little nuances, like her thoughts and feelings around her wishes”, and then advocating for those wishes and preferences. Renée stated it becomes “demoralizing” and “very frustrating” to be constrained from performing activities that she perceives are part of her role.

When asked what Renée’s relationship was like with the patient, she said that at first they seemed to have “a very strong rapport”. Before the situation became morally difficult, Renée described spending time with the patient and listening to her stories and reflections on life. Renée described that a part of her work that she treasures is “providing an ear for somebody you know is likely not going to be there much longer.” Renée thought that listening to the patient and allowing her to tell her story was “valuable” because it brought the patient comfort. However, Renée explained that when the healthcare team “started not listening to her”, the relationship deteriorated and became “hostile”.

When asked if she had since learned anything from this experience, Renée talked about her moral integrity, which she described as being “more congruent” in her values and actions. She explained that when she perceives that something is wrong or unjust, she now feels the need

to “take steps” to follow through with addressing the situation. When explaining this in the context of the story she presented, she stated:

I should not have tied that woman down. And I will never do it again. If I do not feel comfortable, knowing that this patient is of sound mind, I will not do it and I will accept the consequences.

Renée stated that she believes that nurses have the capacity to effect change, because nurses are on the “front lines” and “see problems on a day-to-day, more regular basis”. She stated, “We are in the trenches, we see when something is broken and needs to be fixed in real time.” As such, Renée described the importance for her and other nurses to voice their concerns; however, she expressed that in order for change to happen, there needs to be a culture where nurses are listened to. She stated, “I don’t necessarily think that that culture exists.”

“It would be like abandoning him.” As the sole nurse practitioner for continuing care in her community, Lori often cares for patients over many years in the long-term care setting. This was the case for one of her patients, a man who was a resident at one of the long-term care facilities Lori practices in. Lori described this man as having “extensive, debilitating disease” that caused him to often experience very frequent and rapid destabilization. Lori explained how this patient was “frustrated” with his overall health status. Following an acute event that led him to the emergency department, he returned to the long-term care facility for care at the EOL. Lori describes that they had initial conversations about the “palliative approach” and how they could manage his symptoms to keep him comfortable. They continued along this palliative care “continuum” for a few weeks until he asked Lori to perform MAID, making him the first patient to request MAiD from Lori under the new legislation (as a nurse practitioner, providing MAiD is a part of Lori’s scope of practice).

Lori describes that she was “surprised” to find herself in an “ethical dilemma” because when the Carter decision came into effect and federal legislation was changed, she felt as though she knew what her beliefs about MAiD were. Lori was actively involved in national committees for nurse practitioners around the issue of MAiD “at the time that all of this was evolving”, so she had spent time reflecting on what her thoughts on MAiD were “knowing that this might be something that would arise” in her clinical area. Lori described that she thought she knew what her beliefs were, and that she believed in an individual’s right to seek MAiD as an EOL care option when “they are suffering and have an incurable, irreversible condition”. However, once she was faced with being asked to perform MAiD, she had to decide whether she would actually be able to perform the act. In Lori's words, “It is no longer a kind of global, ethical values kind of thinking. It’s actually specific to a person.”

Lori decided that she needed to embark on “a lot of ethical reflection” in order to clarify what her beliefs were, and to understand herself on a deeper level to know whether she could actually do this, and why or why not. Lori described that she needed to do this reflection quickly because, if she could not “ethically do it” – if her “moral obligations” were such that she could not perform MAiD – it was her duty to find him a clinician who could. Lori stated that her “soul-searching” revolved around her “values” around the right to access MAiD, but also her values around human suffering.

Lori described knowing this person very well. She had been involved in his care for a long time and knew that he would not survive much longer. Lori explained that she also knew that he was suffering. When describing the result of her reflection, she stated:

So the result of my decision making was that I decided that I was... I couldn’t refuse this man. And part of what swayed me over to being involved was the fact that this man and I had this incredibly close professional relationship, right? I had been his primary care

provider, as opposed to his physician [whose contact with the patient was more episodic], for a few years. And I thought, how can I let him down? How can I not be in the room at this pivotal moment in his life? It would be like abandoning him, because he would have a complete stranger in the room, because his family physician was actually away. So it would be a complete stranger, or strangers if there [were] two physicians, in the room with him, providing this care at a pivotal time [i.e. the moment of his death]. And, so I just felt that it would be the absolute epitome of letting somebody down at a time when they almost needed more than ever. And so I just couldn't do it. Yeah. So I did it.

When speaking about the relationship she had with this man, Lori talks about the real sense of responsibility she felt towards him. Lori describes that she would often check in on him, ensure his symptoms were well-managed, and through proximity and time she was able to get to know him, perhaps more deeply than she would otherwise know someone in her care. It is through this therapeutic relationship that she says that she built trust with him and that she was able to learn more “about his past life”, “the things that were important to him”, “about his family”, and “about his values in life”. Lori believed that by regularly checking in on him, she gave him “peace of mind” knowing he was being looked after. Lori felt as though the patient trusted her “very, very much”. She acknowledged that clinicians in long-term care have a unique relationship with their patients, because they often care for them over many years and become “part of their world”. According to Lori, many of the patients in continuing care are approaching the end of their life, and so, as part of their world, she is “walking along with them on that journey”.

Although she described this situation as an “ethical dilemma”, Lori explained that this situation did not distress her because she fundamentally believed it was the right thing to do and that it was this man's right to receive MAiD. She knew she would grieve, but she stated that,

“Human suffering is probably the worst thing we deal with.” It was through reflecting on her beliefs about suffering and the relationship she had with this man that she was able to make and follow through with her decision, as well as cope with the grief that followed. When asked what she has since learned from this experience, Lori stated, “I have learned that I believe in a human being’s right to end suffering” and since this encounter, Lori has become a “powerful advocate” for MAID. Near the end of her interview, Lori stated: “I believe in what I do, and I am grateful that I can be part of their journey and that they let me be part of their journey.”

Ethically enriching situations.

“Thank you for being there.” From her past experiences, Michelle has come to learn that she cannot always eliminate suffering or sadness in EOL care situations, but she can “be there” and be “witness to it”. Michelle spoke about a patient and family she worked with early in her career – this particular patient was a young person who was experiencing pain at the EOL, but no matter what the health care team did, they could not “get on top” of his pain. Because of this, Michelle perceived that this patient did not have a “nice death”. She described that the healthcare team had tried to change medication combinations and “all sorts of things”; but no matter what they did it seems as though the only thing Michelle could do is “be there with them”.

Months following the patient’s death, Michelle saw the family outside of the hospital. In the following passage, Michelle recounted what seeing the family was like for her:

The warmth and the love. (...) I wasn’t sure how she, the mother, in particular, was going to react. Because I felt like I was the reminder of this young person’s death and it was not a nice death. The warmth, the embrace, and she, you know, she didn’t say anything other than “thank you.” And, you know, “thank you for being there.”

According to Michelle, although this situation left her with moral residue, she was able to reframe how she understood this experience. She now understands that, sometimes, it is not

about the events that occurred during the EOL period, but it is more about the time she spent with the family bearing witness to their experience. While Michelle's memory of this experience was that of an "awful death", what the mother remembered was that "somebody was there to share it."

Michelle explained that while some cases could lead her to say "I can't do this anymore" – such as the other story she told about the prolonged death of an infant – experiences like this (where the family was able to cope and come to some sense of resolution in spite of the death of their loved one) sustain her motivation to "continue" working in palliative care. She explained that while the tension between being pushed away and being pulled back into this work is always there, this tension has become "less and less" with experience. She described that the situations where "things didn't go well" happened earlier in her career, as she has since been able to learn from these experiences. Michelle stated, "I find myself in ethical situations every day." Michelle explained that by having the opportunity to speak with others, to work together collaboratively, and to engage in self-reflection, she can continue to feel as though her work contributes to something positive. For Michelle, as long as she feels as though she is continuing "to grow as a nurse, as a professional, but also as a human being", she is able to remain in palliative care.

Michelle later explained that she believes in the idea of a "good death". She has come to understand that "very few people" can look back on an EOL experience and think immediately, "Ya, that was good". For her, a good death is that the family "felt like they were able to get what they needed out of the experience to feel like they can continue to, that they can be whole again." It is an "extreme honour" and "pleasure" for Michelle to be able to "be there" during a patient and family's EOL experience and to bear witness to that. By doing so, she hopes that she can foster an experience that allows them, "maybe not in a few years, maybe not in a year, maybe it'll be years later", to eventually feel whole again.

“We all thought we had done the right thing.” Julie explained that when she looks back on her experiences of providing care to dying patients that she and the hospice team “usually do things right”. In her example of this, Julie recalls caring for an ALS patient, which she described as a “very difficult palliative situation”, who had a very complex social history. To her, this patient’s arrival at the hospice was a “huge relief” for him in “many ways”. Julie explained that he was on a BiPAP mask and had “all kinds” of other equipment, which were “keeping him alive”.

Julie explained that in this case, she had the opportunity to use her judgement and autonomy to initiate conversations within the circle of care about whether or not they were “unnaturally extending” this patient’s life. Julie recalls having discussions with the physician, other members of the healthcare team, and the patient and family. When these conversations started unfolding, Julie described the patient as “not too cognitive by then”, but nevertheless, “he knew what [she] was saying to him”. The patient agreed to the withdrawal of BiPAP and she described the family as being “very, very much on board”. Before proceeding with the actual withdrawal of treatment, Julie described spending a few days engaging in dialogue with the other staff, “just getting everybody’s thoughts on it”, and “making sure that everybody understood ethically what we were doing”.

About a week later, the team initiated sedation, removed the BiPAP mask, and the patient died within five minutes. In the following passage, Julie described what the climate of the room was like when the patient died:

It was very sad. We were all very tearful in that room. I don’t know how much, how often you’ve been with dying patients, but it was a very, very, very emotional time, but a really lovely time because we all thought we had done the right thing. For the family, for

the patient, especially. And that we hadn't crossed lines, that we hadn't violated any of the guidelines that we stand by in the hospice, on paper or in our hearts.

Julie explained that it is moments such as these that allow her to keep doing this work. In this situation, Julie described being able to make decisions about what her actions were going to be – she stated that she is not “trying to do anything weird or wonderful”, but just doing what she’s “called to do” as a nurse. Julie explained that she is able to actualize what she is “called to do” by facilitating a “natural death”, “supporting patients and their families”, “taking away suffering in every realm, every sphere”, and “being able to start and end treatment accordingly”.

In the following excerpt, Julie described how her overall approach to caring for people is focused on their personhood, which for her derives, in part, from a religious view of humanity. She stated:

My overall approach to people in general, not just my patients, is that they are made in the image of God, that they have intrinsic value because of that, that makes them different than my dog, or my cat. They have souls that are eternal, and that matter. That my responsibility to them encompasses body, mind, and soul. That one of my duties, not just in hospice, but everywhere, is to relieve the suffering in this life and the next. And so, those principles rule everything I do.

“Once you know you can move towards death, then you can work on making it a dignified and meaningful experience.” When I asked Renée if she had an example of providing care at the EOL that was particularly meaningful to her, she replied, “Oh absolutely, you always remember those!” Renée recounted caring for a young woman in her twenties, recently married to her high school sweetheart, who was crossing a busy highway in her vehicle when she was hit by a cement truck. Renée recalled that the healthcare team had performed “any intervention” they “could think of” for the patient, but that “her injuries were just not sustainable with life”.

Renée described that the patient's husband, "despite also being very, very young", was accepting and understanding of that. Renée explained that she felt "lucky" because, "for whatever reason", he understood that his wife was going to die and that "the outcome was not going to be any different", and so he was "on board" with the initiation of care at the EOL.

Renée explained how they "took the time to get to know them", and got to know the patient "through him". She asked about what they enjoyed doing and what their life together looked like. She learned through this dialogue that one of their "favourite things to do" was to pull out their "hide-a-bed" sofa in the middle of the day and watch a movie together. In the following passage, Renée explained how she and her colleagues recreated this favourite pastime of theirs:

And so, we made her, at least somewhat presentable, and kind of moved her to one side of the bed, and we got a TV and threw on a movie, and we let him crawl into bed beside her. And she passed away while they were watching the movie and he was holding her. Renée explained that this was "definitely a meaningful example" of care at the EOL, to her, and that she does not "see that very often". She explained further that in order for this situation to occur, "a lot of factors came together", namely that the husband had to understand that "this is the way it was going to be and be accepting of that". Renée stated, "once you get that permission, once you know you can move towards death, then you can work on making it a dignified and meaningful experience." While this situation was "still sad", it was a "good passing" to her.

Renée explained that this type of situation makes her feel "validated". She explained that being a nurse "isn't just necessarily putting on Band-Aids, and it isn't always getting to see people leave the hospital" – being able to provide a meaningful death for someone validated the "caring aspects" of her work. "I think that if you talk to almost any nurse, that's what they got

into the field for, is to provide care”, she stated. Renée reveals the ethical significance of this story when she says, “you kind of feel happy, because you’ve done what you know is right.” For Renée, despite this patient being “so young”, there were no “conflictions” with respect to her death; the patient wasn't alone, she was doing something that she loved, and she died peacefully.

Part 2: What do the participants’ experiences reveal about nurses as moral agents?

In this section, I present a thematic interpretation of what the participants’ experiences reveal about themselves as moral agents. Recall, moral agency is understood as the capacity of nurses to direct their motives or actions to some ethical end (CNA, 2017). The themes presented characterize my impressions of these nurses as thoughtful, relational, and morally sensitive, as revealed through the narrative descriptions of their experiences. The ways in which nurses engage in reflection, maintain relationships, and enact moral sensitivity has implications for how they act in response to ethically meaningful situations in the context of EOL care.

Reflection. The participants’ experiences in the face of ethically meaningful situations in the context of EOL care reveal that nurses are highly reflective. Reflection is the process by which the participants think about and try to make sense of what is happening in a given situation, or what has happened in the past. Their thoughtfulness not only informs their moment-to-moment decision-making, but it is also a process that is lived over time, in the months and years that follow a salient encounter. Furthermore, the participants’ accounts reveal that it is through reflection that these nurses are able to reconcile the morally difficult situations they face and realize the opportunity to adapt their practice as a result of these encounters. The first theme of ‘Reflection’ will be presented through three subthemes: 1) Reflection in the moment; 2) Reflection over time; and 3) Potential for growth.

Reflection in the moment. The participants actively engage in self-reflection as part of their everyday practice – this thoughtfulness helps them make sense of and cope with the

situations they face as part of their day-to-day work. In reference to Lori's narrative about receiving her first request for MAiD as a nurse practitioner, she described embarking "on a lot of ethical reflection" in order for her to navigate the "ethical dilemma". Lori's reflections about whether or not she would be able to perform MAiD required her to critically examine and clarify her values and beliefs about suffering. In her narrative, Lori referred to her "moral obligations" to the patient as an aspect of her self-reflection:

And it involved a lot of ethical reflection in a really rapid time frame, because if I couldn't ethically do it, if morally, if my own moral obligations, I couldn't do this for this resident, I needed to provide him with someone who could. And so it involved a lot actual soul-searching about my true beliefs, on a deeper level about whether I could actually do this and why.

It is clear that Lori understands the moral salience of her work, and that there are certain obligations and commitments she believes she must uphold, such as her responsibility to facilitate the patient's access to MAiD even if she decides she cannot perform the act. The "moral obligations" Lori has to her patient serve as a framework for her reflexivity. Ultimately, Lori's reflection on her values and obligations had real-time implications for her practice – how she would respond to this first request for MAiD would define her practice going forward.

Michelle's accounts also serve as an example of 'Reflection in the moment', but unlike Lori (who achieved a sense of clarity through her reflection), Michelle's reflection was steeped in uncertainty and doubt. In her narrative about the prolonged dying of an infant, Michelle explained that as time went on and the child remained alive, she began to question her "inner voice", her role, and the values she puts forth in her practice. She stated:

I think the other part of moral distress was for me (...) it started to make me question the value proposition that I had always put forward for palliative care, being the idea that it's

not about the length of time, it's about the quality of that time. And I felt like I'm not...

How can I say in this case I have done anything to improve the quality of this time? The quality of this time looks awful.

While Lori was able to, through reflection, come to a sense of resolution and make a decision about her practice, Michelle's reflection in the moment raised questions about whether or not she had made the right decision for this patient and family. At the time, Michelle's thoughts and reflections resulted in "moral distress" – to her, this moral distress impaired her capacity to support the family adequately.

Taken together, these examples reveal nurses' thoughtfulness and the extent to which they contemplate their actions. In situations that are ethically meaningful, nurses embark on reflection to not only determine the best course of action, but also as a means to evaluate the decisions made and actions taken.

Reflection over time. The participants' experiences also reveal that their reflections, particularly in the face of ethically difficult situations, have implications for months or years to come. They often described their experiences in the context of how much time had passed since the situation occurred and what impact it had on their practice going forward. For example, in reference to Michelle's narrative about the infant and family, she described the "moral residue" she experienced years later as a result of this encounter and that she "hesitates" whenever she is counselling a family about "what this might look like" ('this' being the period of time preceding the death of a loved one). Traces of the experience remain with her to this day and Michelle continued to reflect on the experience in the years that followed, and tried to make sense of it using understandings she has gained from other experiences she has had since. In her narrative, Michelle explained that she has come to recognize that her role is such that she is "not necessarily meant to be the person that takes away somebody's suffering", but instead "bear

witness” to it. In the following passage, Michelle explained how she uses the more recent appreciation of her role to bear witness as a way to reconcile past encounters:

Even though I still have some moral residue about that case and even though whenever I’m presented with similar types of things, or similar types of situations. (...) I think that I’ve come to feel like the bearing witness is maybe what the role is really meant to have been. And that part of the moral distress was me not recognizing or not understanding that that was my role, and coming to learn how to understand that, embrace that, and accept it.

By integrating ‘what happened then’ with ‘what she knows now’, Michelle is able to reconcile some of the moral distress she experienced from that encounter she had with the infant and family in her care all those years ago.

The notion ‘reflection over time’ was also revealed in Julie’s narrative about providing care at the EOL to a patient with ALS in the hospice. Much like how Michelle’s experience of moral distress left a lasting impression on her, the ethically enriching experience of providing care that felt “right” created a lasting memory for Julie. Julie prefaced this story by explaining that it is through reflection on her past experiences – specifically, the ones that she can reflect on and say “we usually do things right” – that she is able to reconcile the morally difficult situations she faces and stay in palliative care. Recall Julie’s account of withdrawing BiPAP on an ALS patient in the hospice, which she described as a “very emotional time, but a really lovely time because we all thought we had done the right thing.” When describing this story, Julie stated: “So, it was beautiful. So those are the kinds of things that make me stay there.” Similar to how Michelle integrated her past experience of moral distress in the context of what she knows and understands now, Julie was able to cope with her acute experience of moral distress by reflecting

on the ethically enriching encounters from the past, which remind her of the value and importance of her work.

Potential for growth. The participants' accounts also reveal that nurses' have the capacity to learn and grow, through their reflections about the ethically meaningful situations they encounter. The notion that nurses, through thoughtfulness and reflection, have the potential for growth was particularly apparent when Michelle stated that she also understands her hesitation as an opportunity to consider all of the potential ways a situation could play out. Michelle described that she has learned to be open to considering other options when withdrawing nutrition and hydration; for instance, she will now consider letting intravenous fluids run "a little bit longer" if it becomes too difficult for the family to cease hydration. Michelle's hesitation and willingness to continue hydration in the interest of the family's suffering is directly related to the experience she had with the dying infant many years prior. In that situation, despite the "best evidence" and despite doing everything they "should" have done for the patient, the family still suffered. By deciding to continue intravenous fluids, in spite of the evidence that contraindicates feeding and hydration at the EOL, she is recognizing that the focus of policies and evidence that guide the practice to withdraw nutrition and/or hydration at the EOL do not always align with what is at stake for the family.

The narratives of the participants' experiences in the face of ethically challenging situations also reveal what the participants will no longer stand for. Earlier, I presented Renée's narrative about an elderly woman in the ICU who wished to receive palliative care, but had her wishes overturned by her children. Renée described that she "should have never tied that woman down" and "will never do it again", and she is willing to accept the consequences dealt to her as a result. The moral distress Renée felt as a result of restraining this woman to provide care that

was inconsistent with her wishes affected Renée in long-lasting ways that shape who she is as a nurse and what she takes responsibility for.

Similarly, in the months that followed Julie's experience with "Jane", the patient who received palliative sedation as an alternative to MAiD, Julie explained how she raised her concerns about this situation through a number of channels, including talking to her manager, the director of medical care, and consulting the ethics support committee. By continually voicing her concerns and initiating an ethical review of that case, Julie made it clear that she would not stand for this to happen again. As described earlier, Julie stated that the process by which palliative sedation can be initiated in the hospice actually changed following Julie's response to this encounter. As a result of her taking action, Julie was able to effect actual change in the hospice that would help prevent the circumstances that allowed this ethically challenging situation to occur in the first place.

The theme 'Reflection' demonstrates, in part, what the participants' moral experiences reveal about their moral agency. In summary, this theme demonstrates that nurses are reflective and engaged thinkers – their reflections are temporal and lived in both the everyday moments that make up their experience, and over time in the months or years that follow. Nurses use reflection to make sense of the ethically meaningful situations they face and to integrate past experiences with what they know and understand now. The participants' accounts reveal that nurses critically reflect on their actions in the face of ethically meaningful situations; this critical reflection can lead to learning and growth that shape how nurses understand and respond to their responsibilities.

Relationships. The participants' occurred from within their relational contexts. These encompass the interpersonal relationships they form with the patients and families in their care, and also other contextual realities that shape their work. The following section will first speak to

the participants' engagement in interpersonal relationship, and how this relational engagement influences their moral agency and moral responsibilities. Next, I will discuss what their experiences reveal about the contextual realities they face, and how these realities influence their capacity to take ethical action.

Interpersonal relationships. In describing their experiences of ethically meaningful situations, all of the participants situated their narratives within the context of the relationships they have with other people. For example, when Dana described the patient who requested MAiD despite her best efforts to provide good care at the EOL, she explained that she struggled with this case because she and the patient “had developed a really good relationship”. Similarly, Lori described the “incredibly close professional relationship” she developed with her patient, which had a significant impact on how she navigated his request for MAiD. In Renée’s account of the young trauma patient in the ICU, she described how she spent time with the husband to learn what was important to her patient. Julie acknowledged, in her story about the patient who received palliative sedation, the relationship she and the patient had formed was one of reciprocity when she stated, “we knew each other so well from being together for those months, that she could read me just as well as I could read her.” Recall, the patient asked “what’s wrong” even though Julie did not verbalize her moral distress about this situation.

When the participants describe their moral experiences in the context of the relationships they hold with those in their care, they reveal that these relationships are important to how they understand and interpret the ethically meaningful situations they face. Moreover, relationships appear to inform how the nurses understand their moral responsibilities. For instance, due to the nature of continuing care, the proximity and longevity of the relationships Lori has with her patients means she becomes “part of their world”. When she described how she came to the decision to perform MAiD for her patient, Lori stated, “Part of what swayed me over to being

involved was the fact that this man and I had this incredibly close professional relationship.” In saying this, she reveals that what she perceives her moral responsibilities and commitments to be are shaped by the relationships she holds. Lori elaborated further and stated, “And I thought, how can I let him down? How can I not be in the room at this pivotal moment in his life? It would be like abandoning him.” Here, Lori reveals that she values the trust formed over many years of care – how Lori perceives the relationship she had with the patient informed how she navigated the ethical challenge and, ultimately, impacted the action she took.

The participants’ experiences also reveal that “knowing” the patient and/or family – through spending time with them and asking personal questions – can be an important source of ethical knowledge that allows nurses to direct their care in ways that are meaningful to the patient, enhance quality of life, and support the patient’s personhood at the EOL. In the context of caring for the patient who requested MAiD, Lori described the relationship they formed when she stated:

Because I saw him so often and as that trust relationship built, he told me more and more about his past life, about the things that were important to him, about his family and his family relationships through the years, about his values in life. And so it becomes a different kind of professional relationship because I had all that knowledge of who this man fundamentally was, what his religious beliefs were, what afterlife beliefs were, all those things that he had valued in his life, I knew because of our conversations when I’d be checking in with him.

By forming a trusting relationship, through time spent together and proximity, Lori and the patient co-created the conditions that allowed for him to feel comfortable sharing information about himself to her. Over time, Lori described arriving at a point where she “had all that

knowledge of who this man fundamentally was”. By knowing her patients, Lori is better equipped to direct care in ways that are consistent with the patient’s values.

Renée’s narrative about the young woman who died in her husband’s embrace while watching a movie was only made possible because she took the time to get to know the family. While Lori’s relationship with her patient was built on years of knowing him, Renée’s account demonstrates that gaining knowledge about what is important to the patient and family can happen even over a brief period of time. In the following excerpt, Renée explained how she came to learn what the patient and her husband enjoyed doing in their everyday life:

So we set them up, we took the time to kind of get to know them, through him. So, “tell us, what do you guys like to do? Oh, you guys are high school sweethearts, what did that look like?” Right? And one of their favourite things to do was just throw in like a movie and they would crawl into their hide-a-bed, you know one of those couches that would fold out, and they would right in the middle of their living room, anytime of day, just throw out the hide-a-bed and they would watch a movie.

By asking the patient’s husband about their life together, Renée was able to learn about her patient’s life, who she was, the life she lived, and the activities that she enjoyed with her husband. The information gathered as a result of her questions allowed Renée to organize care in a way that paid tribute to the life lived. In doing so, Renée not only cares for the patient, but also the patient’s husband – by recognizing the patient’s personhood through the husband and by organizing care around an activity the couple enjoyed together, Renée also brings to focus the life the patient lived with him.

In the other story Renée told about the elderly patient’s autonomy being thwarted by her children, Renée described what she has since learned from that encounter when she stated:

So if a patient says to me, “I can’t do this anymore, I just want to die”. I have that conversation right then. “What do you mean by that?”, “can you explain to me how you are feeling?”, so I have actually taken more time to examine what the patient is actually saying. And then, passing that on to somebody else, so that it’s not just me hearing that information, you know, passing it on whether it’s to the next shift, or to the physician team so that they can explore that with the patient, that’s definitely... And documenting that.

By probing for more information when patients make statements like the one above, Renée sees an opportunity to get at the root of what the patient is thinking and feeling. Furthermore, actively implicating herself to gain knowledge about the patient has direct implications for her practice. For example, Renée described how she responds to this type of interaction by ensuring what she has learned about the patient’s values and preferences is shared with those in the circle of care and well-documented. For Renée, exploring and advocating for the patients’ wishes is part of her role.

In her interview, Dana also described the importance of getting to know her patients, but her approach focuses on listening to the patient, as opposed to probing them with personal questions. In the following passage, Dana described the importance of listening and how letting patients “fill the silence” can elicit some important information:

The listening is more important than the talking, because I think there’s lots of times we want to fill in gaps ourselves, and if we just shut up for a minute and just let somebody else fill in those gaps, then you learn some pretty valuable information. (...) So if you stop and let your patients fill the silence, then you learn some *really* interesting things. Interestingly, the fact that Dana would rather listen and allow her patients to “fill in gaps” of information, rather than implicate herself by asking personal questions, appears consistent with

her understanding of professionalism, which requires her to keep herself separate from the interactions she has with those in her care. She does not impose her own values or judgements on the patient, as to not be distracted from the patient's needs, values and beliefs. Where Renée emphasizes implicating herself by 'stepping in' – asking questions of the patient to examine and clarify what they mean when they say certain things – Dana emphasizes 'stepping back' and listening.

Dana's conception of professional as separate from self also informs how she perceives and measures the actions of her colleagues. For example, she stated, "our social worker, I like to think, is quite professional" (in this case, Dana referred to a situation where the social worker remained engaged with a patient despite the disclosure of information that some would find morally reprehensible) and "I think that was unethical, as a professional, for her [another nurse] to do" (in this case, Dana is referred to a situation where a nurse refused to care for a patient based on personal beliefs about the sanctity of life). Dana's reflections about her colleagues' practice further reveals how professionalism – understood, to her, as the responsibility to support the patient regardless of one's personal beliefs or values – is important to her in the provision of care at the EOL.

Other participants were not so clear on the distinction between personal and professional relationships. Take Michelle, for example, who described taking on a maternal role when caring for the parents of an infant receiving care at the EOL at home. Michelle explained that, at the time, she felt tensions between the role she was supposed to be playing as the clinician and the maternal role she assumed. Michelle described that the maternal role that developed stemmed from the parents being so young and in need of so much support. The personal connection Michelle formed with these parents influenced how she understood her responsibility to them – she wanted to do right by them because they were in so much need of her support and guidance.

Michelle felt as though they needed to be parented themselves in a lot of ways, and so when the infant lived longer than anticipated and the parents started to feel distressed, Michelle felt personally accountable for their suffering. As a result of the ‘maternal’ connection she formed with them, she shouldered the distress they felt in ways that perhaps went beyond what would be expected of her as their clinician, which added to the intensity of her own experience of moral distress.

Michelle acknowledged that, in that specific case, there was some conflict between that maternal role she assumed and the professional role she was meant to be playing. She stated that even now she finds herself in professional relationships where a personal connection forms. While this does not happen with everyone, Michelle described that it does happen when there is a certain degree of “personalization”, such as when she relates to a patient and family who have elderly parents like she does. In contrast to Dana, Michelle believes that fostering a personal connection can enhance the caring relationship, even in circumstances where she does not necessarily agree with the patient’s choices; she explained this when she stated:

Recognizing that I could still make a personal connection because it really enhances the therapeutic relationship. (...) What has been really interesting is the opportunity to see that even though I may disagree with where they may be headed, I still have an ability to make a personal connection with them and support them in their decision-making, and I don’t feel any distress by it.

For Michelle, there is always an opportunity to engage and feel connected, while still supporting individual autonomy and decision-making.

Michelle is an example of how nurses can successfully engage with patients and families ‘personally’ within the context of their professional role, where such engagement enhances, not hinders, the caring relationship. This stands in contrast to Dana’s conception of her professional

identity as completely disconnected from her personal values and beliefs. While Dana's belief in abdicating her sense of self so that she does not impose her values and judgements on the patient is rooted in wanting to build a trusting relationship, it raises questions about whether or not she can authentically engage with patients without sharing any of herself with them. We know that some patients at the EOL are craving engagement and personal connection. Take, for example, Lori's statement about her patient's death being a "pivotal time" and a moment "when they almost needed [her] more than ever." Patients may turn to the nurse, whom they consider to be a well-versed expert in experiences relating to the EOL, for guidance on navigating their own mortality and EOL experience. By turning away from personal connections, there is potentially a missed opportunity to co-create an EOL experience where the patient feels secure and well-supported.

The participants' experiences also reveal the importance of trust – by building trusting relationship, nurses create a relational space where patient and family's needs and wishes can be heard and care can be directed ways that are meaningful to them. In circumstances where trust is lost or never there to begin with, it seems unlikely that an enriching experience at the EOL can be established. In another part of her interview, Renée described the rapport that families have with nurses is worse than it was in the past because they "don't believe anything" – the family no longer needs to rely on the knowledge and experience of nurses because all of the information they want is available "at their fingertips". Renée explained that family members "are *definitely* harder to take care of than the patient that's laying in the bed" because they can turn to "Dr. Google" and "come up with a different answer" than what the nurses are telling them. Renée stated that people who do this do not place any value on nurses' experience. Renée's description of this as a reality of her work reveals mutual mistrust – Renée is just as mistrusting of the family as they are of her. Recall also that Renée is the participant for whom family acceptance of

inevitable death is very important. By closing herself off to engagement with the family who mistrust and/or do not accept, instead of clarifying their needs and working with them to interpret what they are experiencing, Renée misses an opportunity to create a trusting relationship.

Contextual realities. Through the participants' accounts of their experiences, it became clear that the contextual realities within which the participants work have implications for the degree to which nurses can enact their moral agency. For instance, in the ICU Renée practices in, they often work understaffed. Throughout her interview, Renée expressed her frustrations with the lack of staffing and other resources that impact her ability to provide care that is consistent with what is important to her. Renée explained in her interview that when staffing is inadequate, she does not have time to document "things that are actually meaningful", like a conversation with a patient where their values, wishes, and goals of care were clarified. Renée explained that documenting this conversation is important because it is a way for her to advocate for the patient's needs and wishes. Renée also explained that a lack of physical resources, such as a chair or a blanket, impact her ability to meet the basic needs of the family members who wish to stay at the bedside of their dying loved one. Renée's dialogue about the various lack of resources that impact her practice reveals how organizational structures can impact nurses' capacity to act in ways that are consistent with what it means, to them, to provide good care at the EOL.

Dana spoke to how constraints on the healthcare system directly impact her work in the community. She described how in the community context, patients and families often struggle with navigating the system, with many clinicians, in Dana's opinion, not taking responsibility for these patients. Dana explained that this creates gaps in care for patients in the community, and, in some ways, she feels as though the palliative care consult team has been able to fill some of those gaps. In Dana's current role as consult nurse, patients are referred to her – once she is part of their circle of care, she remains involved over the course of their palliative care trajectory.

Dana explained the pressure she feels from changes being made at the provincial level that might make her role less involved with patient care, where a ‘consult’ would be that “you go and make some recommendations and step out.” When speaking to this, Dana stated, “you can’t fill a lot of gaps with a consult.” Dana laughed at the idea of supporting someone in grief in a brief consult:

Grief is much more complex than just here’s my recommendations for you to, you know, make a journal and whatever. You don’t walk away from that. So, a lot... I feel like a lot of what we do if we do it right, then we help the family afterwards to be able to grieve.

In this excerpt, Dana reveals that some issues important to palliative care, such as grief, are simply too complex for a consulting model of care that involves the nurse stepping in, only for a moment, and then stepping back out. Dana’s concern for how changes at the provincial level may affect her ability to adequately care for patients at the EOL reveals how socio-political structures can influence nurses’ capacity to enact care that is consistent with what they believe is right.

Both of Renée and Dana’s examples reveal that a lack of resources can impact how nurses are able to provide care that is consistent with their values. Without the necessary resources to provide care that they believe is important, nurses are unable to fully actualize their efforts. Renée and Dana both identified systemic issues that impact their ability to provide good care and meet the needs of their patients, whether it be at the local level, as in Renée’s example, or at a broader societal level like Dana’s reflections. Renée said herself that she believes nurses have the capacity to be agents of change and that it is important for them to “voice” their concerns, but the culture of the unit needs to be such that a “higher power” is listening and responding to those concerns.

Relationships within the healthcare team can both constrain or facilitate nurses’ capacity to do good and provide care consistent with their values. Interpersonal conflicts such as working

with physicians who have differing philosophies about care can constrain nurse's ability to provide care that fosters a comfortable, dignified death for the patient. Renée provided the example of physicians who have an "ICU mentality that we can save everybody." Another example is the physician who made a unilateral decision to provide palliative sedation in the place of MAiD for Julie's patient in hospice. Physicians typically hold more power and authority than nurses (in practice if not in theory), as they often make the final decisions about care and have the authority to issue directives that nurses then implement. It is important to acknowledge that the role of physicians and nurses differ such that they shoulder different responsibilities when it comes to enacting care at the EOL – for example, physicians bear the weight of the decision to withdraw care in an ICU differently than the nurses, because their directives ultimately determine whether someone lives or dies. That said, the responsibilities borne by physicians are not more important than those of nurses or vice versa; their responsibilities are simply different. Julie's struggle with the physician's unilateral decision did not stem from her not understanding or appreciating the nuanced differences between their responsibilities, but instead from the physician not demonstrating accountability for his actions. In the following dialogue, Julie explained how issues around responsibility and accountability existed in this situation:

Kristina: You said something about how, you know, nurses having both autonomy and responsibility is something that is important to, you used the words, ethical dilemma. So why is that? Why is it that autonomy and nurses' responsibility are so important to that?

Julie: That's exactly what didn't happen in my first story. That I had all the responsibility, and the physician did not even come when we put palliative sedation, you know got the pump going. I think it was a Versed pump. And never saw the patient or family again.

Makes the decision, drops the bomb, leaves the building, it blows up in our faces, and we

have all the responsibility of the emotional and physical impact of that on us and on the patient, and we don't even agree with the decision.

The physician's behavior (specifically, his lack of accountability, engagement with the nursing colleagues about the decision to initiate palliative sedation, and acknowledgement of their distress) in her narrative highlights what is at stake when mutual respect between colleagues is violated. The physician's lack of consultation with other members of the health care team was a missed opportunity for the team to engage in dialogue and create a mutually agreed-upon plan about how to proceed in a way that would be morally acceptable to everyone involved. Instead, the ability for Julie to act in ways that would foster a good death for this patient were thwarted.

While some collegial relationships have the potential to constrain nurses' capacity to enact care that is consistent with their values and beliefs, others have the potential to foster conditions that allow nurses to regain "confidence" or "hope" in the face of ethically difficult encounters. For example, when I asked Renée what is helpful to her when she is faced with ethically challenging situations, she stated:

Lots of things help me like gain confidence or hope. Primarily, it's comradery. I think colleagues are so important to helping you overcome that loss of confidence, or that loss of hope, that dismay that can come with feeling undervalued almost, because we do value each other. And I think a lot of the times, they're the only ones that truly understand.

Renée's comment reveals that in the face of deeply troubling and distressing situations, feeling supported and understood by colleagues can have a significant impact on one's ability to re-establish the hope and confidence that was once lost. Renée explained her answer further and described how feeling respected and treated as an equal by physician colleagues can help her address the demoralized feelings she has as a result of ethically challenging situations. She stated:

The other thing that I find that can help, kind of, add hope is when... like our unit we are very lucky in that we have a very horizontal relationship with our management and also our physician, but in times like this, it becomes less horizontal, right? You know, because we are on one level and it feels like the person who is making the decision is on a higher level. So, I think that, it adds hope when you have somebody take that step back down. So O.K. maybe the physician is making that decision, but they are actually coming down and providing rationale for why the decision is made. And that can actually help re-moralize you, that open dialogue, that communication, because I think part of it is not understanding.

In this passage, Renée reveals that dialogue and communication flourish in relational spaces built on mutual respect. When physicians demonstrate mutual respect to nursing colleagues and vice versa, there is an opportunity for the team to come to a shared understanding of what is happening and why.

Apart from comradery, other aspects of the participants' contextual realities facilitated their ability to do good and provide care consistent with their values. For instance, Julie described of how she was able to voice her ethical concerns to various stakeholders at all levels of her organization. This reflects a culture much different than the one Renée described when she said that nurses are capable of effecting change, but "there has to be someone who's listening to us. And I don't necessarily think that that culture exists." In Julie's context, it appears that the organizational culture is such that the leadership staff take seriously the ethical concerns nurses raise, to the point where nearly three months following the incident Julie described, they are still debriefing about that specific case.

Michelle also alluded to the importance of the organizational culture in supporting her practice. She described how it is important for her to work in an organization that "upholds the

same values” that she does around care at the EOL, such as compassion. She elaborated further on compassion and mutual respect in the context of the organization culture when she stated, “So not just compassion for patients and families, but compassion for each other as health care professionals. And that idea of a sense of wellbeing for everyone.”

In summary, the theme “Relationships” encompasses how the participants’ experiences reveal that nurses as moral agents are inextricable from their relational contexts. The interpersonal relationships nurses find themselves within and create shape how they understand their moral responsibilities to their patients. Furthermore, by taking the time to understand who the patient and family are and what is important to them, nurses are able to direct their care in ways that create an individualized experience for the dying patient and their loved ones.

Importantly, nurses are also situated with contextual realities that shape the degree to which they are able to enact their moral agency. Lack of resources, power dynamics, and organizational cultures that do not uphold the value of mutual respect can prevent nurses from being able to enact what they perceive is good or right in a given situation. That being said, organizational cultures that take seriously the ethical concerns nurses raise can foster nurses’ capacity to effect change, which can potentially alter the conditions that allow ethically difficult situations to occur in the first place.

Moral sensitivity. As revealed through the participants’ experiences, moral sensitivity is a skill that is enacted by recognizing what is at stake for those in one’s care. Through their narratives, participants reveal their moral sensitivity to the moral dimensions of their practice in both the dramatic and the mundane moments that make up their experience. The participants could easily recall the dramatic experiences that were ethically significant to them (which implies that these moments are deeply impactful, and so they never forget about them). For instance, when asked the broad question “Can you tell me about a time when you faced an

ethically challenging and/or ethically meaningful situation in the provision of end-of-life care?”, participants easily recalled detailed examples of thwarted autonomy, situations of futility and torture, and concerns relating to prognostication and prolonged dying.

Perhaps less evocative, but equally relevant, was how the participants’ experiences also reveal their engagement with the moral dimensions of their work in the mundane, everyday moments that make up their practice. For example, when speaking about the lack of resources in her setting, Renée illustrated what is at stake when even a simple object, like a chair, is not available:

So, our unit is just really not set up to have, and I know we’re an ICU, but we’re not set up to facilitate comfort of people staying with the family. And I spoke to how I want the people who are important to that patient to be with them. Right? I want, if it’s a mother in the bed then the children can be there. And often death isn’t instantaneous, so if you’re going to be with us while your mother comfortably passes away, I feel like I should be able to offer you a chair. And simple resources, like a chair or a blanket, they’re not in the budget.

In this passage, Renée reveals that everyday nursing actions have moral weight. Renée being able to offer a chair amounts to more than just an act of kindness or a polite gesture – it is an action informed by her values of what it means to provide good care at the EOL.

Lori also demonstrates how nurses enact moral sensitivity in everyday moments when, at one point in her interview, she described advocating for her patient who was frustrated about not receiving his medications on time.

(...) He wanted the nurses to give him his pills on time. And it frustrated him if they didn’t. Right? And so, you know, I would go and talk with the nursing manager and I say, “Look, I know that the day-to-day operations in a facility are challenging, and I know

that, you know, according to policy you have a half hour window on either side to give a medication, but this is upsetting him. Do we need to upset him?"

Lori was able to recognize how giving and receiving medication had implications for the quality of life of this patient. She recognized that a concrete action, like ensuring medication is received on time, can have implications for an individual's experience in relation to the things that matter most to them.

These examples demonstrate that moral sensitivity requires nurses to recognize what is at stake for patients and families, and then direct their actions in ways that support their needs, wishes, and values. In another example, Dana described a family in her care that was struggling to accept various aspects of care at the EOL, such as the withdrawal of nutrition, as a result of previous experiences with the death of a loved one that had created negative memories for them. Dana explained that, despite her best efforts, she is not always able to get patients and family members to a place where they are able to recognize that additional treatments "are going to prolong [death] instead of prolong life". Dana described these situations as "heartbreaking", which led to a dialogue about her role in situations such as these.

Dana: I have a family like that right now, that every kind of medication we talk about, every kind of situation we talk about, kind of, there's a family member that they've had along the way that, that was a really emotional event. Or something happened within that family member's illness that triggers tears and significant emotions for them at each topic it seems like. So, like they said that, "Dad died, and they didn't feed him when he was dying, so we don't want that to happen to Mom." Well, that's a natural part of the process that people don't eat when they're dying. They are kind of unconscious and it's not safe to feed them. So I'm not sure how that's going to go for that family, and I'm not sure that... I mean, we've discussed it, about why the choking risk and all those kinds of

things, but I'm still not sure that that family is not going to be demanding feeding tubes for Mom when she's dying. That even though that's not going to help her in any way, but I'm not sure that they are not going to... I'm not sure that I have the ability to get them prepared that that's not on the list of option that are going to happen.

Kristina: So, you know, given that you think that sometimes maybe you don't know if you are going to be able to get them there, to what extent do you think you can make a positive impact in these kinds of situations? Maybe positive's not the right word, but make an impact in the right direction anyway.

Dana: Ya, um. Well I'm going to keep trying. That's all I can do, really. If it means that, they don't carry Mom's... cause Mom's going to die soon probably, you know. And this ends up being a lady I've known probably most of my life. So it's going to be... is there a way that I can continue to work with them and help them to understand that this is a normal part of the process. And yes, it happened to Dad but it was a different situation, and actually when we stop and look back at Dad's situation maybe they get some better understanding so that they can let some of that go as well.

In this conversation, Dana reveals the effort she makes to contextualize the behaviour of the family as tied to their social history and past experiences with death. She is sensitive to what is at stake for the family and persists in trying to help them navigate towards acceptance, despite knowing that acceptance might never come. Dana shows compassion and understanding towards the family by not giving up on them and by directing her care in a way that gives them a chance to come terms with their mother's death, and perhaps even help them to achieve some resolution or closure with their past experience of losing their other parent.

Dana's narrative about persevering when the family is not accepting of certain aspects of care at the EOL is very different from Renée's narrative about the elderly patient whose

individual autonomy was thwarted by her sons. Renée refers to her care as “family-centered” and provided some salient examples of how she engages with families, such as actively implicating herself by asking questions to gain knowledge about the patient in order to direct care in ways that are meaningful to them. That said, it appears that for Renée, the family’s acceptance of imminent death is necessary for her to fully engage with them. In her ethically enriching story about the young woman who died in her husband’s arms while watching a movie, Renée explained that the husband’s acceptance of his wife’s impending death created the circumstances that allowed this meaningful EOL experience to happen. This stands in contrast to her experience with the elderly woman and her children – the patient’s sons were not accepting of their mother’s wish to die, and instead of articulating a role for herself to understand what was at stake for them, she blames them for the unethical way her patient died. Had Renée directed her actions towards trying to understand the sons’ perspectives, perhaps there would have been an opportunity to create a more ethical EOL experience for everyone involved.

In recounting her experiences, Michelle demonstrated that she is sensitive to the suffering of others, but recognizes that suffering cannot always be eliminated – in moments like these, Michelle stated, “I think that I’ve come to feel like the bearing witness is maybe what the role is really meant to have been.” When asked to describe what bearing witness looked like to her, she said:

What it looks like is being able to be in a situation where I may not be able to fix what is happening, and being O.K. with that, and being able to tell the family, “I’m sorry for the pain you are going through, I wish that I could fix this. I can’t, but I am here with you and let me shoulder this with you.”

While Michelle might not always be able to eliminate suffering or “fix what is happening”, there is still an opportunity to engage with the patient and family by bearing witness and sharing in the

experience with them. Learning how to respond to the suffering of others has informed how Michelle understands her role and responsibilities in care at the EOL. To her, even in moments that seem helpless, there is always something that can be done.

The participants' experiences also reveal that nurses enact moral sensitivity when they recognize the 'high-stakes' nature of EOL experiences, for patients as well as for families. These are situations where nurses often have only "one chance" to get things right. In describing how she makes herself available whenever someone is approaching the EOL in the long-term care facilities that she practices in, Lori stated:

It's actually a part of my practice that I value highly, is the ability to make those final days and hours of somebody's life comfortable and meaningful for them and the family. And I think it's an area that requires a lot of medical finesse, right? With medication and just comfort measures and basic nursing care. So I often make myself very available, when somebody is at the end-of-life at one of our facilities, I often just go in on the weekend, and make sure that the nurses are not, sort of, in a bit of jam with symptom management. Because I just think you don't get another chance to make it right, right? You get one chance. This is the end for this person, it's pivotal moment in the family's life or friend's, it could be friends at the bedside. And why wouldn't I be there? If I can do something to help make that time easier and more meaningful for somebody, then to me that's part of what I value in my job.

In this passage, Lori reveals that she recognizes the significance of death as a life-changing moment for a family. Lori provides care at the EOL with intentionality, because she is sensitive to the meanings and memories the family will create as a result of this experience. Lori coming into the facility on the weekend or making herself "very available" cannot and should not be

reduced to her simply going ‘above and beyond’ – by doing these things, Lori is directing her actions towards the good she feels that patients and families deserve.

Michelle is also sensitive to the notion that the family’s perceptions about nursing care during the EOL of a loved one can have lasting implications for their bereavement and grief. Michelle spoke to this when I asked her what matters most to her in the face of ethically meaningful EOL situations:

(...) That, in reflection, the family can say they felt like they were able to get what they needed out of the experience to feel like they can continue to, that they can be whole again. Because most people don’t feel whole for a very long time, and if I have the, we’ll say, the pleasure, the extreme honour to be able to be there and bear witness to that, hopefully my role can be somehow in allowing them to be able to come out of the experience, maybe not in a few years, maybe not in a year, maybe it’ll be years later. But somehow they’re able to come out of that experience and at some point feel whole again.

Michelle takes responsibility for the family’s experience well beyond the time of death because she is perceptive to the fact individuals close to the patient generate meanings out of the care that is provided to the patient at the EOL. Michelle demonstrates that nurses as morally sensitive clinicians have the capacity to influence how the family reconciles the loss of their loved one long after the caring relationship ends.

The theme ‘Moral sensitivity’ speaks to the ways in which the participants work at recognizing what is at stake for those in their care, and moreover, how they are perceptive to the moral significance of their work in both the dramatic and mundane moments that make up their experience. Through moral sensitivity, nurses adjust and adapt their approach to care in order to best meet the needs of the patients and families, and to contribute to memories of this care that will follow the family into their experience of grief and bereavement.

Summary of Findings

In summary, the participants' accounts of ethically meaningful situations revealed that nurses are active moral agents who shoulder many responsibilities in the provision of care at the EOL. The three themes of 'Reflection', 'Relationships' and 'Moral sensitivity' encompass attributes of the participants' moral agency. The theme 'Reflection' demonstrates that the participants' are thoughtful about what is happening or has happened in a given encounter, and their contemplations inform their actions in the moment, but also in the months and years that follow. Furthermore, the participants' accounts reveal that, through reflection, they are able to reconcile the morally difficult situations they face and recognize the opportunity to learn and grow as a result of these encounters.

The theme 'Relationships' describes how the ethical practice of nurses is inherently situated within relational contexts. The participants' accounts reveal that their understandings of responsibility are generated through the relationships they hold with the patients and families in their care. The relational context also encompasses the contextual realities and structures within which the nurses work, and the implications these realities have on their ability to enact their moral agency.

The final theme, 'Moral sensitivity', demonstrates how the participants recognize what is at stake for the patients and families in their care. The participants' accounts reveal how they are perceptive to the moral weight of their work, in both dramatic and everyday moments. By enacting moral sensitivity, the participants strive to provide care that is consistent with the individualized values and needs of dying patients and their families.

Chapter 5: Discussion

The purpose of the study was to explore the moral experiences of nurses faced with ethically meaningful situations in the provision of EOL care. The motivating curiosity that guided this inquiry was two-fold: first, my personal nursing experiences of EOL care; and second, an engagement with nursing ethics literature as a graduate student that fostered increasing skepticism about moral distress and quandary ethics. As dominant discourses, these lead to a narrative of powerlessness in nursing. Just as the ethical reflections of nurses evolve over time (as described in Chapter 4), my own thinking about the central concepts of this study evolved over the course of writing this thesis. Although I began this study with an explicit intent to conduct nursing ethics research that might move beyond the conceptual confines of moral distress, I would often find it difficult to see beyond this notion in the narratives of my participants.

Recall, the research findings presented in Chapter 4 (Findings) were oriented around two guiding questions that served as aims for this study. These questions are:

1. How do nurses describe ethically meaningful situations in the provision of EOL care?
2. What do these experiences reveal about nurses as moral agents?

The first part of the research findings attempted to articulate a descriptive account of the participants' encounters with ethically meaningful situations. The second part presented a thematic interpretation of what the participants' experiences revealed about their moral agency, articulated through three themes: 'Reflection', 'Relationships', and 'Moral sensitivity'. The participants' experiences revealed that, in enacting moral agency, nurses are deeply thoughtful and perceptive of the responsibilities they hold and their capacity to act on their commitments is facilitated or constrained by relationships. The themes presented in Chapter 4 (Findings) articulate the interrelated attributes that can foster and sustain nurses' capacity for ethical action.

The following discussion presents how the findings relate to relevant, existing literature. First, I explore how the research findings relate to and expand upon the theoretical scaffold presented in Chapter 3. Next, I present the implications this research has for nursing practice, education, and research. Finally, I present the limitations of this study and offer my final reflections on the use of interpretive description and maintaining credibility in qualitative research.

Theoretical Perspectives: Revisiting Nursing as Moral Practice

In Chapter 3, I presented my theoretical allegiance to the notion of ‘nursing as moral practice’. While the term ‘moral practice’ has been used loosely in other works, it is in Gastmans and colleagues’ (1998) philosophical-ethical interpretation of nursing practice that nursing as an inherently moral practice is clarified and formally elaborated on. Since their articulation of nursing as moral practice in 1998, other distinct but related concepts have emerged as relevant to nursing’s ethical landscape. As such, my theoretical forestructure upon entering the study was oriented around Gastmans and colleagues’ seminal work and contemporary concepts in nursing ethics (i.e. moral identity, moral agency, and moral experience). In the following sections, I examine and discuss the findings of the research against the theoretical lens that informed this inquiry.

This research study is critical, in so far as I have taken a position on moral distress as a damaging and dominating discourse. I organized this study in an attempt to give recognition of and consideration for nurses’ morally distressing experiences, while simultaneously striving to explore and uncover other dimensions of moral experience that characterize the provision of palliative and EOL nursing care. As a nurse who has experienced moral distress, there were moments throughout the trajectory of this study that I felt compelled – often unconsciously – to focus on describing the pain and suffering experienced by nurses in the face of ethically difficult situations, despite my own intentions of wanting to engage in a broader understanding of nursing

moral practice. Even as a nurse and researcher critical of the meta-narrative of powerlessness that moral distress creates, I found myself vulnerable to the power that this discourse has. I acknowledge this, as a point of discussion, because I often returned to the theoretical forestructure – the literature and concepts that led to my criticism of a narrative of powerlessness in the first place – to renew my focus on what I was striving to explore and uncover through this work.

In the following section, I discuss how the findings relate to and expand upon the concepts – specifically moral identity, moral agency, and moral experience – that make up my theoretical orientation of nursing as moral practice. In the following section of this chapter, under the subheading ‘Moral identity’, I attempt to discern the participants’ moral identities by exploring the values that appear to guide the nurses’ EOL care practice, drawing on both the research findings and pertinent scholarly literature. Next, under ‘Moral agency’, I discuss the extant literature on moral agency as it relates to the three themes (i.e. ‘Reflection’, ‘Relationships’, and ‘Moral sensitivity’) presented in Chapter 4 (Findings). Finally, in the discussion section titled ‘Moral experience’, I discuss how the participants’ accounts relate to the current literature on moral distress and moral resilience.

Moral identity. Recall, according to Peter, Simmonds and Liaschenko (2016) moral identity reflects an “ongoing moral history of what we take responsibility for, respond to, are concerned about, care for, and value” (p. 3). Through the sharing of stories, nurses reveal their moral thinking and their experiences reflect their moral identities (Peter et al., 2016). The ways in which nurses articulate their moral responsibilities helps define their identities, values, and relationships (Peter et al., 2016). Moral responsibilities define what nurses hold themselves accountable for and what the scope of their agency is (Peter et al., 2013). Moral identities and

responsibilities are socially constructed and relational – they are developed and sustained through interactions with others (Peter et al., 2016).

In this study, the participants revealed their moral identities and what they take responsibility for. All of the participants shared a deep commitment to the experience of patients and families at the EOL – these responsibilities and commitments are understood through the beliefs they hold about EOL care and the values they bring to their practice. In this section, I attempt to discern the values that guide the participants’ practice, drawing on their accounts of ethically meaningful situations and relevant extant literature, in an attempt to convey their moral identities. Throughout the following discussion, I continue to remain close to the data, at times using direct quotes (some of which are repeated from earlier sections), to articulate the participants’ shared values of enhancing quality of life, bearing witness, accepting, maintaining hope, and enacting mutual respect.

Enhancing quality of life. Quality of life is defined by the World Health Organization (1997) as “an individuals’ perception of their position in life (...) in relation to their goals, expectations, standards and concerns” (p. 1). Quality of life is often recognized as a fundamental guiding virtue of palliative care (Ferris et al., 2002; Health Quality Ontario, 2016; Jocham, Dassen, Widdershoven, & Halfens, 2006), yet there are diverse and conflicting ways in which quality of life is understood (D. K. Wright, 2012). Quality of life is often conceptualized as something that can be readily measured using standardized instruments or that can be used as an indicator for the effectiveness of nursing and/or palliative care (Albers et al., 2010; Kaasa & Loge, 2003). However, other authors suggest that such a view is reductionist, as quality of life is inherently individual and “uniquely definable by the person living the life in question and is therefore knowable only by way of knowing that person as a human being” (D. K. Wright, 2012, p. 44). In the following section, I articulate how the participants in my study engage with this

more subjective and relational construct of quality of life by ‘knowing’ the patient, doing the ‘small things’ that are important to the patient, engaging the patient’s personhood, and ‘sharing the journey’.

According to D. K. Wright and colleagues (2017), quality of life is actualized or thwarted in the everyday moments that make up a person’s individual experience. Lori exemplified that she values quality of life for her patients when she described advocating for the man who was frustrated about not receiving his medications on time. Lori demonstrated that simple actions, like giving and receiving medication, can have implications for an individual’s experience when it pertains to the things that matter most to them. D. K. Wright and colleagues (2017) state that in order to know what is important and what makes a particular person “happy” requires knowing them as an individual. According to Perry (2009), “nurses not only need to do the small things; they need to do the right small things, those that are important to a particular person” (p. 19). Initially, Lori was only able to recognize this man’s frustration as being related to his medications through getting to know who he is and what he cares about. By engaging with the patient regularly and getting to know who he was as a person, Lori formed a relationship built on trust and understanding, and created the necessary space that allowed for his goals and wishes to be clarified. When attentive to the ‘small things’ or the aspects of care that are important to a particular person, nurses “acknowledge the other’s unique humanity” (Perry, 2009, p. 19). It is in the everyday and essentially ordinary experiences that nurses convey compassion and engage with their patients’ personhood – they recognize them as more than a series of tasks, but as unique persons who have value and significance.

Lori’s narrative demonstrated how she was able to ‘know’ the patient through sustained engagement over many years of care. On the contrary, Renée, as a critical care nurse, must sometimes make a connection with the patient and family over a brief period of time. In Renée’s

example about the young woman who was dying following a motor vehicle collision, she described asking questions of the husband to gain knowledge about who the patient is and what she enjoyed doing in life. Even in this brief encounter, Renée was able to learn about what the patient valued and organized her care in a way that paid tribute to the life she lived. Renée's ability to (re)connect the patient to her unique social context echoes similar findings by Peter and colleagues (2016), in their study on the moral identities of nurses as revealed through their narrative stories about an important moment in their career. In their study, Peter and colleagues (2016) found that nurses find ways to connect patients to their social traditions through seemingly little or ordinary things. In Renée's example, the 'social tradition' that the patient and her husband enjoyed was that of watching a movie in bed together. Like the nurses in Peter and colleagues' (2016) study, Renée found a way to connect the patient to the social world around her, and in doing so, recognizes the patient's personhood and fosters quality of life for the family, even in the brief amount of time Renée has to connect with them. According to Perry (2005), "the connection (...) may occur in mere moments by a highly skilled caregiver through the right touch, word, or listening ear" (p. 47). Even in circumstances where time is short, nurses have the capacity and skill to create a valuable relational moment that can have a powerful impact on the patient and family's well-being.

Perry (2005) also argues that nurses "share the journey" with their patients, that "they entwine themselves in a mutually dependent way with others including patients, learning and growing together" (p. 48). Several participants in this study demonstrated the mutuality and reciprocity that exist within the relationships they form with others. For instance, recall Julie's statement: "we knew each other so well from being together for those months, that she could read me just as well as I could read her." In this moment, Julie reveals the mutual interdependence between herself and her patient, and demonstrates how the nurse is also affected

by the relationship (Perry, 2005). Similarly, Lori, as a nurse practitioner caring for patients in long-term care over many years, described that she becomes “part of their world” and is “walking along with them” in their journey towards the EOL. Moreover, when speaking about the patient who asked her to perform MAiD, she explained that she knew she would grieve his death. Through these statements, Lori demonstrates the mutuality that exists within nurse-patient relationships; the nurse and patient are co-participants in the caring that takes place within the relationship, and just as the patient is affected by receiving care, Lori is affected in return (Perry, 2009). Perry (2009) argues that it is in this reciprocal relationship that compassion is experienced and quality of life is enhanced.

Bearing witness. Individual autonomy is typically understood as an individual’s right to make decisions about his or her life in a manner that reflects the preferences and values that he or she determines to be meaningful (Ells, Hunt, & Chambers-Evans, 2011). The Canadian Hospice Palliative Care Association (2015) defines autonomy as:

The capacity for self-determination, and one of the rights associated with liberty. Respect for autonomy means acknowledging the person’s right to make choices and take actions based on their own values and belief system and not interfering with the person when he or she exercises that right. (p. 56)

A traditional view holds that autonomous individuals have the capacity and sufficient competency to make a decision, are adequately informed, choose reasonably from the available options, and are not coerced by others (Rodney, Burgess, Pauly, & Phillips, 2013). In her concept analysis on the notion of a ‘good death’, Kehl (2006) found that maintaining control at the EOL is an essential attribute of a good death. According to Kehl (2006), elements of ‘being in control’ include having wishes being honoured and having control over the death event, such as control over the location, timing, and presence or absence of others. However, a more

contemporary view of ‘relational autonomy’ calls into question this individualistic view of autonomy and draws attention to a broader and more contextualized understanding of autonomy in health care (Rodney, Burgess, et al., 2013). In the following section, I describe the ways in which the participants demonstrate the traditional, individualized view of autonomy as important to their provision of EOL care. Then, by drawing on the participants’ accounts and relevant scholarly literature, I articulate how bearing witness has the potential to nurture relational autonomy.

Two participants in particular, Renée and Dana, made clear through their narratives that supporting individual autonomy for their patients was important to their practice. Renée’s narrative about the “torture” of an elderly woman who had wished to receive palliative care in the ICU was ultimately about thwarted individual autonomy, resulting in Renée performing care that was inconsistent with what she believed was right or just. Renée described the repercussions this situation had on her (the emotional and moral ramifications that required her to think critically about her practice) and her colleagues (who were “going off on stress leave” as a result of this situation), which reveal what is at stake for nurses when the value of self-determination and individual autonomy is not upheld at the EOL.

Renée’s character as a nurse also reflects the importance of individual autonomy to her. She perceives advocacy as part of her role, where such advocacy means that she must “bring forth concerns” on behalf of the patient to facilitate their wishes and needs being heard. In the context of the story mentioned above, she stated: “and so it’s the nurses that are, you know, *fighting* essentially to have her wishes be heard.” Renée explained that when constraints prevent her from enacting her role as advocate, it becomes “de-moralizing”. Renée’s experience is consistent with previous literature that suggests that nurses view their role, as the primary providers of care at the EOL, as needing to advocate for the wishes of the patient and family –

when the nursing voice is unheard or undervalued, the agency of nurses is constrained and their ability to enact this role at the EOL is challenged (Hamric, 2001; Hamric & Blackhall, 2007; Johnson & Gray, 2013; Searle & Mcinerney, 2008; Sekse et al., 2017).

Autonomy came through as an important value in other interviews. Recall Dana, who explained the importance of keeping her personal identity separate from her professional duty. Empathizing and understanding the experience of those in her care requires, to her, putting her values, beliefs, and judgments aside to focus entirely on the patient. This finding resonates with the definition of autonomy presented above, where autonomy is closely associated with liberty and individuals are not to be interfered with when exercising their right to liberty and choice (Canadian Hospice Palliative Care Association, 2015). However, as previously stated, the construct of relational autonomy posits a broader and more contextualized articulation of autonomy (Rodney, Burgess, et al., 2013).

According to Sherwin (1998), a relational view of autonomy holds that autonomy “is developed (or constrained) by social circumstances. It is exercised within relationships, and social structures that jointly help to shape the individual while also affecting others’ responses to her efforts at autonomy” (as cited in Rodney, Burgess, et al., 2013, p. 93). In other words, the lived reality of autonomy is developed and exercised through human relationships. As stated by Bergum (2013), “there is no autonomy for human beings in isolation from each other” (p. 133). The notion of relational autonomy resonates with the findings from Michelle’s interview when she spoke about the importance of bearing witness for her role in EOL care. Michelle explained that, even when the patient makes a decision about their care that she might not choose for herself, there is still an opportunity to bear witness and foster a personal connection. To bear witness is understood as attesting to the authenticity of what a person, family, or community has

experienced through one's personal presence (Bunkers, 2014; Naef, 2006). Moreover, Naef (2006) offers the following description of bearing witness:

(...) bearing witness is a special way of being with persons because it involves being attentive to persons' lived experiences and truths, honouring uniqueness in respecting different ways of living a situation, supporting persons' choices, espousing the belief that persons know themselves best, and recognizing human interconnectedness. (p. 147)

Naef (2006) argues that bearing witness is inherently ethical, in that it is an action that arises from our moral responsibility to attend to another's vulnerability, suffering, and humanity. Thus, bearing witness is an approach to enacting moral agency – nurses choose to engage or turn away, but “disengaging the other is a missed opportunity” (Naef, 2006, p. 155).

This conceptualization of bearing witness aligns with notions of relational autonomy, in that autonomy as relational is developed, exercised, and potentially constrained through relationships. Bearing witness is the act of being with another that is underpinned by moral responsibility; a commitment to honour, attend to, and stay with the other's “truths, perspectives, priorities, hopes, and dreams” (Naef, 2006, p. 149). I see Michelle's bearing witness as an ethical endeavour, one that creates the necessary relational circumstances that allow autonomy to flourish.

Accepting. An important goal of the palliative care movement is to move beyond a death denying society to one where death is understood as an inevitable part of life (Canadian Hospice Palliative Care Association, 2015). The discourse on acceptance emphasizes that recognition, acknowledgement, and even embracing the inevitability of death are considered attributes of a good death. The idea that it is possible and desirable to ‘accept’ death and dying is, therefore, essential to palliative care, both as a unifying, philosophical ideal to aspire to and as a psychological goal for patients and families (Cottrell & Duggleby, 2016; Kehl, 2006;

Zimmermann, 2012). According to Zimmermann (2012), acceptance functions as a ‘facilitator’ in the provision of EOL care, as it can “not only make dying ‘easier’ for the patient and his or her family, but also facilitate care of the dying patient by the nursing staff” (p. 221). In the following section, I demonstrate how the participants in my study rely on acceptance as a ‘useful’ construct in their provision of EOL care. However, I also highlight the harms of such a discourse, like the potential for nurses to disrespect and disengage from those who choose to not accept their fate.

Renée described how it can be ethically difficult to navigate situations of perceived futility when those in her care are unwilling to recognize and accept death as inevitable. When asked to recount an ethically challenging and/or ethically meaningful situation she has faced in her practice at the EOL, she stated, “One that I can speak of is this overwhelming inability to accept [that] death is a part of life. So that movement from absolute care to the palliation.” In her story about the elderly woman in the ICU, the family’s refusal to accept their mother’s impending death, to Renée, impeded the ability for the nurses to promote a dignified death for the patient. This is consistent with findings from Zimmermann’s (2012) discourse analysis on the concept of acceptance in the palliative care literature, where denial is seen as an obstacle to the provision of effective palliative care. Renée’s other narrative about the young woman who was dying in the ICU following a motor vehicle collision reveals her feelings that acceptance is important to EOL care. In this circumstance, Renée described that the health care team was able to move toward creating a good death because the patient’s husband recognized and accepted the inevitability of his wife’s death.

For Renée, the value of acceptance has implications for the extent to which she engages with the family – where the family that accepts death is met with admiration, the other is met with opposition and conflict. In contrast, Dana understands the value of helping the family

achieve acceptance of death, but also recognizes that some families will never be ready when death occurs, and she is accepting of this. In her example of the family refusing to withdraw nutrition at their mother's EOL, Dana explained that she would not "give up" on them, and that she would continue to engage with them, even if acceptance is never realized.

While some nurses believe acceptance makes caring for dying patients 'easier', systemic structures that shape organizational practices create the necessary circumstances for acceptant patients and families to be favoured over those that resist death (Zimmermann, 2012). As stated by Zimmermann (2012), it is the "necessity of a system that relies on open discussion for the efficient management of the dying person" that creates the imperative for acceptance (p. 222). Although the discourse on acceptance sustains an ideal of the preferred way to die, nurses must recognize that acceptance might not always be possible or even ideal. For instance, D. K. Wright (2012) argues that while some narratives of a good death emphasize peacefulness, others emphasize the patient fighting until the end or remaining "ambivalent about their fate" (p. 34). As her narrative suggests, Dana is accepting of even those that cannot – or do not want to – accept the reality of death. Dana demonstrates that nurses have an opportunity to engage with and support these families too.

Maintaining hope. A core assumption of the philosophy of palliative care is that no person, no matter how dire their circumstances, is beyond hope (D. K. Wright et al., 2017). Hope is often discussed in relation to the hope that patients or family members maintain at the EOL, but health care providers have hope too. According to Dufault and Martocchio (1985), hope is a "multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good, which to the hoping person is realistically possible and personally significant" (as cited in Penz & Duggleby, 2011, p. 282). Hope in health care providers is relational, in that it is sustained and enhanced in the context of the relationships we hold with

others and the difference we can make in another's life (Kulig, 2001; Penz & Duggleby, 2011; D. K. Wright et al., 2009). Hope in nurses may also foster positive work outcomes, as literature suggests that hope for something positive in the future can lower levels of burnout, improve engagement in work, and enhance quality of patient care (Duggleby & Wright, 2007; Penz & Duggleby, 2011).

The participants described being hopeful that the care they provide to dying patients and their families will lead to improved bereavement and grief outcomes for the family following the loss of their loved one. Their aspirations were consistent with Dufault and Martocchio's (1985) definition of hope, particularly where the authors describe the character of hope as "a confident yet uncertain expectation of achieving a future good" (as cited in Penz & Duggleby, 2011, p. 282). Michelle, for example, seemed unsure about whether or not the care she provides would achieve her wish to improve the family's bereavement experience, but she remained hopeful that it would. Similarly, when Dana was struggling to navigate a family towards withdrawing nutrition at their mother's EOL, she explained that she would "keep trying" to help them come to terms with the imminent death, despite recognizing that she might not be able to "get them prepared". Despite being uncertain in that particular situation, Dana confidently stated: "I feel like a lot of what we do if we do it right, then we help the family afterwards to be able to grieve."

In the participants' accounts, hope stimulated action – it influenced how the participants directed their care in a way to bring about a future good, despite being uncertain about the outcome. This is consistent with findings from a grounded theory study on experiences of hope in community palliative care nurses, where the authors state that "hope involved action and striving for something, hope was a choice (...) even though what they hoped for might not be attainable or the outcomes might be uncertain" (Penz & Duggleby, 2011, p. 286). Hope is underpinned by a desire and effort to achieve what is good and to make a difference in the lives

of others – according to Peter and colleagues (2016), “making a difference in the lives of people has been a longstanding aspect of nurses’ collective identity” (p. 7). The findings of my study suggest a relationship between hope, moral agency, and moral identity, which has been the focus of few empirical studies in nursing to date.

Enacting mutual respect. As a central theme of relational ethics, mutual respect arises out of interconnectedness of people to one another (Bergum, 2013). Our identities encompass our attitude toward others but also the meanings we construct from the attitude of others towards us (Bergum, 2013). The challenge we have as relational beings is to enact mutual respect when there are differences of opinions, beliefs, or values (Bergum, 2013; D. K. Wright et al., 2009). Our moral identities are developed and maintained through relationships with those who hold our identities (Peter et al., 2016). According to Peter and colleagues (2016):

When identities are held well the flourishing of people is fostered, but when they are held badly, people can be destructively identified with a social group that is believed to be socially or morally inferior, resulting in damaged identities and at times moral distress.

As nurses’ moral identities are held by individuals who are inherently different from themselves – for instance, in power, knowledge, beliefs, experience, attitude, and values – enacting mutual respect can be challenging (Bergum, 2013). Mutual respect requires attention to the interactive and reciprocal nature of respect, whereby one must look for ways to achieve coexistence with others who are different, but of equal value and significance (Bergum, 2013).

The participants’ accounts of their experiences reveal that mutual respect among colleagues grounds their practice. When mutual respect is enacted among colleagues, it has the potential to foster resilience and confidence; however, when it is thwarted, the participants describe feeling powerless and inferior. In Julie’s narrative about ‘Jane’, the patient who received palliative sedation in the hospice, the physician made a unilateral decision that the

nursing staff did not agree with and, to her, he did not uphold his responsibility and accountability to the patient, family, and other staff when he left it to the nurses to manage the emotional ramifications of initiating palliative sedation. Julie likened the physician's "personal ethic" to that of a follower of a communist regime, a decidedly evocative analogy that highlights how offended she was by his lack of leadership. In Julie's account, there was a missed opportunity for the nurse and the physician, individuals that are unique in their own right, to collaborate in a way in which both individuals are heard and respected, which may have mitigated or prevented her experience of moral distress (Bergum, 2013).

In her interview, Renée speaks to the ways in which nurses and physicians navigate their differences in power and authority can either foster collaboration or create hostility within the health care team. For instance, in her narrative about the patient in the ICU who had her wishes overturned by the family, Renée reveals that she highly values her role as a patient advocate and the knowledge and training she has to assess the patient's cognition and explore their values and beliefs about the EOL. The moral distress she felt as a result of this situation was, in part, related to the physician not demonstrating respect for the aspects of her role that she values and cares about most.

Renée explained that feeling respected and treated as an equal by physician colleagues can help her address feelings of powerlessness. Her colleagues do this by engaging in "open dialogue", "conversation", and by "providing rationale" for the decisions that are being made, which can help her better understand their perspective. This finding supports the notion that mutual respect is interactive and reciprocal, and that nurses and physicians share the responsibility to work together in collaborative ways, rather than within hierarchical structures (Bergum, 2013). Renée's account is also consistent with work by D. K. Wright and colleagues (2009), who describe that, sometimes, the source of moral distress is not the actual issue at hand

(such as disagreement in decisions about goals of care), but the way in which the issue is handled.

When I asked Renée how she reconciles the “demoralizing” experiences she has had, she stated that it is primarily “comradery” between nursing colleagues that helps her regain “hope” and “confidence”. She explained that her colleagues help her overcome feelings of “dismay” that result from “feeling undervalued”, because they value each other and relate to common experiences. When Renée’s reflections are considered using the language offered by Peter and colleagues (2016), we can see how Renée and her colleagues ‘hold’ the moral identities of one another. They hold them with respect and admiration for their worth and significance as nurses and as human beings. When their identities are held well, nurses can potentially preserve the integrity of their identities in the face of moral threats (Peter et al., 2016).

In the preceding sections I have articulated the moral identity of the participants through the values that guide their provision of EOL care. For these nurses, the values articulated (i.e. quality of life, individual autonomy, acceptance, hope, and mutual respect) create the foundation for ethically meaningful practice, in that their moral identities inform how they perceive and respond to the situations they encounter. Furthermore, these values demonstrate the horizon of nurses’ responsibility to those in their care at the EOL. Having articulated the participants’ moral identities, the subsequent section will draw on extant literature to articulate how the participants’ values and responsibilities direct ethical action.

Moral Agency. As described in Chapter 3: Theoretical and Methodological Considerations, moral agency is the “capacity to recognize, deliberate/reflect on, and act on moral responsibilities” (Peter & Liaschenko, 2004, p. 221). According to Rodney, Kadyschuk, and colleagues (2013), “nurses are not disengaged thinkers” (p.160). Moral agency is enacted from what is known or believed about a particular case or context and through the

responsibilities and commitments we hold (Rodney, Kadyschuk, et al., 2013). Importantly, moral agency is relational and influenced by socio-political structures that can constrain its enactment (Rodney, Kadyschuk, et al., 2013).

The participants' moral experiences reveal that nurses as moral agents are reflective, relationally embedded, and sensitive. The themes 'Reflection', 'Relationships', and 'Moral sensitivity' reflect how nurses are 'engaged thinkers' – it is through these dimensions that nurses derive the necessary knowledge required to make choices about the best course of action in a given encounter.

Reflection. As discussed in Chapter 4, through reflection in the moment and over time, nurses reveal the thoughtfulness and contemplation that is behind their every action, in the present and in the future. In the moment, nurses are required to weigh various courses of action and the anticipated outcomes of each option. Through reflection on past experiences, the participants clarified their commitments and values, and what they will and will not stand for. Ethically meaningful situations, particularly those that are challenging, shape nurses in irreversible ways – they continue to reflect on the encounter long after it occurred and this thoughtfulness shapes nurses' moral practice, in that it allows them to become better equipped to meet the needs of their patients at the EOL in the future.

Rashotte (2005) claims that nurses frequently reflect upon the 'best' and 'worst' deaths that they have encountered, particularly when faced with a new EOL care experience. The experiences that nurses dwell on, the unforgettable encounters, are those that stimulate reflection upon one's practice and raise questions about how one's practice could be better (Rashotte, 2005). Rashotte (2005) explains, "their doubt becomes a good attribute. It becomes a *knowing*, it becomes a critic. The nurse asks what it is that is ugly in the care that has been provided" (p. 39-40). There is a sense of hope in the meanings that nurses create from EOL experiences that

‘haunt’ them and such emotions of guilt, remorse, and powerlessness will “somehow create something positive for the future” (Rashotte, 2005, p. 40). In reflecting on their past experiences with dying patients, the participants were able to critically appraise their practice and use the generated understandings as a form of knowledge to inform their provision of EOL care going forward.

Rashotte (2005) also provides insight on the importance of time; time is a treasured ally in diminishing the pain associated with ethically challenging encounters. Over time, the feelings associated with a particular encounter become less sharp and allow us to continue our practice at the EOL (Rashotte, 2005). Yet time also adds depth to our understanding of particular encounters, as it can help create new meanings by (re)contextualizing what happened in the past with what is known now in the present (Rashotte, 2005). The participants’ thoughts about the past as ‘lived over time’ reflects how they made sense of previous encounters, by situating them in the present day. For instance, since learning to embrace bearing witness as part of her role, Michelle has been able to reconcile some of the moral residue she carries from past experiences of moral distress. Recall Rashotte’s (2005) work, also cited earlier in Chapter 3, where she speaks to the notion of time in her article about the stories that haunt nurses. She writes:

Time allows this to happen because it is time that provides us with the opportunity to revisit our past experiences, to dwell with them, particularly in light of the ongoing experiences that add to our understanding and offer new appreciations. Time, thinking, frequently revisiting, and dwelling with our stories is an opportunity to create new meanings. We are never finished with the past. Just as the past provides us comfort in the present, the present can help to make meaning of the past. (Rashotte, 2005, p. 36)

While reflective practice might be understood by some as a cognitive skill, both this study and Rashotte’s work reveal that it is a process – a process by which nurses analyze, critique, and

learn from their actions to become better informed in their practice going forward. It serves as a form of moral education, the lessons of which can be implemented in the care of others at the EOL. Nurses' moral agency as deliberative reveals the value that can be found in all experiences, even those that appear to be morally problematic.

Relationships. If the nurse-patient relationship is understood as the moral foundation of nursing practice, then it is the site where moral agency is enacted. According to Rodney, Kadyschuk, and colleagues (2013), the very nature of nursing work arises from the nurse-patient relationship and the commitment nurses have to those in their care. In the context of palliative and EOL care, D. K. Wright and colleagues (2009) propose relational ethics as a framework for palliative care nursing, given that fostering relational connections between the patient, family, and nurse are essential to the provision of good care at EOL care (Calvin et al., 2007; Ferguson, 2018; Georges et al., 2002; King et al., 2010; Kirby et al., 2014; McMillen, 2008; Noome et al., 2016; Offren, 2015; Sekse et al., 2017).

The theme 'Relationships' reflects both the interpersonal relationships formed between the nurse and patient/family, and the contextual realities that the participants are beholden to when navigating ethically meaningful situations. The interpersonal relationships that the participants hold with those in their care reveal that it is through relationships that nurses understand and interpret their moral experiences. The relationships they hold with others inform how they understand their moral responsibilities, and these commitments give rise to nurses' ethical action.

The participants revealed that 'knowing' the patient is an important source of ethical knowledge for nurses. This is consistent with work done by Rodney, Kadyschuk, and colleagues (2013), who claim that knowledge, in various forms, is critical to moral action. One such form of knowledge is 'social knowledge', whereby the patient is regarded as a subject and not an object

(Rodney, Kadyschuk, et al., 2013). What the authors mean by this is that knowledge can be derived from understanding *who* the patient is – that is, what they value and believe and how they are situated within their social and historical contexts (Rodney, Kadyschuk, et al., 2013). As stated by Rodney, Kadyschuk, and colleagues (2013), “This knowledge both informs and arises from moral action and makes it possible” (p. 165).

The narratives of the participants in this current study also revealed that nurses are concerned about the extent to which they are or should be emotionally and/or personally involved in the caring relationship developed with patients and families. For some, strict professional boundaries that separate one’s own identity from the encounter are understood as the only way to engage in a truly ethical relationship, where the patient is free from the nurse’s influence. For others, fostering personal connections with patients and families are valued aspects of care that enhance one’s ability to do ‘good’ in the provision of EOL care.

The tensions between whether nurses should be personally involved or professionally disengaged are prominent in the literature, often articulated through the concept of ‘boundaries’. As described in Chapter 2, boundaries are what delineates appropriate behaviour from what is inappropriate or ‘out of bounds’ in the context of a relationship between a professional and a patient (Austin et al., 2006). The notion of ‘maintaining boundaries’ as an essential aspect of the nurse-patient relationship is communicated through professional and practice standards put forth by regulatory bodies across Canada – boundaries are intended to protect the sanctity of the ‘professional’ relationship (CNA, 2017; College and Association of Registered Nurses of Alberta, 2011; College of Registered Nurses of British Columbia, 2018).

That said, nursing scholars are increasingly articulating that nurses and patients function in a relational context that necessarily requires emotion *and* reason to be inextricably connected (Sumner, 2010). According to Sumner (2010), “nurse and patient function in a unique social

world to which each brings their lifelong experiences, values, beliefs, and expectations of the other” (p. 162). Sumner (2010) explains further that the personal self, which is intersubjective and dialogical, has implications for how each participant experiences the relationship. While boundaries stem from a concern for over-involvement and abusive practices, there is an equal concern for under-involvement or disengagement in the caring relationship (Bergum, 2013). Bergum (2013) argues that disengagement or disconnection between people can harm both the patient and the professional. In a purely ‘technical’ relationship, nurses are interchangeable with one another as are patients; patients become objectified and treated as diseases and nurses become “faceless practitioners that mechanically carry out their duties” (Bergum, 2013, p. 136). Engagement can be protective, in that it offers professionals an opportunity to renew their focus on the meaning found in their work (Bergum, 2013). Furthermore, relational engagement and decisions to disclose personal experience or personal beliefs can allow for dialogical connections between the nurse and patient/family; in the context of EOL care, dying patients may yearn for such a personal connection (D. K. Wright et al., 2009).

The capacity for nurses, as moral agents, to foster personal connections with their patients is influenced by the social and organizational structures they practice within. A culture that privileges technical rationality over relational engagement often results in a model of care that is organized around tasks and efficiencies, leaving little room for addressing existential concerns and/or engaging in meaningful relationships with others (Barnard et al., 2006; Georges et al., 2002; Kirby et al., 2014; Sekse et al., 2017). According to Bergum (2013), “as nurses find that they are expected to do more with insufficient time, and while they want to do good, they find that they cannot do so in the manner they believe is best for their patients” (p. 136). Organizational structures that dictate how care is organized, such as day-to-day nursing tasks, time constraints, and nurse to patient ratios, create missed opportunities for nurses to participate

in care that is considered meaningful, for both the patient and the nurse (Kirby et al., 2014; Molina-Mula, Gallo-Estrada, & Perelló-Campaner, 2018; Wittenberg-Lyles, Goldsmith, & Ragan, 2011).

The participants in my study revealed how socio-political and organizational structures influence their ability to enact moral agency, as demonstrated through the subtheme “Contextual realities”. As Rodney, Kadyschuk, and colleagues (2013) state, “the traditional focus on rationality and self-interest neglects the relational, contextual nature of moral agency” (p. 161). Inadequate staffing, lack of time, and lack of physical resources were revealed as constraints to nurses’ moral agency. Flaws in how nursing work is organized create barriers for nurses to carry out their moral responsibilities and provide care that is morally acceptable to them. For instance, Dana discussed changes at the provincial level that would change her role in the community to a consultant (where the palliative care nurse steps into the circle of care, offers recommendations, and then steps out), which she felt would not serve patients adequately. These findings support the notion that moral deliberations and moral actions are influenced by the social and political contexts of the individual moral agents (Rodney et al., 2009; Rodney, 2013).

Moral sensitivity. The final theme presented in Chapter 4, ‘Moral sensitivity’, reflects the skill that is enacted by nurses in recognizing what is at stake for those in their care. The participants’ narratives reveal that they are sensitive to the moral dimensions of their practice in both dramatic moments (i.e. navigating MAiD, perceived futility, and thwarted patient autonomy) and the everyday encounters that make up their experience. They were also attuned to the values at stake for the various players in a particular encounter, and oriented care in effort to support their needs, wishes, and values. The participants demonstrated that nurses recognize the death of a loved one as an exceptionally salient – ‘high-stakes’ - moment in a family’s life. The findings of this current study suggested that moral sensitivity is a skill that nurses develop and

enact. This is consistent with Benner (2000), who argues that nurses' perceptual capabilities enable reasoning and moral agency. In building on Benner's work, Sumner (2010) claims that experienced nurses develop a 'purposeful professional attunement' which enables ethical action. Moral sensitivity is the skill that enables nurses to perceive the needs, wishes, threats, and opportunities in a patient/family encounter and respond to them accordingly.

The participants' experiences reveal that nurses recognize that the care they provide has implications for the family's bereavement experience. Several participants articulated that they were hopeful that the care they provided in the present could help families reconcile the loss of their loved one in the future. The idea that family members carry the memories of the care provided into bereavement is articulated by D. K. Wright and colleagues (2009), who state:

Families pay very special attention to the care that is delivered to their loved ones at the end of life, construct their own meanings about dignity and quality of life based on these experiences, and carry these meanings forward into their own bereavement. (p. 221)

Similarly, in a recent qualitative study where researchers performed a content analysis on documents (such as thank you cards) written by families to a palliative home care service, the authors found that family members experienced feelings of serenity and calm during bereavement due to the care that was provided to their dying loved one (Aparicio, Centeno, Carrasco, Barbosa, & Arantzamendi, 2017). The following passage from one of the documents analyzed is a powerful example of how care providers can affect the moral experience of family members in bereavement through the care that is provided prior to death:

You let me prevent further suffering at the most critical moments and at the same time, give more love to somebody who had little else left. So important that it makes me feel calm of spirit, comforted in bereavement. (p. 7)

As revealed through the participants' moral experiences, moral agency requires nurses to make decisions about when to 'step in' and when to 'step back' (Oliveira, 2013). This was revealed in how Renée chose to implicate herself by asking questions of the patient to examine and clarify what they mean when they say certain things, whereas Dana chose to listen and let her patient "fill the silence". Michelle's experiences have led her to understand that suffering cannot always be eliminated despite the best-evidence and interventions that exist in modern health care – as such, she has learned that 'stepping back' and bearing witness can help the patient and/or family feel supported in times of suffering. According to Benner, Tanner, and Chesla (2009b), "an increased ability to read the situation allows the nurse to step in and step back as the situation demands" (p. 167). Moral agency requires nurses to be attuned to the needs and threats of those present in an encounter and to adjust their actions according to their perceptions (Benner et al., 2009b). To 'step back' is just as much a moral action as it is to 'step in' – the way Dana listened to her patient, rather than probe or ask questions, was a choice. According to Back and colleagues (2009):

Silences are filled with texture and feeling, and can have therapeutic, neutral, or destructive effects on the therapeutic relationship. While there are silences that feel awkward, indifferent, or even hostile, there are also silences that feel comforting, affirming, and safe. (p. 1113)

As stated in Chapter 4, it is interesting to consider Dana's disposition towards letting her patients "fill the silence" together with her firm belief that she must keep her values and judgements separate from the relationships she forms with those in her care. Dana's reflections on listening as opposed to talking were not part of the main narrative she chose to share and, therefore, it is unclear whether or not her silence can be interpreted as enriching to the caring relationship or a missed opportunity for engagement. Regardless, Dana's experience highlights the tensions

between silence as invitational and compassionate versus silence as hostile or the withholding of one's self, and only reinforces the delicate complexity of 'stepping in' and 'stepping back' (Back et al, 2009).

Moral experience. As seen in Chapter 3, recall that moral experience is conceptualized by Hunt and Carnevale (2011) as follows:

Moral experience encompasses a person's sense that values that he or she deems important are being realised or thwarted in everyday life. This includes a person's interpretations of a lived encounter, or a set of lived encounters, that fall on spectrums of right-wrong, good-bad or just-unjust. (p. 659)

Moral experience encompasses the range of responses nurses have to morally relevant encounters that make up one's day-to-day experience (Hunt & Carnevale, 2011). In the section that follows, I present the participants' moral experiences as they relate to existing literature.

In Chapter 4, the findings of this study were organized in two sections: a descriptive presentation of nurses' ethically meaningful experiences and a thematic interpretation of what these experiences reveal about nurses as moral agents. Recall, ethically meaningful encounters are conceptualized, for the purpose of this study, as encounters that are ethically challenging or ethically enriching. Although I sometimes discuss these separately, they are not mutually exclusive. As expected, the participants' narratives about the ethically challenging situations they face echo previous work that explores the antecedents and related causes of moral distress. The participants' accounts reveal that situations of futility, thwarted patient autonomy, prolonged dying, conflict with the family or physician, and the navigation of requests for MAiD have the potential to create moral impasses for nurses. This is consistent with previous literature that suggests that EOL care can be morally problematic for nurses – futility, prolonging life, and conflict between various stakeholders in decision-making have been frequently cited as ethically

challenging situations for nurses to overcome (Johnson & Gray, 2013; Karlsson et al., 2013; McCarthy & Deady, 2008; Peter, Mohammed, & Simmonds, 2014; Storch, Starzomski, & Rodney, 2013). However, while the findings of this study revealed that MAiD is an ethical preoccupation for the participants, but literature about the role of nurses in the provision of MAiD is scarce. Hence the absence of this topic in Chapter 2. While this may be attributed to the fact that the nursing role in MAiD is new in Canada, it also speaks to a disconnect between the literature and the complexity of end-of-life nursing practice that now includes assisted death. Further research is needed on nurses' moral experiences of participating in MAiD to address this gap.

The findings also reveal that organizational structures, such as lack of adequate resources, can be a source of moral distress for nurses trying to provide care that is consistent with their beliefs about 'good' care. Resources identified as lacking by the participants include time, staffing, and physical resources (such as a chair or a blanket). Other scholars have demonstrated that organizational and social structures can generate conditions that allow moral distress to occur (Hold, 2017; Johnson & Gray, 2013; LeBaron et al., 2014). The capacity for nurses to uphold their values and commitments to patients and families are hindered when nurses have a lack of time, resources, staffing, or a poor workplace culture (Lachman, 2016; Mason et al., 2014; Rice et al., 2008). Power dynamics were found to influence nurses' moral experience in my study, which is consistent with other empirical work that has found power dynamics and oppressive environments can prevent nurses from acting on their moral judgments, leading to moral distress (Johnson & Gray, 2013; LeBaron et al., 2014; Peter et al., 2016; Rodney, 2013; Rushton, 2017).

At the same time, the participants' narrations of EOL care were not limited to descriptions of morally problematic situations. The participants' accounts of enriching

experiences were articulated as moments when the nurse, patient, and family worked together to achieve a death that was peaceful, comfortable, and consistent with the patient's wishes. Three of the five participants used the term "good death". Dana explained in her interview that a good death is "what the patient recognizes as a good death" and "it would be what they want for themselves." Another participant, Michelle, stated that a good death was one where the family "felt like they were able to get what they needed out of the experience to feel like they can continue to, that they can be whole again." While some participants did not describe ethically enriching experiences at the EOL using the language of a good death, they revealed common beliefs about the principles that guide good EOL care, including fostering positive relationships with patients and families, easing pain and suffering across different dimensions of personhood (e.g. physical, existential, emotional), and promoting a good death.

A good death is understood in the literature as a death experience with dignity, awareness, peace, adjustment, closure, comfort, and acceptance (Barnard et al., 2006; Hold, 2017; Kehl, 2006; Robinson et al., 2017). Although these are common attributes that help define a good death more generally, a good death is unique for each person and is based on individual preferences, which is consistent with Dana's conceptualization above (Hold, 2017; Kehl, 2006). An individual's perception of a good death is influenced by their values, beliefs, and experiences, as well as the relational, sociological, spiritual, and cultural dimensions of their identity (Hold, 2017; Kehl, 2006; Robinson et al., 2017). Optimizing family relationships is considered a key component to the achievement of a good death and nurses seek to create and support meaningful connections between the dying patient and their family (Hold, 2017; Kehl, 2006; D. K. Wright et al., 2009). Findings from Barnard and colleagues' (2006) phenomenological study on the lived experience of being a palliative care nurse suggest that nurses work together with the patient and family to achieve common goals, which resonates with

the participants' experiences in this study in that when these goals were achieved, the participants described their experiences as ethically enriching.

In Kehl's (2006) evolutionary concept analysis on a good death, she found that consequences of a good death are not well understood. Among the articles reviewed for her analysis, very few discussed the potential consequences of achieving a good death (Kehl, 2006). That said, Kehl (2006) theorizes that peace is a major outcome of a good death, which encompasses a peaceful death for the patient and the creation of peaceful memories for the family. Interestingly, the creation of peaceful memories for the family aligns with the participants' desire to create an EOL care experience that will help the family cope with the loss of their loved one following death. Kehl (2006) proposes that the consequences of a good death on nurses include professional satisfaction, gaining a better understanding of self and others, and being more comfortable with one's own mortality. She also suggests that feelings of privilege may result from promoting a peaceful death, which is consistent with both the participants in this study and other empirical research on nurses' experiences of providing EOL care (Calvin et al., 2007; Fridh et al., 2009; Kehl, 2006; Offren, 2015; D. K. Wright, 2012). Peaceful death meant different things to the participants; for Julie, a good death was one where the patient died a "natural death" and life was not "unnaturally" extended using curative treatments and life-sustaining technologies. For Renée, a peaceful death was one where the patient was comfortable and not alone – in her narrative, the patient died doing something she enjoyed in life, which made Renée "feel happy" because she felt like she did the "right" thing for that patient. While the participants brought a great deal of emotional labour to their work with dying patients, they described the value and meaning they find in their work. For instance, Lori stated, "I believe in what I do" and she is "grateful" to be part of the patient's journey at the EOL. Dana also described feeling a great deal of satisfaction in her work and stated, "It's not all sitting talking

about death. It's me, talking about fishing, talking about hunting, talking about life." For Michelle it is an "extreme honour" to be present and bear witness to the patient and family's experience at the EOL.

In summary, the moral experiences of the participants in this study appear to be characterized by an oscillation between moral distress and moral resilience. In other words, it appears that the participants fluctuate between experiences that constrain and experiences that motivate and empower. The participants reveal that situations are ethically challenging and result in moral distress threaten their moral integrity and, in extremely distressing encounters, raise doubts about whether or not the nurse can carry on her work. On the other hand, ethically enriching situations bring renewed attention and validation to the meaning found in their work, fostering resilience and the capacity to endure hardship. As stated by Michelle, "the one case could have led to me saying I can't do this anymore, the other case has allowed me to continue".

The participants' moral experiences reveal that salient moral encounters stay with them for months or years following the experience. This finding presents an opportunity to reflect on how a temporal conceptualization of moral experience might help reframe understandings of moral distress. Considering moral experiences as lived over time allows us to appreciate the seriousness of moral distress, given the way it shapes nurses in irreversible ways and leaves lasting impacts on their moral identity, while simultaneously allowing us to consider that there might also be something gained from even the most morally anguishing encounters, such as growth and learning.

Moral resilience is predominantly conceptualized in the literature as an experience that arises from moral distress, likened to a 'catalyst' for positive outcomes in the face of adversity (Rushton, 2017; Rushton, Caldwell, & Kurtz, 2016; Young & Rushton, 2017). The findings of this study, such as the potential for learning and growth that arose from the participants'

experiences with morally challenging situations, suggest that nurses can, in fact, derive constructive meanings from moral distress. That said, the findings of this study suggest that nurses can also cultivate moral resilience from the morally enriching experiences they face in the provision of EOL care. The actualization of a good death can be restorative and protective; it is an experience that can renew hope and confidence that was once lost and reestablish pride in one's work. The findings of my study should stimulate further questions about whether our current conception of moral resilience (as an experience that emerges from moral distress) should be considered more broadly, such as arising from experiences that are independent from moral distress.

Traynor (2018), a nursing scholar in the United Kingdom, also questions the uncritical use of the term 'resilience' in nursing discourse. Traynor (2018) argues that current conceptualizations promote a passive and all too individualist version of resilience – nurses who are 'resilient' are those who can 'roll with the punches', 'bounce back', or have a sense of humour, yet few papers offer the notion of resilience as the basis for challenging the status quo and engaging in activism. Traynor (2018) argues that by conceiving and encouraging resilience as nothing more than a personal characteristic or behaviour, "individual nurses are basically being asked to take responsibility for political decisions and systematic failures" (p. 6). An individualist notion of resilience all but ignores the sociopolitical and organizational contexts that create the circumstances that require nurses to be resilient in the first place. Traynor (2018) offers an alternative conception of resilience, which he calls "critical resilience", that is relational instead of individual (p. 7). Critical resilience involves developing consciousness of oneself in relation to society, where such consciousness results from becoming informed about the sociopolitical forces that act on nurses' day-to-day working life and through mutually supportive discussion with colleagues or other stakeholders (Traynor, 2018). Further theoretical and

empirical exploration of broader conceptions of moral resilience, such as Traynor's critical resilience, are warranted.

Interestingly, nearly all of the participants in this study used a 'language of ethics' to express the morally challenging experiences they face. Terms such as "moral distress", "ethical dilemma", "moral residue", "agency", and "identity" were used by participants in their accounts. Previous studies have found that nurses do not typically use ethical language to describe the moral dimensions of their practice (Musto et al., 2015; Rodney et al., 2009). It is possible that the participants in this study were more engaged in scholarly literature, where they might have been exposed to the language of ethics as a result of graduate education (two of five nurses are Master's educated) or studying for specialty certification (four of five participants are specialty certified). However, while the participants could easily conjure up stories about ethically difficult situations and appeared to have the language to communicate their experiences, they appeared to have greater difficulty describing the ethically enriching situations they encounter, often struggling to find the words to use to explain their experiences. For instance, in Renée's story, she stated, "I don't want to say it's a joy of my job" and "I don't want to use the word happy, but you kind of feel happy". Similarly, Michelle stated, "I don't want to say positive either" and "for lack of a better word, you click with some people". In her interview, Dana stated, "So it resonates somehow, I'm just not sure why". I myself struggled with language in the writing of this study. Words like positive and rewarding seemed too superficial; I knew from my own experiences that the word 'positive' would be insufficient or inappropriate in conveying my experiences with dying patients that went well or felt right. Consideration for the use of language and potential opportunities for further research are discussed in the following section of this chapter.

As described in the preceding sections, the findings of this study are in many ways consistent with the existing literature. Furthermore, the concepts of moral identity, moral agency, and moral experience together provide a helpful lens in articulating the moral dimensions of the participants' practice. While considering the findings against the theoretical scaffold has allowed me to articulate the nurses' experiences in relation to the relevant extant literature, it has also stimulated new considerations for some of the concepts within the theoretical scaffold. Figure 1 offers a visual representation of where the findings 'fit' in relation to the theoretical forestructure presented in Chapter 3. The purpose of this diagram is to summarize the discussion that has been presented thus far. The detail of the connections that can be made between the research findings and the theoretical forestructure is found in the preceding sections of this chapter.

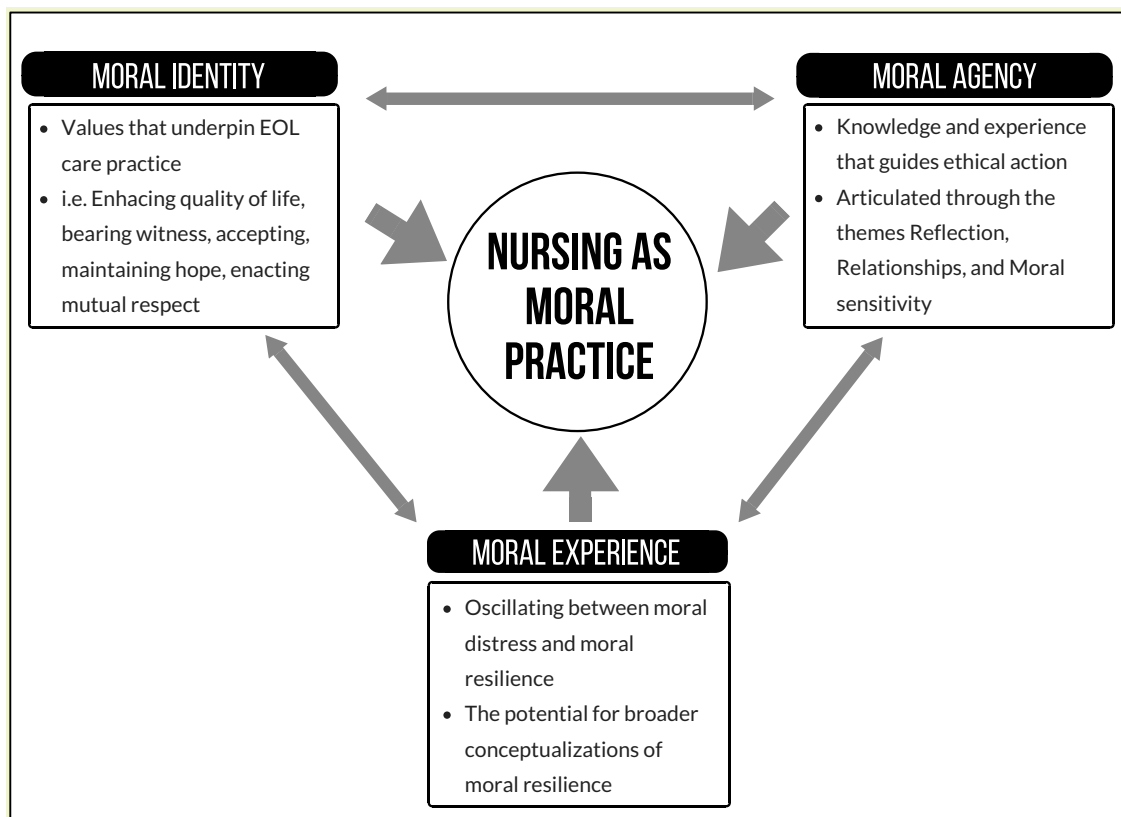


Figure 1. A visual representation of how the findings relate to the theoretical forestructure. This visual provides an overview of the preceding sections of Chapter 5: Discussion.

Implications for Practice, Education, and Research

The findings generated as a result of this research have implications for nursing practice, education, and research; the following section presents these implications and recommendations.

Implications for Practice. The participants' narratives reveal that the moral experience of nurses is informed by their moral identities (what they value and take responsibility for) and moral agency (their capacity for ethical action). The findings of this study support previous literature that articulates both of these concepts as relational. Furthermore, the findings add to previously existing knowledge that nurses do not exist in isolation from the socio-political structures that influence their moral identities and the scope of their agency (Musto et al., 2015; Rodney, 2017). It is imperative that nurses voice their concerns and enact moral agency to foster morally inhabitable environments for themselves and for others, but the responsibility does not rest on the nurse alone (Rodney, 2017). Other health care professionals and organizational leaders must also share in the responsibility of creating a moral community that is healthy for all stakeholders (Rodney, 2017). The CNA Code of Ethics (2017) offers the following definition of moral community:

A workplace where values are made clear and are shared, where these values direct ethical action. Coherence between publicly professed values and the lived reality is necessary for there to be a genuine moral community and where individuals feel safe to be heard. (p. 24)

According to Storch (2013), moral communities help create a climate and culture of ethical reflection and dialogue, where members of the community can learn from one another and resolve difficult situations that impede the provision of 'good' care.

At an individual level, nurses can contribute to the development of moral communities in their respective organizational contexts by voicing their concerns in a productive way and by

taking steps to develop ethical competency, through the bolstering of one's moral sensitivity and communication skills and by engaging in continuous self-reflection (Rushton et al., 2016).

Nurses can also share in the responsibility in developing moral communities by supporting the moral identities and the moral agency of others and by working collaboratively to develop a culture in which ethical practice is expected, discussed, valued, and supported (Pariseau-Legault & Lallier, 2016; Rushton et al., 2016).

At the organizational level, the most basic way in which the moral climate for nursing practice and the fostering of moral communities can be improved is to address the contextual forces that constrain nurses' moral agency. According to Rodney and colleagues (2013), "nurses' workplaces require better resources, including adequate staffing, regular work schedules, job security, positive interdisciplinary relationships, educational support, and available nurse leaders" (p. 198). Improving resources availability is often framed as the most basic or minimal requirement to fostering moral communities. The bigger challenge, however, is in promoting values-based change in the organizational culture. Carnevale (2013b) suggests that organizations should develop clear and safe channels "for nurses to voice their moral concerns as high in the organizational hierarchy as possible" (p. 37). Carnevale (2013b) also advocates for organizational regulations that require nurses to elect a nursing representative to the board of directors to ensure that, at a senior administrative level, nursing concerns are heard and nursing input is sought on organizational decisions. Nurse leaders – in fact, all individuals in a leadership position – need to be visible, accessible, and authentically present for all members of the moral community in order for leadership to be effective (Rodney, Kadyschuk, et al., 2013). Furthermore, individuals in leadership positions must be supportive and responsive to nurses' and other health care providers' moral concerns (Makaroff, Storch, Pauly, & Newton, 2014).

Implications for Education. The participants in this study used ethical concepts and terms to describe their experiences. The participants were easily able to conjure up descriptions of morally difficult situations they face, and it would seem that ethical terms, such as ‘moral distress’, ‘moral residue’, and ‘ethical dilemma’, provided the necessary language for the participants to communicate their experiences and the moral dimensions of their encounters. Lützén and Kvist (2012) argue that ethical language can help nurses identify the moral content of the ethical issues they face and having terminology to describe one’s experience may even alleviate some of the negative reactions to moral threats. In a study by Makaraoff and colleagues (2014), the authors found that front-line nurses’ use of ethical language help them communicate the everyday ethical dimensions of their work. Rodney and colleagues (2009) argue that, to some extent, nurses’ voices may not be heard when articulating moral problems because they tend to not explicitly label them as ethical. As such, the use of ethical language can help support nurses’ moral agency to bring forward and act on ethical concerns.

That said, it was much more difficult for the participants to describe their ethically enriching experiences. As explained earlier, the participants often struggled to find the language to explain how their experiences were enriching or valuable. The lack of ethical language to articulate morally enriching experiences is not an indication that nurses are not experiencing these types of encounters; instead, I would argue that the narrative of powerlessness associated with moral distress, as well as a continued focus on quandary ethics in theory and in practice, overshadows the other moral experiences that nurses have in everyday practice. The articulation and development of concepts like moral resilience shift the focus away from powerlessness and offer new ways in which nurses can conceptualize their moral practice as comprised of more than moral distress.

Several nursing scholars argue that educators should prepare nurses and nursing students for the moral realities of day-to-day practice by teaching them the language of nursing ethics (Nathaniel, 2006; Rodney et al., 2009; Rushton, Schoonover-Shoffner, & Shawn Kennedy, 2017). Such education might give nurses the necessary skills and language to enter into dialogue with other professionals or organizational leaders about ethical concerns, so that individuals and systems can work together to proactively address moral problems before they lead to moral distress (Nathaniel, 2006; Rushton et al., 2017). The findings of this study suggest that ethical language allowed the participants to articulate ethical problems, but they still struggled with articulating ethically enriching experiences. As such, I agree that educators should continue to engage students in the language of ethics to provide them the necessary vocabulary to articulate the morally relevant situations in their practice – however, educators should focus their efforts equally on other relevant concepts. I have focused on moral resilience, but other concepts, such as moral courage (Bickhoff, Levett-Jones, & Sinclair, 2016), have potential to help nurses recognize and articulate the ethically enriching experiences they face. This is important given that the findings of this study suggest that such experiences are protective and restorative for nurses.

The findings of this study suggest that moral distress, while troubling and painful, has the potential to stimulate growth and learning in nurses. Several participants, through reflection on their experiences with moral distress, were able to critically examine their moral responsibilities and adjust their practice moving forward. Rushton (2016) argues that it is unrealistic to believe that moral conflicts and moral distress can be entirely avoided or eliminated and, as such, an important aspect of fostering moral resilience is to teach nurses about the opportunities for learning and growth that can be gained from moral challenging experiences. Nursing educators should encourage students to reflect on and be curious about the ethical dimensions of clinical

situations, and foster a culture that sees moral engagement (and the inevitability of moral distress) as an opportunity for growth.

Implications for Research. Building on what has been presented in ‘Implications for Education’, the lack of ethical language to articulate morally enriching experiences contributes to the predominance of moral distress in nursing ethics literature. The findings of this study suggest that ethically enriching experiences foster professional pride and renew meaning in one’s work. Moreover, these experiences appear to be protective and restorative for nurses in the face of moral distress. Further primary research explicitly oriented toward ethically enriching experiences is needed to expand our understanding of how such experiences shape nurses’ moral practice. Specifically, given that the participants appear to cultivate resilience from both ethically enriching and ethically challenging experiences, the findings of this study raise questions about whether conceptualizing moral resilience as arising from moral distress is too narrow and limiting. Furthermore, researchers should continue to strive to develop concepts and language related to enriching moral experiences. According to Carnevale (2013a), “language does not merely point to things; it also articulates the meaningfulness of those things” (p. 88). The development of language that describes experiences related to ethically enriching encounters is an opportunity to demonstrate that these experiences are valuable, important, and equally worthy of investigation as are morally damaging experiences.

The majority of the ethically meaningful experiences the participants chose to share were ethically challenging. In carrying out the interviews and in writing up this thesis, I experienced a considerable ‘pull’ to engage only in the morally distressing features of nurses’ practice, as those dominated the participants’ narratives. I often caught myself focusing on the ethically challenging narratives because they were evocative, emotionally complex, and resonated with my own experiences of moral distress. Even as a student researcher explicitly critical of the

discourse of moral distress and wanting to explore other moral experiences, I have felt the power of moral distress as a dominating discourse and, at times, strayed from my focus on the underlying aims of this research endeavour. The use of ‘moral experience’ as a theoretical lens for this study was helpful in navigating the ‘detours’ that shifted the focus towards moral distress – by returning to the conceptual language of moral experience, I was able to renew my focus and attention on the range of experiences that are morally relevant, not just those that are distressing.

In Chapter 3, I suggested that the ethical concepts of moral identity and moral agency can help us arrive at a richer conception of moral experience. I characterized moral practice as the intersection of moral identity, moral agency, and moral experience, where such practice is necessarily relational because it is experienced, enacted, and sustained through the relationships we hold, both with people and structures. Consideration for nursing as moral practice and relational ethics as key theoretical lenses for nursing ethics research can help guide future research in two ways. First, this theoretical orientation holds that all nursing encounters are inherently ethical and worthy of consideration. This introduces the opportunity to explore nursing ethics in contexts that one may have not previously imagined as ethically significant. Second, it is a framework through which we can consider ethically enriching experiences as equally worthy of research as those that are ethically difficult – challenging researchers to move beyond the narrative of powerlessness sustained by a narrow focus on moral distress. Future use of this framework can encourage researchers to think creatively about the ways in which nurses engage in the ethics of their practice, and to consider in more depth the contextual realities and socio-political structures that shape nurses’ moral practice.

Limitations

This study sought to explore nurses’ moral experiences of ethically meaningful situations in EOL care. As a study on human experience, the goal of this research was to generate a

narrative and contextual understanding of the participants' practice and perspectives. As such, the findings do not claim to represent all nurses, nor are they expected to be reflective of all nurses who provide EOL care. Furthermore, the sample size was small ($n=5$) and was comprised of nurses from different settings, which is certainly not inclusive of all settings in which nurses provide care to dying persons. While the findings and subsequent discussion points should be considered with these limitations in mind, I believe the value of this study exists just as much in the articulation of a theoretical lens for examining nurses' moral practice as it does in the presentation of empirical findings of these nurses' experiences in EOL care.

Another limitation of this study was that all of the participants were women. Without insights from other gender identities, I am unable to discern whether the findings – namely, the attributes of moral agency as reflective, relationally embedded, and sensitive – are relevant to other nurses who do not identify as female. Furthermore, many of the participants are specialty certified ($n=4$) and/or have received graduate-level education ($n=2$). All of the participants had many years of experience in nursing, ranging from 14 years to 39 years. I acknowledge that these characteristics may not be reflective of many registered nurses who comprise the nursing profession. I encourage future research in this area to achieve a sample with greater cultural and gender diversity, as well as inclusivity of nurses from all nursing categories (i.e. licensed practical nurses, registered nurses, and advanced practice nurses). Moreover, future research should endeavor to recruit novice nurses in addition to more experienced nurses.

Final Reflection on Interpretive Description

Drawing on techniques from Thorne's (2016) interpretive description design this study sought to explore nursing experiences. As described in Chapter 3 (Theoretical and Methodological Considerations), the aim of interpretive description is to generate practice-based knowledge relevant to nursing's distinct disciplinary orientation (Thorne, 2016; Thorne et al.,

1997). Interpretive description is characterized as a noncategorical alternative to traditional qualitative methodologies, such as phenomenology, ethnography, and grounded theory (Thorne, 2016; Thorne et al., 1997). In the following section, I draw on my experience of developing and implementing a qualitative research study informed by interpretive description and offer my reflections on the application of a generic (or ‘noncategorical’) qualitative design.

As stated in Chapter 3 (Theoretical and Methodological Considerations), what drew me to interpretive description was its disciplinary orientation, as well as coherent logic that was accessible to a novice researcher (Hunt, 2009; Thorne, 2016). While interpretive description offers an alternative approach to qualitative research, as opposed to more traditional qualitative methods, debate continues about the extent to which credibility and rigour can be maintained outside of the guidelines of established methodologies (Kahlke, 2014). Kahlke (2014) claims that the main critiques of generic qualitative methodologies include a supposed ‘theoretical void’, a lack of robust literature critical to the development of a research framework, and the risk of ‘method slurring’. Kahlke (2014) argues that researchers undertaking generic qualitative approaches must be sensitive to these critiques, but can take steps to mitigate the pitfalls of generic approaches. In the following section, I address each critique (i.e. theoretical void, lack of robust methodological literature, and method slurring) and offer my reflections on how I have tried to mitigate these risks in order to put forth a robust version of interpretive description.

Theoretical void. Generic qualitative research methodologies, particularly those that emphasize a practice-based approach like interpretive description, are often critiqued for not articulating a consistent set of theoretical assumptions (Kahlke, 2014). According to Eakin (2016), “emphasis on practical research has been used to justify a stepping back from theoretically driven or even theoretically informed QR” (p. 110). It is argued that qualitative research designs that lack clear theoretical assumptions, or perhaps endorse an atheoretical

approach, risk oversimplifying qualitative research (Eakin, 2016). Eakin (2016) argues that interpretive description is one such methodology that explicitly avoids theory as an interpretive tool. However, I believe that Thorne's (2016) articulation of a 'theoretical scaffold' leaves space for the researcher to take up theoretical allegiances that are commensurate to the research question and design of the individual research study (Kahlke, 2014). As described in Chapter 3 (Theoretical and Methodological Considerations), I used this space to think through certain theoretical considerations that then influenced the construction of the study.

Lack of robust methodological literature. The second critique of interpretive description is the lack of robust critical literature that is crucial to the development of novel approaches to generic qualitative research (Hunt, 2009; Kahlke, 2014). According to Kahlke (2014), critics argue that without a robust foundation of methodological literature, issues of congruence within and between elements of the research design may exist, which has implications for the quality of the research produced. Kahlke (2014) argues that if researchers employing generic methods fail to adequately articulate their epistemological position, they risk presenting a research approach and findings that have unacknowledged biases. In an attempt to avoid this, I have been thoughtful about the epistemological coherence at every stage of the research study. For instance, conducting a broad and thorough literature review and articulating my theoretical allegiances established the extent to which theory played a role in the construction of this research study. As another example, the procedures for data collection were transactional, as semi-structured interviews necessarily required me to be involved, by way of asking questions that sought their accounts, in the participants' stories. As such, Chapter 4 (Findings) represents the co-constructed insights that were discovered through an interaction and dialogue, which offers further commensurability with the theoretical forestructure and the nature of nursing as moral practice which, in Chapter 3 (Theoretical and Methodological Considerations), I articulate

as relational and socially constructed. In light of the critiques that there is a paucity of strong examples of interpretive description in the literature, this study offers a contribution to help resolve this gap (Hunt, 2009; Kahlke, 2014).

Method slurring. Interpretive description is articulated as a noncategorical research design (Thorne et al., 1997). Thorne (2016) claims that researchers can thoughtfully borrow elements from conventional methodological approaches, such as narrative inquiry or phenomenology, so long as they are compatible with the purpose and logic of the research study. Critics argue that mixing established methodologies risks producing research that has inconsistent or incongruent methods for data collection and analysis, resulting in a product that is considered “not good science” (Kahlke, 2014, p. 13). However, Kahlke (2014) argues that some researchers claim that “a single established methodology is insufficient or inappropriate for capturing the phenomenon” of interest (p. 13). Kahlke (2014) claims that the insufficiency in established methodologies raises important questions about whether new approaches should be considered, including those that work together to answer the research question.

My research study draws heavily on the participants’ narrative accounts in exploring their moral experiences. In fact, the first part of Chapter 4 (Findings) is entirely dedicated to describing the participants’ stories. This use of narrative was not uncritically applied – Thorne (2016) herself advocates for researchers to temporarily separate out the participants’ narratives from the researcher’s own interpretive statements. In particular, she encourages graduate students to set aside, if only briefly, their own interpretations in order to remain authentic to the data and frame a convincing and credible research report (Thorne, 2016). In Chapter 4 (Findings), I chose to present a descriptive interpretation of the participants’ narratives first, followed by my thematic interpretation of what their experiences reveal. I felt it was necessary to do so in order to do justice to the participants’ experiences. That said, it is important to make

clear that, even the descriptive ‘re-telling’ of the participants’ stories in Chapter 4 (Findings), required a certain degree of analytic engagement and is ‘interpretive’ in its own right.

Summary. The criticisms of generic qualitative research are not unfounded. A lack of theoretical engagement, robust methodological literature, and clear direction on how to ensure commensurability between methods are legitimate concerns that threaten the integrity of generic qualitative research studies. Researchers wishing to employ generic qualitative methodologies, like interpretive description, should be sensitive to these concerns. I hope that the epistemological integrity that I strive to maintain throughout this thesis offers up an example of where interpretive description can be taken as an emerging methodology and contributes to the methodological literature that is crucial for the development of interpretive description as a noncategorical approach to qualitative nursing research.

Final Reflection on Credibility

According to Thorne (2016), research in health science disciplines arises from a social mandate to develop knowledge that benefits individuals and the collective. As such, researchers have a disciplinary responsibility to expand beyond traditional evaluative criteria, toward consideration for how the findings might reasonably be interpreted (Thorne, 2016). In her work, Thorne (2016) developed four principles for assessing credibility in interpretive description studies, whereby the research is judged on theoretical, epistemological, and technical grounds. Recall, these four principles – i.e. epistemological integrity, analytic logic, representative credibility, and interpretive authority – are described in Chapter 3.

In Chapter 5, I have reflected on the ways in which I have engaged with the theoretical scaffold of the study, inclusive of both the pertinent literature and the theoretical allegiances. As described earlier, the theoretical scaffold was imperative to the overall epistemological integrity of the study, particularly in maintaining authenticity and consistency about the goals and

intentions of the research. Importantly, representative credibility and interpretive authority are judged by the reader based on how I present both the findings and reflections within this discussion chapter. The decision to create two distinct sections within the findings chapter, one as descriptive accounts of the participants' experiences and the other a thematic interpretation of these accounts, allowed for the reader to be familiar with the narrative context of my interpretations. In doing so, I hope to have generated an authentic and trustworthy account of the participants' experiences. Through the 'Limitations' section above, I discuss the certain limitations of this work, such as the inability to make broad claims about what the findings mean for the provision of nursing care at the EOL. Instead, I maintain representative credibility by offering alternative ways to consider the knowledge generated from this study as useful and stimulating further questions that are worthy of investigation.

Conclusion

The findings of this study contribute to our understanding of nurses' moral practice in EOL care. The participants' narrative stories about the ethically meaningful situations revealed that nurses are active moral agents who shoulder many responsibilities in the provision of EOL care. Their experiences reveal that nurses as moral agents are reflective, relationally-embedded, and morally sensitive. These themes are not mutually exclusive and should be considered as interrelated characteristics that foster and sustain nurses' capacity for ethical action.

This study demonstrates how 'nursing as moral practice', a theoretical lens underpinned by ethical concepts of moral identity, moral agency, and moral experience, can be a useful frame that allows researchers to explore nurses' moral experiences more broadly. Located within a relational ontology, this theoretical lens challenges researchers to think creatively about the ways in which nurses engage in the ethics of their practice, while simultaneously giving due consideration to the contextual realities and socio-political structures that constrain nurses' moral

practice. It is my sincere hope that this theoretical lens will stimulate further qualitative inquiries on the moral experiences of nurses in EOL care that are not limited to moral distress.

Furthermore, I hope that scholars are inspired to develop empirical research on nursing as moral practice in other contexts and settings.

In conclusion, I would like to offer my final reflections on the experience of conducting this research. Listening to and engaging with the experiences of the participants who generously gave their time prompted memories of my own ethically meaningful encounters in EOL care. The journey in completing this thesis was, in and of itself, a source of ethical reflection, learning, and growth. Akin to the participants in this study, time and experience has allowed me to re-contextualize the ethically meaningful situations of my past, based on what I know and understand now. As I look ahead to life beyond this thesis work, I look forward to the continuous reconstructions of my own moral experiences.

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Appendix A: Summary of Search Strategy for the Literature Review

The following appendix details the initial search strategies undertaken to explore the literature as presented in Chapter 2. In order to obtain literature about the role of nurses in the context of EOL care, the following MESH terms were selected: ‘terminal care’, ‘palliative care’, and ‘nursing role’. Additional keywords, such as ‘end-of-life care’ and ‘nurses’ role’ were included to ensure a comprehensive search. The search terms were combined using Boolean operators: ‘terminal care’, ‘palliative care’, and ‘end-of-life’ care were combined with OR; ‘nursing role’ and ‘nurses’ role’ were combined with OR, and then both groups were combined with AND. Three databases were used for this review: CINAHL, Medline, and PsychINFO. A similar strategy using MESH terms and Boolean operators was used across all three databases, with slight adjustments accounting for the unique features of each database. Articles were hand-selected from the results by reviewing the title and abstract, as well as reviewing the bibliographies of relevant articles for additional references. Subsequent searches were completed in order to explore the ethical challenges (MESH terms ‘terminal care’ and ‘palliative care’, ‘registered nurses’, ‘ethics, nursing’, and ‘ethics’; keywords ‘end-of-life care’, ‘nurses’, ‘ethical challenges’, and ‘ethical issues’) and nurse’s moral resilience (MESH terms ‘terminal care’ and ‘palliative care’, ‘registered nurses’, ‘ethics, nursing’, and ‘ethics’; keywords ‘end-of-life care’, ‘nurses’, ‘moral resilience’, ‘resilience’, ‘growth’, ‘learning’) in the context of EOL care.

Appendix B: Interview Guide

Note: These questions will be reviewed on an ongoing basis throughout the project, and modified based on input from the advisory committee as well as on how participants respond over the course of data collection.

Good morning/afternoon/evening. My name is Kristina Ma and I am conducting interviews with nurses regarding the ethical dimensions of their work when providing end-of-life care. In the interview, we invite you to describe a situation or situations that you have found ethically challenging and/or ethically meaningful. We will ask how you responded to these situations, and what went well and what didn't go well. I am also going to ask you for your perspectives about how these encounters impact you, your practice, and others. Depending on your responses, I expect the interview will take approximately 45-90 minutes.

Question Guide

Tell me about where you work – describe the type of unit and hospital, the number of beds, and the types of patients you encounter.

Please describe, what does ethical nursing practice mean to you?

- *Prompt to direct the discussion towards end-of-life care if needed:*
 - o Based on what you just told me, ethical nursing practice to you is... (Summarize what they have stated). In what ways is this reflected in your care at end-of-life?

Tell me about a situation you faced, when providing end-of-life care, that you found challenging and/or meaningful in your practice. (This question will be given in advance of the interview).

Additional prompts (as required):

- *General:*
 - o How did you respond or react to this situation?
 - o What went well?
 - o What didn't go well? What would you do differently, if anything?
 - o What have you since learned from this experience?
- *Relational Ethics* (if they identify relationships of significance)
 - o Can you tell me a little more about the relationship you had with ____?
- *Moral identity:*
 - o What matters most to you in situations such as these?
 - o Are there any parts of yourself that you bring into situations like these (i.e. certain personal characteristics, values, beliefs, etc.)?

- *Moral agency:*
 - What do you believe your role, as a nurse, is in situations such as these?
 - To what extent are you able to, as a nurse, make a positive impact in situations such as these?
- *Moral experience:*
 - In what ways did this situation (or these situations) affect you? How have they affected your day to day practice?
- *Understanding context:*
 - What are some aspects of your workplace that support your ability to do good when providing end-of-life care? (Examples if needed: teamwork, support from management, adequate staffing, an environment that allows for discussion of ethical topics)
 - What are some aspects of your workplace that impede your ability to do good when providing end-of-life care? (Examples if needed: inadequate staffing, power dynamics, lack of organizational support for nurses, lack of ongoing education regarding ethics or end-of-life care)

Demographic Questions

1. What is your age?
2. What is your gender?
3. In which city and province do you practice?
4. What is the highest level of education you have completed (i.e. College Diploma, Bachelors, Masters, PhD)
5. In what area do you practice (ex. ICU, hospice palliative care, hemodialysis unit)?
6. How long have you been a nurse?
7. Is the organization where you practice considered rural or urban?
8. Do you work full time, part time or casually?

Thank you for your time



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Appendix C: Information Letter

Dear colleague,

Thank you for your interest in this study – please read the following information to better understand the nature of our research endeavours.

PURPOSE OF THE STUDY:

The purpose of the study is to study is to understand the experiences of nurses who have encountered ethically challenging situations at end-of-life and how they have responded to these encounters.

TO PARTICIPATE, YOU MUST:

- Be a Registered Nurse in Canada
- Hold current Canadian Nurses Association (CNA) certification in:
 - Critical care nursing (adult),
 - Critical care nursing (pediatrics),
 - Hospice palliative care nursing,
 - Nephrology nursing, or
 - Oncology nursing
- Be currently practicing in your specialty area
- Be able to read and understand English

YOUR PARTICIPATION WILL CONSIST OF:

- Completing a telephone or audio Skype interview that will last approximately 45- to 90-minutes. You will be asked to share your experiences with ethical issues, as a specialty certified nurse engaged in the ethics of end-of-life care
 - We are looking for stories of how your engagement in the ethical issues unique to end-of-life care has affected you and your practice
 - The investigators will use the results to achieve a broader understanding of nurses' moral engagement and the nature of moral practice in complex end-of-life care situations.

If you have any questions, please contact Kristina Ma, the primary investigator, by email at [REDACTED]. The research project was approved by the University of Ottawa Research Ethics Board.

We thank you in advance for your interest!

Kristina Ma, RN, BScN, MScN Student

School of Nursing, Faculty of Health Sciences
University of Ottawa

[REDACTED]

Under the supervision of:

David K. Wright, RN, PhD, CHPCN(c)

Assistant Professor

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Faculty of Health Sciences

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Appendix D: Amended Information Letter

Dear colleague,

Thank you for your interest in this study – please read the following information to better understand the nature of our research endeavours.

PURPOSE OF THE STUDY:

The purpose of the study is to study is to understand the experiences of nurses who have encountered ethically challenging situations at end-of-life and how they have responded to these encounters.

TO PARTICIPATE, YOU MUST:

- Be a Registered Nurse (General or Extended Class) in Canada
- Be currently practicing in a clinical setting where end-of-life care is part of your role
- Be able to read, speak, and understand English

YOUR PARTICIPATION WILL CONSIST OF:

- Completing a telephone or audio Skype interview that will last approximately 45- to 90-minutes. You will be asked share your experiences with ethical issues as Registered Nurse engaged in the ethics of end-of-life care
 - We are looking for stories of how your engagement in the ethical issues unique to end-of-life care has affected you and your practice
- The investigators will use the results to achieve a broader understanding of nurses' moral engagement and the nature of moral practice in complex end-of-life care situations.

If you have any questions, please contact Kristina Ma, the primary investigator, by email at nursingethics@uottawa.ca. The research project was approved by the University of Ottawa Research Ethics Board.

We thank you in advance for your interest!

Kristina Ma, RN, BScN, MScN Student

School of Nursing, Faculty of Health Sciences
University of Ottawa



Under the supervision of:

David K. Wright, RN, PhD, CHPCN(c)

Assistant Professor
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Appendix E: Consent Form

Consent Form for Research Study

Beyond moral distress: toward a stronger understanding of nurses' moral practice in end-of-life care

Student Investigator:

Kristina Ma, RN, BScN, MScN (student)
School of Nursing, Faculty of Health Sciences
University of Ottawa
[REDACTED]

Under the supervision of:

Dr. David Wright, RN, PhD
Assistant Professor
School of Nursing
University of Ottawa
[REDACTED]

Invitation to Participate: I am invited to participate in the research study titled "Beyond moral distress: toward a stronger understanding of nurses' moral practice in end-of-life care", conducted by Kristina Ma, under the supervision of Dr. Wright.

Purpose of the Study: The purpose of the study is to understand the experiences of nurses who encounter ethically challenging situations when providing end-of-life care and how they respond to these encounters.

Participation: My participation will consist essentially of one individual telephone or Skype interview, lasting approximately 45 to 90 minutes, during which I will be asked to describe ethically challenging encounters I have faced when providing end-of-life care, and how these encounters have affected me or my practice. Specifically, I will be asked to describe the positive dimensions of my ethical practice. The interview has been scheduled at a time at my convenience.

Risks: My participation in this study will entail that I describe ethically difficult encounters in my clinical practice, and this may cause me to feel emotional discomfort. I have received assurance from the researcher that every effort will be made to minimize these risk, including offering to stop the interview if it is too emotionally distressing.

Benefits: My participation in this study will benefit the advancement of knowledge regarding the nature of nursing moral practice in the context of end-of-life care.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for data analysis and that my confidentiality will be protected through the removal of identifiers in the transcripts. I understand that the transcripts from this interview, with all

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identifiers removed, may be conserved indefinitely and used in the future for secondary projects.

Anonymity will be protected in the following manner: a code will be assigned to me at the beginning of the study and any data collected will refer to the code and not contain any identifiers. The code sheet will be kept separate from any identifying documents.

Conservation of data: The data collected, including audio recordings, transcripts, and the signed consent form, will be kept in a secure manner – written documents will be kept in a locked filing cabinet in a locked office at the University of Ottawa. Electronic documents will be kept in a password-secured folder on the locked laptop computer of the primary investigator. Only the primary investigator and research supervisors will have access to the code sheet with identifiers, consent forms, audio recordings, and full transcripts.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative repercussions. If I choose to withdraw, all data gathered until the time of withdrawal will be destroyed – written documents will be shredded and electronic files will be securely deleted.

Acceptance: I, _____, agree to participate in the above research study conducted by Kristina Ma of the School of Nursing, University of Ottawa, which is under the supervision of Dr. Wright.

If I have any questions about the study, I may contact the researcher or her supervisor.

If I have any questions regarding the ethical conduct of this study, I may contact:

The Protocol Officer for Ethics in Research
Tabaret Hall, University of Ottawa
550 Cumberland Street, Room 154
Ottawa, ON K1N 6N5
Tel.: (613) 562-5387
Email: ethics@uottawa.ca

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Appendix F: Research Ethics Board Approval

File Number: H09-17-03

Date (mm/dd/yyyy): 10/06/2017



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Brandi	Vanderspank-Wright	Health Sciences / Nursing	Supervisor
David Kenneth	Wright	Health Sciences / Nursing	Co-Supervisor
Kristina	Ma	Health Sciences / Nursing	Student Researcher

File Number: H09-17-03

Type of Project: Master's Thesis

Title: Beyond moral distress: toward a stronger understanding of nurses' moral practice in end-of-life care

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
10/06/2017	10/05/2018	Approval

Special Conditions / Comments:
N/A

File Number: H09-17-03

Date (mm/dd/yyyy): 10/06/2017



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

This is to confirm that the University of Ottawa Research Ethics Board identified above, which operates in accordance with the Tri-Council Policy Statement (2010) and other applicable laws and regulations in Ontario, has examined and approved the ethics application for the above named research project. Ethics approval is valid for the period indicated above and subject to the conditions listed in the section entitled "Special Conditions / Comments".

During the course of the project, the protocol may not be modified without prior written approval from the REB except when necessary to remove participants from immediate endangerment or when the modification(s) pertain to only administrative or logistical components of the project (e.g., change of telephone number). Investigators must also promptly alert the REB of any changes which increase the risk to participant(s), any changes which considerably affect the conduct of the project, all unanticipated and harmful events that occur, and new information that may negatively affect the conduct of the project and safety of the participant(s). Modifications to the project, including consent and recruitment documentation, should be submitted to the Ethics Office for approval using the "Modification to research project" form available at: <https://research.uottawa.ca/ethics/forms>.

Please submit an annual report to the Ethics Office four weeks before the above-referenced expiry date to request a renewal of this ethics approval. To close the file, a final report must be submitted. These documents can be found at: <https://research.uottawa.ca/ethics/forms>.

If you have any questions, please do not hesitate to contact the Ethics Office at extension 5387 or by e-mail at: ethics@uOttawa.ca.

Signature:

Gabriel Petitti
Protocol Officer for Ethics in Research
For Daniel Lagarec, Chair of the Health Sciences and Sciences REB



Modification Request - File #H09-17-03

Ethics <ethics@uottawa.ca>

Wed, Feb 14, 2018 at 9:52 AM

To: Kristina Ma [REDACTED]

Cc: David Kenneth Wright <[REDACTED]>

Hello Kristina,

Thank you for submitting a modification request for your research project entitled: “**Beyond moral distress: toward a stronger understanding of nurses' moral practice in end-of-life care**” (file #H09-17-03). The REB Chair has reviewed your request and the following modifications have now been approved:

1. Participant sample: The inclusion criteria has been widened so as to eliminate the need for participants to hold a speciality certification.
2. Research team: Dr. David Wright is now the sole supervisor of the project.
3. Documents: All relevant documentation has been updated to reflect the above-mentioned changes.

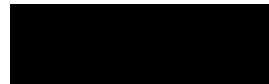
These modifications are covered under your current ethics certificate, which is still valid until October 5, 2018.

Best regards,

Mélanie Rioux

Coordonnatrice d'éthique / Ethics Coordinator

Bureau d'éthique et d'intégrité de la recherche / Office of Research Ethics and Integrity
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