

Intensive Care Nurses' Meaningful Experiences in Providing End-of-Life Care.

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Abstract

End-of-life care (EOLC) has become a significant area of expertise in the intensive care unit (ICU). Critical care nurses are the primary caregivers of patients in the ICU and they provide EOLC for patients and families daily. Nurses have portrayed EOLC as difficult and demanding work; yet, they have also described their experiences of providing EOLC as rewarding, gratifying, and a privilege. The purpose of this study was to explore nurses' meaningful experiences with providing EOLC for patients and families in the context of the ICU. Van Manen's approach to interpretive phenomenology was used. Unstructured face-to-face interviews were conducted with six registered nurses who were employed in a medical/surgical tertiary care ICU. The interviews were audio-recorded, transcribed, and analyzed. The essence of nurses' meaningful experiences in providing EOLC was 'being able to make a difference'. For the nurses, being able to make a difference reflected their efforts to create a good death for the dying patient and their family. The nurses had to navigate a variety of challenges that affected the creation of a good death, however, they made it work by building relationships quickly with families, taking care of themselves, and recognizing it's a privilege to provide EOLC. These research findings contribute to an expanding body of knowledge and understanding with regards to nurses' role with the provision of EOLC in the ICU.

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Chapter 1: Introduction

Critical care nursing is an area of specialty practice with the purpose of providing care for patients who are experiencing life-threatening emergencies, critical illnesses, and/or acute injuries (American Association of Critical Care Nurses [AACN], 2016). According to the Canadian Association of Critical Care Nurses [CACCN] (2009), “nursing the critically ill patient is continuous and intensive, aided by technology. Critical care nurses require advanced problem-solving abilities using specialized knowledge regarding the human response to critical illness” (p. 1). As front-line care providers, critical care nurses plan, educate, implement, manage, and advocate to meet the needs of patients and families (CACCN, 2009). Critical care nursing is a broad term that is inclusive of nurses who work in intensive care units (ICUs), emergency departments, post-anesthesia recovery rooms, step-down units, and cardiac care units (AACN, 2016). In this thesis and in the design of this research study, critical care nurse refers specifically to registered nurses working in intensive care units. The terms ‘critical care nurse’ and ‘intensive care nurse’ are used interchangeably in this thesis.

Death and dying are prevalent in ICUs due to the severity of illness and injury in addition to the often unpredictable responses of critically ill patients to treatment strategies. In the uncertain and fast-paced environment of the ICU, nurses are the principal providers of end-of-life care (EOLC) to patients and their families. Critical care nurses work collaboratively with an interdisciplinary team to provide holistic care and advocate for patients wishes at the end-of-life (EOL) (CACCN, 2009). Although they may not always receive any formal education or training in EOLC (Hansen, Goodell, Dehaven, & Smith, 2009), ICU nurses provide EOLC regularly and often learn to provide this care through experiential learning with patients and learning by example from other nurses (Holms, Milligan, & Kydd, 2014; Puntillo & McAdam, 2006;

Zomorodi & Lynn, 2010). Nurses have described experiences of providing EOLC as rewarding, gratifying, and a privilege, yet very little is known about what these experiences are within the context of the ICU (Oliveira, Fothergill-Bourbonnais, McPherson, & Vanderspank-Wright, 2016; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). The focus of this research study was to explore what ICU nurses' experience as 'meaningful' and 'gratifying' with the provision of EOLC.

1.1 Researcher's Stance

My interest in EOLC developed from personal experiences as an ICU nurse. Without any formal education or training in EOLC, I learned how to care for dying patients and their families through experience, being mentored, and by observing other nurses. After several years as a critical care nurse, I had an encounter with a patient and family that was pivotal in shaping my nursing experience. The patient was a middle-aged male who had fallen down a flight of stairs and had tragically suffered a severe head injury. The prognosis was very poor right from admission to the ICU. After brain stem testing was done and neurological death (brain death) was determined, the physician explained the diagnosis to the family. Together, the physician and the family made the excruciating decision that they would withdraw life-sustaining treatment when the family was ready to do so.

The same day that neurological death was determined, I had a heartfelt conversation with the patient's wife who told me that she had felt his spirit leave almost immediately and she had already accepted that he was gone. That night, after our conversation, the night shift nurse put the bed rails down and the wife curled up in the bed beside him. She held onto him despite him being on the mechanical ventilator and attached to all the tubes and wires. Over the course of the two days, following the declaration of neurological brain death, the family celebrated and

honoured his life. They played his favorite music at the bedside, shared pictures, and told stories about his life. The family accepted me to be a part of their experience by sharing these personal moments and memories with me as well. The experience was heart-wrenching but was, at the same time, both rewarding and a privilege for me to provide the care. Despite the experience being inherently tragic and difficult, the connection I had created with this family was meaningful. It was meaningful for me because I had developed a close and trusting relationship with the family where I felt privileged to provide EOLC for them and their loved one. I strove to provide 'good' EOLC and I encouraged the family to create positive memories. The experience was also difficult for me because I felt so much compassion for the family, with the realization of what a great loss this was for them. It brought out sentiments of sadness and grief and I cried with the family at the bedside and shared hugs with them in the hallway. After this experience, I recognized other experiences in which I had provided EOLC as meaningful and gratifying. These invaluable experiences have inspired me to learn more about other nurse's experiences and what they identify as meaningful and gratifying with the provision of EOLC.

1.2 Background

Historically, critical care units such as the ICU, are environments where health care providers have maintained a focus on curative care and life-sustaining treatment (King & Thomas, 2013; Ransie, Yates, & Coyer, 2012; Truog et al., 2008; Vanderspank-Wright et al., 2011). However, despite curative foci, patients continue to die in this clinical setting. The Canadian Institute for Health Information (2016) suggested that the number of patients admitted to the ICU will continue to increase due to population growth, the complexity of patient illnesses, and an ageing population. Studies reveal that mortality rates in ICU's vary from 10 to

30 percent yearly (Coombs, Addington-Hall, & Long-Suthehall, 2012; Society of Critical Care Medicine, 2017).

Death can be unpredictable in the ICU because no one is able to determine with absolute certainty, how patients will respond to treatment or if they will recover from their critical illness. Nevertheless, the ICU is unique in that most deaths in this clinical context occur after the decision has been made to withdraw life-sustaining treatment (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003; Hov, Hedelin, & Athlin, 2007; Truog et al., 2008; Vanderspank-Wright et al., 2011). Withdrawal of life-sustaining treatment is a decision that is typically made by the substitute decision maker(s), the family and/or the patient (when possible), along with the health care team. The decision implies the discontinuation of life-sustaining therapies and the transition to providing EOLC – a focus on patient comfort and supportive care for patient and family is maintained (Coombs et al., 2012; Halcomb, Daly, Jackson, & Davidson, 2004; Hov et al., 2007; Vanderspank-Wright et al., 2011). The decision to withdraw life-sustaining treatment is usually made after all curative medical treatments and therapies have been attempted and are deemed unsuccessful (Heyland et al., 2003; Hov et al., 2007; Vanderspank-Wright et al., 2011).

In this thesis, EOLC in the ICU is the care provided to dying patients to promote comfort, lessen suffering, provide adequate pain and symptom control, and to support dignified deaths (CACCN, 2009; Canadian Nurses Association [CNA], 2008a). It encompasses ongoing, patient and family-centered care that provides support to patients and families where discussions surrounding patients' wishes for EOL are important (CACCN, 2009).

In Canadian ICUs, nurse to patient ratios are typically one to one due to the complexity of patient illnesses (particularly where mechanical ventilation is required) and the use of intensive monitoring and life-sustaining technologies (Vanderspank-Wright et al., 2011). Nurses

spend the most time, out of all the health care providers in the ICU, caring for patients and families thereby situating them as the primary providers of care in this setting. They conduct extensive ongoing assessments, carry out complex interventions, provide comfort through pharmacological and non-pharmacological management, they engage in effective communication with families, manage the environment, and provide dignity by respecting patients' privacy and lifestyle choices (CACCN, 2009).

Over the past decade, literature has emphasized challenges to nurses providing 'good' EOLC within the critical care environment (Attia, Abd-Elaziz, & Kandeel, 2012; Beckstrand, Callister, & Kirchhoff, 2006; Kirchhoff & Kowalkowski, 2010; Ranse et al., 2012). These challenges include: (1) poor communication between physicians and families and also between physicians and nurses which can lead to patients not having their wishes or goals of care respected and/or carried out at the EOL; (2) the lack of structured support in dealing with distressing situations via debriefing with the multidisciplinary team, counseling, or managerial support; (3) lack of time to engage with families which can hinder nurse-family relationships; (4) lack of formal education and training in EOLC whereby nurses may feel underprepared, and; (5) the technological mandate of the ICU with its focus on treatments such as mechanical ventilation that can create prolonged suffering, discomfort, and prevent a dignified death for patients (Attia et al., 2012; Beckstrand et al., 2006; Kirchhoff & Kowalkowski 2010; Ranse et al., 2012).

Despite these challenges, the stories of nurses providing EOLC revealed sentiments of feeling privileged, rewarded, and gratified which led to the use and incorporation of the descriptors 'meaningful' and 'gratifying' in this study to further explore nurses' experiences. Merriam-Webster defines 'meaningful' as "having purpose, full of meaning; significant" (Meaningful, n.d.). In this study, the term 'meaningful' is an adjective used to describe the

important and valuable experiences of the ICU nurses providing EOLC. The term ‘gratifying’ is defined as “an adjective that means giving or causing satisfaction; pleasing” (Gratifying, n.d.). In this study, the term ‘gratifying’ is an adjective that is used to describe the experiences of ICU nurses that are satisfactory and pleasing while providing EOLC.

However, little is known about what ICU nurses attribute to meaningful and gratifying experiences in the context of providing EOLC. Understanding nurses’ meaningful experiences is important because they demonstrate how nurses enable EOLC for patients and families (Oliveira et al., 2016; Vanderspank-Wright et al., 2011).

1.3 Purpose of the Research Study

The purpose of this study was to explore nurses’ meaningful and gratifying experiences providing end-of-life care for patients and families in the context of the ICU.

1.4 Objectives of the Research Study

The objectives were:

- 1.** To describe and seek to better understand ICU nurses meaningful and gratifying experiences providing end-of-life care.
- 2.** To identify challenges to nurses’ meaningful and gratifying experiences with end-of-life care.
- 3.** To identify facilitators to nurses’ meaningful and gratifying experiences with end-of-life care.

Chapter 2: Literature Review

This chapter provides an overview of ICU, ICU nursing, and EOLC in order to clearly describe the context of care. The literature review presents a description of ICU services, ICU nursing, and the transition to EOLC in the ICU. Nurses perceptions regarding EOLC and a good death are depicted. A comprehensive literature review with no date limitations was done by searching the following databases: CINAHL, PubMed, and ProQuest. CINAHL and ProQuest were selected to perform searches due to their large, full text database of scholarly nursing and allied health journals. PubMed was chosen due to the use of MeSH (medical subject headings), a method similar to a thesaurus that enables searching for certain core journal articles. Reference lists of key papers were searched and relevant journal articles were used. The keywords searched were “nurses’ experiences”, “end-of-life care”, “end-of-life”, “end-of-life care in the ICU”, “death”, “dying”, “rewarding”, “privilege”, “positive”, “gratifying”, “meaningful”, “good experiences”, “palliative care”, “role of the ICU nurse”, “critical care nursing”, “withdrawal of life-sustaining treatment”, “good death”, “notion of a good death” and “ICU”. The searches were restricted to English language publications and adult populations. The goal of the literature review was to identify what is known or not known about nurses’ meaningful or gratifying experiences with EOLC in the ICU.

2.1 The Intensive Care Unit

Critical care refers to specialized areas of clinical practice that exist within most hospitals with the aim of providing services to patients who have life-threatening health circumstances that require immediate attention (Critical Care Services Ontario [CCSO], 2012). As such, critical care is an umbrella term inclusive of ICUs, emergency departments, post-anesthesia care units, cardiac intensive care units, pediatric intensive care units, neonatal intensive care units (CACCN,

2011) and step-down units (CCSO, 2012). Within these critical care environments, advanced technology is used to monitor and diagnose patients in order to treat their illnesses and preserve organ function (CCSO, 2012). Nurses have described the ICU environment as unpredictable and filled with noxious stimuli including noise, bright lights, alarms, and technological machinery (Vanderspank-Wright et al., 2011; Wenham & Pittard, 2009).

The overarching goal of critical care units is to stabilize patients to be able to treat their underlying condition(s) (CCSO, 2012) with the hope of recovery (Mani, 2016; Ranse et al., 2012; Zomorodi & Lynn, 2010). These specialized units are a fundamental part of most hospitals. In the ICU, patients are admitted with complex (i.e. multi-system failure in the context of hemodynamic instability), life-threatening illnesses and injuries, and receive technologically advanced medical treatment and nursing care (CACCN, 2011). Patients can be admitted to the ICU directly from the emergency department, or from any unit in the hospital when they show signs of deterioration (e.g., low blood pressure, decreased level of consciousness, and respiratory distress) and after certain types of surgeries (e.g. abdominal aortic aneurysms, high-risk cardiac surgery) (AACN, 2016; CCSO, 2012). Common life-threatening health problems that require admission to the ICU include trauma, aortic aneurysm, neurologic dysfunction, cardiac arrest, sepsis, respiratory failure, multiple organ failure, cancer-related pathology, and severe postoperative complications (AACN, 2016; CCSO, 2012). Patients in the ICU are often considered complex because they can have multiple life-threatening issues, undiagnosed and/or unexplained symptoms, and needs that are constantly changing which can require many different interventions and/or treatments (CACCN, 2011). Other factors that add to the complexity of patients are care and support of family members as well as the use of technology to support and

sustain essential body systems and interventions to control environmental stimuli (CACCN, 2011).

Patients being admitted to the ICU are typically unstable (Espinosa, Young, Symes, Haile, & Walsh, 2010). Stabilization can require aggressive treatments such as fluid resuscitation, vasoactive medications for blood pressure control, and mechanical ventilation for respiratory support among other treatments (AACN, 2016). Patients are closely monitored by the health care team from admission through to discharge. Intense monitoring allows for quick intervention with the aim of mitigating further deterioration (Espinosa et al., 2010). However, despite prompt and medically aggressive interventions, patients can continue to deteriorate. In these instances, discussions between the health care team and the family often ensue and decisions to change the focus of care from curative to a comfort/palliative approach may follow.

2.1.1 Nursing care in the ICU.

Registered nurses are the primary caregivers in the ICU. Care provision aims to meet the needs of patients with life-threatening health conditions within a patient and family-centered model of care (CACCN, 2009). This patient and family-centered model of care is described as a partnership approach to care between patients, families, and health care providers (CACCN, 2009). Nurses acknowledge the significance of families' role in their loved one's health care, as well as the importance of developing relationships with families, communicating information, and providing support for families (CACCN, 2009). ICU nurses receive additional specialized training in critical care in order to have the necessary competencies (i.e. knowledge, skills, and judgement) to care for complex and critically ill patients (AACN, 2016; CACCN, 2009; CNA, 2008a). Multiple times per shift, nurses perform comprehensive head-to-toe assessments, provide nursing care such as positioning and turning, administer medical treatments, implement

interventions, and manage patients on technologies such as mechanical ventilation and cardiac monitoring (AACN, 2016; CACCN, 2009). Critical care nurses work collaboratively within an interdisciplinary team of physicians, respiratory therapists, pharmacists, social workers, spiritual care providers, dieticians, and physiotherapists. Along with the interdisciplinary team, nurses attempt to meet the needs of patients and families by providing holistic care that is physical, psychosocial, cultural, and spiritual in nature (CACCN, 2009). Besides the physical aspects of care, nurses promote care that is psychological, cultural, and spiritual through ongoing communication with patients, families, and the interdisciplinary team, respecting patients' dignity, as well as supporting their cultural and spiritual lifestyle choices.

2.2 Transitioning to End-of-Life Care in the ICU

Transitioning to EOLC in the ICU frequently occurs after all curative medical treatments and therapies have been deemed unsuccessful and a decision has been made by the patient's family and the health care team to discontinue life-sustaining therapy (Ciccarello, 2003; Halcomb et al., 2004; King & Thomas, 2013; Vanderspank-Wright et al., 2011). The process of withdrawal of life-sustaining therapy is usually planned and can include but is not limited to: antibiotic treatment, all medications (except for analgesics and sedatives), dialysis, mechanical ventilation, vasoactive medication, and enteral/parenteral feeding (Downar, Delaney, Hawryluck & Kenny, 2016; Halcomb et al., 2004; Heyland et al., 2003; Vanderspank-Wright et al., 2011). Withdrawal of treatment can be done quickly where all the treatment is removed and discontinued immediately or it can be done more progressively (Cook & Rocker, 2014, Downar et al., 2016). The decision for how quickly life-sustaining therapy will be withdrawn is usually made by the family and the health care team and it is based on the readiness of the family and if all the family members and friends have had their time to say goodbye. Progressive weaning is

done by slowly decreasing the hemodynamic support, weaning the patient from mechanical ventilation and extubating, while providing sedation and analgesics (Long-Sutehall et al., 2011). When life-sustaining treatment is discontinued, time to death is variable: the patient may die within minutes or hours and possibly days (Stacy, 2012; Truog et al., 2008; Vanderspank-Wright et al., 2011).

Downar and colleagues (all physicians) (2016), along with critical care nurses, respiratory therapists, and pharmacists used a Delphi method to develop guidelines to help provide high-quality EOLC including the withdrawal of life-sustaining measures to patients and their families in the ICU. Their recommendations for the process of withdrawal of life-sustaining treatment included informing families about who the team members are and what they do; what symptoms they might see and how they will be managed; having family concerns addressed; and providing support throughout the process (Downar et al., 2016). The guidelines provide recommendations for assessment of pain, delirium, and respiratory distress (using assessment and observation tools) as well as treatment of symptoms (e.g. morphine for pain and dyspnea). Downar et al. (2016) suggest that patients be moved to a private room (when possible), allowing for visitation at any time as well as privacy. Additionally, it is recommended that monitors be turned off so that they do not distract family members.

However, the decision to transition from curative care to EOLC in the ICU can be fraught with challenges. For example, when patients' goals of care are uncertain, which is often the case, it can cause conflicts between nurses and physicians (Long-Sutehall et al., 2011), between the family and the health care team, as well as other healthcare services involved in patients' care (Coombs et al., 2012). Conflict can exist between nurses and physicians when nurses are not included in the EOL decision-making (Bach, Ploeg, & Black, 2009; Coombs et al., 2012; Long-

Sutehall et al., 2011). It can also occur due to the different perspectives of health care team members about when the withdrawal process should start. Physicians might influence a family's decision with their recommendation to start the process of withdrawal of life-sustaining treatment because of the patient's poor prognosis and ineffective response to medical treatment and therapies (Luce & White, 2007; Ranse et al., 2012). However, sometimes families are not ready to accept the patient's prognosis and despite recommendations from physicians (and nurses) to discontinue treatment, the family will want to continue with life-sustaining therapies (Luce & White, 2007; Ranse et al., 2012). As a result, tension can arise between the patient, the family, and the health care team (Luce & White, 2007; Ranse et al., 2012). Long-Sutehall and colleagues (2011), add that physicians from other services (e.g. surgical teams) who are also involved in the patients' care, might not be on the same page as the ICU team with the decision to move towards withdrawal of life-sustaining treatment because of potential surgical options that have not been exhausted. Amidst these challenges, ICU nurses play a fundamental role in attempting to mitigate and manage conflicts through initiating communication and discussions between families and physicians in order to get everyone on the same page (Long-Sutehall et al., 2011; Luce & White, 2007; Ranse et al., 2012).

2.3 The Role of ICU Nurses in EOLC

Critical care nurses have a continuous bedside presence and spend complete shifts with patients and families during the dying process (Adams, Bailey, Anderson, & Docherty, 2011). Formalization of the 'dying process' begins once it is clear the patient will not recover, thus, the health care team and the family come together to discuss and/or re-evaluate goals of care for the patient and the process continues throughout the provision of EOLC and until life-sustaining therapy is withdrawn and the patient dies (Bach et al., 2009; Coombs et al., 2012). Critical care

nurses are the primary providers of EOLC including during the withdrawal of life-sustaining treatment and are actively engaged throughout the process (Ciccarello, 2003; Hov et al., 2007; Vanderspank-Wright et al., 2011). Nursing presence at the bedside facilitates the development of therapeutic and trusting relationships with families of dying patients and provides nurses with a unique perspective on patient's end-of-life experiences (Vanderspank-Wright et al., 2011). ICU nurses are expected to provide dignified care, safety, privacy, comfort measures, and to alleviate suffering at the end-of-life (AACN, 2016; CACCN, 2009). Over approximately two decades, a body of knowledge regarding the experiences of ICU nurses providing EOLC has expanded through nursing research (Ciccarello, 2003; Efstathiou & Clifford, 2011; Hov et al., 2007; King & Thomas, 2013; Kirchhoff & Kowalkowski, 2010; Levy & Randall, 2006; Ranse et al., 2012; Vanderspank-Wright et al., 2011).

Literature reveals that critical care nurses support patients and families throughout the dying process and help them achieve goals of care by working collaboratively with an interdisciplinary team (Bach et al., 2009). Nurses advocate for patient's wishes and make sure that the patient and family have all the necessary knowledge to be able to make informed EOL decisions (AACN, 2016; CACCN, 2009). They sometimes make the connection, before anyone else does, that patient's life-sustaining therapies are unsuccessful and the patient is dying (Bach et al., 2009; Coombs et al., 2012). Nurses will often help families come to an understanding that their loved one is dying (Peden-McAlpine, Liaschenko, Traudt, & Gilmore-Szott, 2015). They work with families to help them understand the dying process including the withdrawal of treatment practices while simultaneously providing support and reassurance to the family that they are still providing care for the patient. Nurses will initiate family meetings to create open communication between the family and the health care team (Peden-McAlpine et al., 2015).

Furthermore, nurses have been known to prepare families prior to the meeting by informing them about what might be discussed as well as informing physicians about what the family knows and their readiness to hear the information (Peden-McAlpine et al., 2015). Communication is a key aspect of the nurses' role to facilitate shared understanding and reduce conflict between the health care team and families (Bach et al., 2009; Ryan & Seymour, 2013).

Once a decision is made to transition to comfort measures, critical care nurses are often the ones who physically initiate the withdrawal process (Ciccarello, 2003; Hov et al., 2007; Vanderspank-Wright et al., 2011). They ensure patient dignity and comfort by removing unnecessary technology and providing symptom management, including non-pharmacological measures such as bathing, mouth care, and repositioning (Long-Sutehall et al., 2011). Nurses use their knowledge and skills to manipulate technologies and medications during the withdrawal process (i.e. keeping the patient fully oxygenated and/or continuing with the vasopressors to maintain a blood pressure) to provide more time for all the family and friends to arrive at the bedside and say their final goodbyes (Fridh, Fosberg, & Bergbom, 2009). They strive to provide a good death for patients and families in the ICU (Beckstrand et al., 2006).

2.4 The Idea of a Good Death

In the 19th century, the majority of deaths occurred at home (Corr & Corr, 1983). However, by the 20th century there was a shift from deaths occurring at home to hospital care of the ill person as well as care of the dying. In 1967, Dame Cicely Saunders established St. Christopher's hospice in London, England in response to the need to allow people to die with dignity and have management of their pain and symptoms (Kinghorn & Gamlin, 2001). It was said that her main goal was to "make the experience of dying *better*" (Walters, 2004, p. 404). The principles of hospice care focused on holistic caring, effective pain and symptom control,

continual assessment of patient's physical, psychological, and spiritual needs and family involvement (Manning, 1984). The hospice movement fostered the development of a palliative care approach. Around that time period, the idea emerged that a good death could occur and it became a significant part of the palliative care movement (Walters, 2004).

2.5 Working Towards a Good Death

Critical care nurses value comfort, dignity, and peace as they strive towards providing a 'good death' for patients and families (Beckstrand et al., 2006). The literature on EOLC identifies the need to understand what constitutes a 'good death' in the ICU (Steinhauser et al., 2000). Two research studies examined the perspectives of health care team members, patients and families working towards a 'good death' (De Jong & Clarke, 2009; Steinhauser et al., 2000). An exploratory study was done by Steinhauser and colleagues (2000) where patients, families, and health care providers (physicians, nurses, social workers, chaplains, hospice volunteers) (n=75) participated in focus groups and in-depth interviews about perceptions of a 'good death'. The groups were recruited from a university medical center, community hospice, and a Veterans Affairs medical center. Analysis of the data revealed four themes: good pain and symptom control, good communication (e.g. between patients and families as well as between patients and health care providers) being prepared for death, and life review (Steinhauser et al., 2000). All the participants voiced a need for good pain and symptom control, with patients expressing fears about waking up in pain or 'air hunger' (Steinhauser et al., 2000, p. 829). A good death was one without pain and also when a health care provider could foresee these concerns (Steinhauser et al., 2000). Health care providers and families described a good death as better communication for decision-making and knowing patient preferences (Steinhauser et al., 2000). Patients and families wanted to be more prepared for death with plans set in place (e.g. writing out a will).

Life review was about patients' faith, religion, dealing with conflicts, saying goodbye, and devoting meaningful time with friends and family (Steinhauser et al., 2000).

Two additional themes that were not as common in the literature included the dying patient contributing to others (reciprocity) and the health care providers treating the person holistically (Steinhauser et al., 2000). Many of the participants wanted to contribute to the health and welfare of others in the form of gifts, time, or knowledge which was described by psychologists as "generativity" (Steinhauser et al., 2000, p. 829). All the participants described the need for patients to be provided with care that affirms the "whole person" (Steinhauser et al., 2000). The findings indicated that physicians had more of a focus on physiologic symptoms whereas other health care providers (nurses, social workers, chaplains, hospice volunteers), patients and families identified the physiologic as well as the psychological characteristics that pertained to the quality of dying as being of equal importance (i.e. psychosocial, spiritual, life review) (Steinhauser et al., 2000). Steinhauser and colleagues (2000) did not set out to explore a bad death, however, a finding in their study was when participants were describing aspects of a good death, they also voiced their fears of a bad death which focused on the fear of dying in physical pain, not being able to get affairs in order or being able to say goodbye, and poor communication between patients/families and health care providers. A limitation of Steinhausers' (2000) study was that it was not always clear which participants were being referred to in the findings or in the discussion (i.e. patients, families, or health care providers).

De Jong and Clarke (2009) conducted a similar study in which patients and primary caregivers, palliative care nurses, and physicians were asked to describe a 'good death'. Fifteen participants (n=15) were recruited from a clinic, a hospital unit, and an in-hospital and home consultation service within a division of palliative medicine. Findings that were comparable to

Steinhauser and colleagues' (2000) study were: a pain-free death, a sense of a life well lived, and preparing for death (De Jong & Clarke, 2009). De Jong and Clarke's (2009) study also added that patients preferred dying at home and preferred not to die alone. However, if patients felt it would have a negative impact or become a burden on their families, their wishes were to die alone and in those situations, they described it as a 'good death' (De Jong & Clarke, 2009). Their study also explored common themes of a 'bad death'. Participants described that "pain was not simply defined as physical pain; it could also be spiritual distress, emotional anguish, or mental illness" (De Jong & Clarke, 2009, p. 64). Other characteristics of a bad death were patients losing their independence and conflict between health care providers (De Jong & Clarke, 2009).

Both studies were unique in that they included the stories told by the caregivers and the patients themselves thereby giving the reader an insider perspective on the attributes of a 'good death' as well as their perceptions of a 'bad death'. De Jong and Clarke (2009) described it as a privilege to listen to the stories of dying patients and their caregivers. From these stories, one can learn how to improve how to relate to patients and discover more about the depth of their needs at EOL (De Jong & Clarke, 2009). De Jong and Clarke (2009) suggested that health care providers can also learn more about themselves and their own values and beliefs from their reactions to these stories. With nurses as the primary caregivers of EOLC, it is important to understand their perspectives on what constitutes a 'good death', how they enact/strive to enable a good death, and ultimately the meaning that ICU nurses ascribe to this aspect of their practice.

2.6 Nurses' Perceptions of a Good Death in the ICU

Research on what critical care nurses define as a 'good death' in the ICU is not necessarily explicit in the extant literature. It is known that registered nurses strive to provide 'good' EOLC, however, a limited amount of research has specifically explored what critical care

nurses perceive as a ‘good death’ in the ICU. One exploratory study (Bratcher, 2010) and one qualitative study (Silva, Pereira, & Mussi, 2015) have contributed to knowledge and a more in-depth understanding of critical care nurses’ perceptions of a ‘good death’.

Bratcher (2010) conducted an exploratory study in a 12-bed medical/surgical ICU in the United States. The purpose of the study was to explore and describe nurses’ characterizations of a good death. The participants included 25 staff nurses between the ages of 36 and 59 with two to 26 years of ICU nursing experience. Three main themes emerged from the data: (1) patients not dying alone; (2) patients not suffering; and (3) death is accepted by the patient and family (Bratcher, 2010).

The findings revealed that nurses emphasized the importance of nursing presence at the EOL for them to be close to their patients so they did not die alone (Bratcher, 2010). The nurses believed it was their role to stay with the patient if no family and/or friends were present. Some participants also felt it was significant to include pets (as family members) to be present at the bedside. The nurses emphasized that they did not want to see any patients suffering and described how they provided pain and symptom management with analgesics and sedatives to ensure patient comfort (Bratcher, 2010). Several participants also felt that a quick death was also a good death in that the patient’s pain and suffering would not be prolonged. Additionally, when there was good communication and understanding between the family and the health care team, the family could accept that death was foreseeable (Bratcher, 2010). Other elements of a good death that were described in subthemes by the study’s participants were dying with dignity, patients having their wishes respected, and patients having their spiritual, religious, and cultural needs identified and met. Participants in this study described several individual aspects of a good death that when put together became a theme about creating a space for dying patients and their families.

Silva and colleagues (2015) conducted a descriptive, qualitative study on nurses' perspectives of a good death in the ICU. Semi-structured interviews took place with ten registered nurses who worked in an oncology ICU. The sample consisted of seven female and three male nurses between the ages of 25 and 29 years with two to seven years of ICU experience. The main finding elaborated on how the nurses provided comfort for a good death including: relieving pain and suffering (physical discomfort), providing emotional and social support for the patient and family, promoting dignity, respecting dying persons wishes, and ensuring good communication (Silva et al., 2015). Physical comfort was provided with the use of analgesics and sedatives. The participants also described promoting physical comfort by avoiding unnecessary procedures that might inflict pain upon the terminally ill person (Silva et al., 2015). The participants provided support (social and emotional) for the patient and family in the form of encouraging family presence, through attentiveness, affection and demonstrating empathy towards the family (Silva et al., 2015). Another key aspect of nurses' perceptions of a good death was maintaining and preserving the patient's dignity. They did this by providing cleanliness and good hygiene to reduce body odors, repositioning the person's body to provide comfort and prevent pressure sores (Silva et al., 2015). These actions created the appearance of comfort and protected the person's body image (Silva et al., 2015).

The findings from both studies (Bratcher, 2010; Silva et al., 2015) identified some similar perceptions of what constitutes a 'good death' in the ICU: good pain and symptom management, dying with dignity, patients having their wishes respected, nurses providing support to families and helping them to accept death, and good communication between patients/family and health care providers. These studies identified key aspects of nurses' perceptions of a good death which correspond with some of the insights of patients and family members from previously described

studies (De Jong & Clarke, 2009; Steinhauser et al., 2000) such as good pain control and patients having their wishes respected. More research is needed on nurses' perceptions of a good death as well as the perceptions of patients and families. The findings across these studies (Bratcher, 2010; De Jong & Clarke, 2009; Silva et al., 2015; Steinhauser et al., 2000), whether from the perspectives of the patients, families, or nurses, described the provision of EOLC as holistic in nature. These studies provide us with knowledge and understanding of how to connect and engage with patients and families at the EOL and ultimately strive towards achieving a good death for the dying person.

2.7 Critical Care Nurses' Provision of Good EOLC

A body of literature exists that has explored the experiences of critical care nurses who have provided EOLC for patients and their families. Studies focused on exploring EOLC in the ICU in general as well as in the specific context of the withdrawal of life-sustaining treatment. From this literature, five studies used a phenomenological approach (Arbour & Wiegand, 2013; Espinosa et al., 2010; Hov et al., 2007; King & Thomas, 2013; Vanderspank-Wright et al., 2011) and three studies used descriptive and exploratory approaches (Efstathiou & Walker, 2014; Fridh et al., 2009; Ranse et al., 2012). While only two studies explicitly focused on a good death (Bratcher, 2010; Silva et al., 2015), other studies have looked more generally at nurses' experiences providing EOLC. This review of qualitative studies has been broken down into sections on aspects of how good EOLC is provided through: good communication, comfort and dignity, being there, caring for families, creating a personal space for families, providing memories, and the privilege of providing EOLC. Selected findings will be presented.

2.7.1 Good communication.

Good communication was described in each of these studies (Arbour & Wiegand, 2013; Espinosa et al., 2010; Fridh et al., 2009; Hov et al., 2007; King & Thomas, 2013; Ranse et al.,

2012; Vanderspank-Wright et al., 2011) as an essential element of good EOLC. Participants in these studies described the different situations in which communication occurred between patients, families, physicians, and nurses. King and Thomas (2013), for example, conducted a phenomenological study using unstructured interviews with 14 ICU nurses to explore the lived experiences of nurses caring for dying patients. Their theme of “promises to be truthful” elaborated on the promises made by participants to have open and honest communication with patients and families about EOL decisions as well as helping them to prepare for the EOL process (King & Thomas, 2013). Participants in this study described how they initiated conversations with family about death and provided them with information to help them make informed EOL decisions (King & Thomas, 2013). They felt that physicians were not always forthright with family in their communication about patients’ prognosis and they did not always address factors such as unsuccessful treatment, thus, the participants had to interpret information for family for them to be able to make decisions (King & Thomas, 2013). Participants described good communication as being open, honest, clear, concise, and direct when talking to the family (King & Thomas, 2013).

ICU nurses used good communication skills to advocate for patients and their families especially when patients could not speak for themselves because they were unconscious or sedated (King & Thomas, 2013). They advocated by communicating patients/families wishes to the health care team. If they felt that patients’ treatments were unsuccessful, they became patient advocates and would approach family about withdrawing treatments or they would postpone the withdrawal until family was mentally prepared (King & Thomas, 2013). Arbour and Wiegand’s (2013) study substantiated this finding of the nurses’ role as advocate for the patient. Participants gave examples of advocacy including nurses advocating for the patient to receive good pain and

symptom management and for patients wishes to be carried out at the EOL. They advocated by simply listening to the patients' needs as well as helping the family understand their loved ones' wishes (Arbour & Wiegand, 2013).

Ranse and colleagues (2012) conducted a descriptive exploratory study using interviews with five ICU nurses. Analysis revealed a theme of "facilitating the family's experience", in which the participants described communicating with the family to find out what kind of support the family needed, if they wanted to participate in the care, and what kind of space the nurses should create for the dying person (Ranse et al., 2012, p. 8). The participants were comfortable answering questions, providing explanations, and giving additional information to the family. They would try to get to know the patient by asking the family members about their loved one and in turn, they would learn more about the patient-family relationship (Ranse et al., 2012).

In an interpretive, phenomenological study conducted by Hov and colleagues (2007), using focus groups, they interviewed 14 nurses to explore good nursing care provided to patients at the EOL. Getting 'everyone on the same page' (family, nurses, physicians) was achieved through clear and effective communication to come to a shared understanding regarding goals of care to ensure that good EOLC was provided (Hov et al., 2007). The participants spoke to the significance of nurses participating in discussions regarding EOL decisions because they could identify physical signs of pain and suffering of patients (Hov et al., 2007).

Communication was a key aspect of good nursing care and incorporated both verbal and non-verbal communication with the patient during EOLC. The nurse-patient relationship was central to nursing care. Participants described how they talked to their patients, whether they were conscious or unconscious, and provided them with reassurance to let them know they were not alone (Hov et al., 2007). They communicated necessary information to dying patients with

the belief that they “had a right to know” certain information related to their care (Hov et al., 2007, p. 336). It was not identified specifically what that information entailed. Using verbal communication with patients also helped lessen their confusion and provided reassurance they were not alone (Hov et al., 2007). A finding in this study that differed from most of the other studies was that participants’ accounts focused on the bodily care of the patient (Hov et al., 2007). They emphasized the use of non-verbal communication to care for patients by using their hands on the patient’s body to communicate safety, comfort, caring, and respect (Hov et al., 2007). The use of therapeutic touch was evidenced in all the categories of this study. Participants used their hands to help reduce patients’ stress, to assess patients’ condition, to provide reassurance, and to meet their needs (Hov et al., 2007).

2.7.2 Patient comfort and dignity.

Providing comfort and dignity for patients and their families was a key finding that was consistent across all the studies (Arbour & Wiegand, 2013; Efstathiou & Walker, 2014; Espinosa et al., 2010; Fridh et al., 2009; Hov et al., 2007; King & Thomas, 2013; Ranse et al., 2012; Vanderspank-Wright et al., 2011). Participants described the physical care they provided to keep patients comfortable and protect their dignity at the EOL. Physical care included providing comfort for the patient and reducing pain and suffering using pharmacological and non-pharmacologic interventions. In their phenomenological study on nurses’ experiences caring for dying patients, King and Thomas (2013) revealed that participants “promised to provide comfort” to patients using sedatives, medications, and analgesics for pain and symptom control (p. 1301). They also made this promise to the family that they would keep their loved one comfortable, free of pain, and eliminate any suffering (King & Thomas, 2013).

Vanderspank-Wright and colleagues (2011) conducted a phenomenological study with six nurses to explore the experiences of nurses caring for patients and families during the withdrawal of life-sustaining treatment. One of the central themes described how participants provided comfort for the patient and the family through physical care including good pain and symptom management (Vanderspank-Wright et al., 2011). When the nurses provided comfort for the patient, their family could observe the nurses caring for their loved one and realize that patient comfort was a priority (Vanderspank-Wright et al., 2011). This was also a way nurses could establish trust and build on their relationships with families. Similar to the King and Thomas (2013) study, to provide good pain and symptom control, the participants used benzodiazepines (midazolam) and opioid analgesics (morphine, hydromorphone), as well as repositioning to make the patient appear comfortable for the family (Vanderspank-Wright et al., 2011). Participants used these types of medications during the withdrawal of life-sustaining treatment to help reduce agitation, difficulty breathing, restlessness, and anxiety (Vanderspank-Wright et al., 2011). They spoke of a “moral check” when using sedation and analgesics so they could justify the amount of medications they needed to use during the withdrawal of life-sustaining treatment (Vanderspank, 2009, p. 59). This moral check helped the nurses to reflect on why the medication was being given to the patient (i.e. to relieve their pain or other symptoms) (Vanderspank-Wright et al., 2011). Over time nurses developed expertise in physical measures to keep patients comfortable. They were “trying to do the right thing”, which was the essence of their experiences, by making the patient comfortable (Vanderspank-Wright et al., 2011, p. 33). Comparably, in a study by Arbour and Wiegand (2013), some participants identified providing pain and symptom management or providing a good death by making sure everyone was “doing

the right thing” (p. 215). Participants were satisfied with the care they provided when patients appeared to be dying comfortably with their wishes respected (Arbour & Wiegand, 2013).

Keeping the patient clean and fresh, removing unnecessary equipment, and maintaining a good appearance were part of promoting comfort but they were also seen as elements of dignified care (Hov et al., 2007). Other types of non-pharmacologic interventions were described as hair care, mouth care, and relieving pressure sores but further details were not provided (Ranse et al., 2012). Hov and colleagues (2007) revealed that providing dignified care to patients at the EOL was what the participants did to protect patients’ bodily image. The participants respected patients by talking to them whether they were conscious or unconscious. Knowing their loved one was receiving dignified care was assumed to create comfort for the family.

2.7.3 Being there.

Certain studies (Arbour & Wiegand, 2013; Efstathiou & Walker, 2014; Fridh et al., 2009; Hov et al., 2007) described how nurses maintained a physical presence at the bedside for patients and families alike. Nurses also actively encouraged family members to be present at the bedside of the dying patient. Participants in Efstathiou and Walker’s (2014) study of 13 nurses, described patients dying alone as an undesirable death in the ICU, thus, the withdrawal of treatment could be delayed until the family arrived. Nurses felt that it was necessary to continue the treatment for that reason but also knew that it may cause patients unnecessary discomfort. They were physically present at the bedside but also tried to give patients and families space and privacy. In a study conducted by Arbour and Wiegand (2013), the participants recognized the importance of family presence; it was encouraged and supported. The participants facilitated families being present at the bedside to say goodbye to their loved ones by letting them in at any time of day or night (Arbour & Wiegand, 2013).

Encouragement was given to the family “to sit with, talk to, and touch their loved one” (Ranse et al., 2012, p.9). Fridh and colleagues (2009) described an important duty for the nurses was to ensure they provided the same empathetic care as they would to any patients at the EOL and that they should not let the patient die alone. Participants would also touch and talk to their patients about day-to-day topics, the care that was being provided, and about the staff and people who were in the room (Fridh et al., 2009). Similarly, the participants in Hov and colleagues’ (2007) study, felt that nurses being present and providing reassurance to the patients that they would not be alone was vital to the provision of good EOLC.

2.7.4 Caring for family.

Caring for the family was a central theme across several of these studies (Arbour & Wiegand, 2013; Espinosa et al., 2010; Fridh et al., 2009; King & Thomas, 2013; Vanderspank-Wright et al., 2011). Caring for the family was just as important as caring for the dying patient and participants described creating close relationships with family members by listening to them as well as providing them with necessary information (Espinosa et al., 2010; Fridh, 2009; Vanderspank-Wright et al., 2011). Vanderspank-Wright and colleagues’ (2011) study theme of “stepping in” portrayed nurses establishing a relationship with the family and caring for them by helping them through the dying process (p. 33). Participants felt it created a sense of comfort and familiarity for the family. This finding coincided with a study by Espinosa and colleagues (2010) where the participants talked about establishing a relationship and building trust with the family through educating them about the dying process. Participants in Fridh and colleagues study (2009) felt that when their patient was comfortable they could then focus more attention on caring for the family. In Ranse and colleagues’ (2012) study, some participants asked family members what they wished for their loved one at the EOL and if they wanted to be involved in

the care. The participants would get to know the patient through the family members by asking them questions which helped to develop the relationship between the nurse and the family.

In Arbour and Wiegand's (2013) study, they described how the nursing role encompassed supporting family members' emotional needs, advocating for them when necessary, providing reassurance, and helping them with acceptance. Participants in their study discussed honouring family's wishes to delay the withdrawal of treatment so that the entire family had time to come and say their goodbyes. A finding that was different from all of the other studies was how the participants in the King and Thomas (2013) study described the connection nurses built with the family and how they "promised to remain connected" even after the patients' death (p. 1303). Participants continued to care for the family through providing emotional support to them by attending funerals and staying connected sometimes even years after the patient's death (King & Thomas, 2013). When the participants remained connected with the family, they derived feelings of satisfaction from the connection and from being acknowledged by the family. Interestingly, Hov and colleagues' (2007) study was the only one that did not include caring for the family as an essential part of good nursing care at the EOL.

2.7.5 Creating a personal space for families.

Creating a space for patients and families was a finding across several studies (Arbour & Wiegand, 2013; Efstathiou & Walker, 2014; Ranse et al., 2012; Vanderspank-Wright et al., 2011). The participants in Ranse and colleague's (2012) study, described how they made a space for patients and family members by modifying the ICU environment to make it more personal and private. Participants discussed the significance of patients being in single, private rooms so they could have more space for family members and visitation could be facilitated at any time (Ranse et al., 2012). They described creating an environment that was less 'hospital like' and

more homelike by removing the technology (tubes, wires, monitors) and by adding dim lighting, music, quilts, photographs (Ranse et al., 2012). Efstathiou and Walker's (2014) study substantiates this theme. They described "reconnecting the patient and family" where the participants recognized the environmental barriers between the family and patient and so they attempted to remove unnecessary monitoring devices and equipment to bring patients and family members closer together (Efstathiou & Walker, 2014, p. 9). Time and space were recognized by the participants as being significant for reconnecting patients and family members (Efstathiou & Walker, 2014). One participant revealed how she created that intimacy for a patient and his partner, by closing the curtains and allowing them to lie together (Efstathiou & Walker, 2014). This theme is reflective of descriptions provided by Vanderspank-Wright and colleagues (2011) as well as Arbour and Wiegand (2013) where critical care nurses sought to create and enable patients and families to be together to experience private, final moments that could be associated with positive memories despite incredibly difficult circumstances.

2.7.6 Providing memories.

Arbour and Wiegand's (2013) category of "protecting families and creating positive memories" was about nurses protecting the family and their memories by making the patient look comfortable, clean, and reducing the technology (p.215). The nurses wanted to facilitate the dying experience for the family by ensuring they were provided with the opportunity to be at the bedside and hold the patient's hand if they wanted too (Arbour & Wiegand, 2013). This finding supported Vanderspank-Wright and colleagues (2011) theme of "providing memories" where the nurses were trying to create an aesthetic for the family to help create positive memories (p. 33). The nurses described the "little things" that they thought would be most meaningful to the family (Vanderspank-Wright et al., 2011, p. 34). For example, one participant described washing the

patient's hair so she would look more like herself for the family before she died (Vanderspank-Wright et al., 2011). Another participant talked about her experience of bringing a dying patient outside to "feel the sunshine for the last time" (Vanderspank-Wright et al., 2011, p. 34). In Ranse and colleagues' (2012) study, the participants discussed how they facilitated family's experience with EOL by the actions they took to help the family create memories. An example of creating memories was described by one of the participants as taking the patient's handprint and collecting a lock of hair for the family (Ranse et al., 2012). When participants were acknowledged by family for their work, they presumed these experiences were significant for the family (Ranse et al., 2012).

"Providing memories" revealed how privileged the nurses felt being able to provide end-of-life care to patients and families (Vanderspank-Wright et al., 2011, p. 33). The nurses in that study ensured patients and families had positive and memorable experiences (Vanderspank-Wright et al., 2011). It was found that nurses aspired for the patient to be comfortable and for the families to have good memories at the EOL (Espinosa et al., 2010). When nurses went above and beyond to help create memories, provide positive experiences, and a good death, it was portrayed by the nurses as meaningful experiences (Arbour & Wiegand, 2013; Vanderspank-Wright et al., 2011).

2.7.7 The privilege of providing EOLC.

Despite the challenges and demanding work, critical care nurses perceived caring for dying patients and their families to be both a privilege (Efstathiou & Walker, 2014; Fridh et al., 2009; Vanderspank-Wright et al., 2011) and rewarding (Calvin, Kite-Powell, & Hickey, 2007; Kirchhoff & Beckstrand, 2000). Nurses working in medical and surgical areas also likened their experiences with EOLC to feeling rewarded, gratified, and privileged when the nurses could meet patient's

emotional needs (Gagnon & Duggleby, 2013; Johansson & Lindahl, 2012; Oliveira et al., 2016). In studies conducted by Vanderspank-Wright et al. (2011) and Oliveira et al. (2016), nurses described feeling privileged by being there for family and being part of those last personal moments of a dying patients' life. Some participants in the Oliveira (2016) study portrayed the provision of comfort and support for patients and families as 'gratifying'. Nurses have reported experiencing fulfillment on a personal and professional level with the provision of EOLC (Gagnon & Duggleby, 2013; Johansson & Lindahl, 2012; Johnson & Gray, 2013; Oliveira et al., 2016). They felt privileged within their role when they strove to create memories and positive experiences for patients and families (Efstathiou & Walker, 2014; Espinosa et al., 2010; Ranse et al., 2012; Vanderspank-Wright et al., 2011).

These research studies (Arbour & Wiegand, 2013; Efstathiou & Walker, 2014; Espinosa et al., 2010; Fridh et al., 2009; Hov et al., 2007; King & Thomas, 2013; Ranse et al., 2012; Vanderspank-Wright et al., 2011) have explored ICU nurses lived experiences with providing EOLC for patients and families. Although the studies were not explicitly about meaningful experiences, their stories have captured how 'good' EOLC is provided in the ICU and how they perceive the provision of 'good' EOLC as meaningful. Across these studies, are descriptions of how nurses provided dignified care, ensured comfort, and attempted to create positive memories and experiences for patients and families. For nurses to provide 'good' EOLC, it is important that they have awareness as to what constitutes a 'good death' in the ICU. Understanding nurses' perceptions of a 'good death' and 'good' EOLC can provide insight as well as an avenue to achieve meaningful and gratifying experiences with EOLC. However, there are challenges that exist that affect the provision of good EOLC as well as the construction of meaningful experiences.

2.8 Working Within Constraints

Research studies on nurses' experiences with EOLC in the ICU have acknowledged and identified challenges that can affect the provision of a 'good death' and consequently, the construction of meaningful experiences that are perceived as positive. Nurses' perceptions of the challenges to providing a 'good death' were described as: (1) lack of time to spend with dying patients and families, to be compassionate, to provide support and inform them; (2) ineffective communication between nurses and physicians; (3) lack of formal education and training in EOLC; (4) lack of respect for patients' wishes; and (5) the technological environment of the ICU (Beckstrand et al., 2006; Kisorio & Langley, 2015; Wilkin & Slevin, 2004; Zomorodi & Lynn, 2010).

Nurses' lack of time to spend with patients and families has been attributed to staffing shortages and higher patient acuity levels (Beckstrand et al., 2006; Kisorio & Langley, 2015; Wilkin & Slevin, 2004; Zomorodi & Lynn, 2010). Not being able to spend enough quality time providing compassionate care to patients and family members was found to decrease the quality of EOLC (Zomorodi & Lynn, 2010). Poor communication between physicians and nurses regarding patient's goals of care has been made explicit in the literature (Beckstrand et al., 2006; Kisorio & Langley, 2015; Mani, 2016; Vanderspank-Wright et al., 2011; Zomorodi & Lynn, 2010). One of the themes in a study by Espinosa and colleagues (2010) was entitled "barriers to optimal care" and it focused on the challenges of communication between families, physicians, and nurses (p. 275). This theme corresponded to Vanderspank-Wright and colleagues (2011) theme of "working in professional angst" which also portrayed the challenges in communication between families, physicians, and nurses regarding patients' goals of care (p. 33). Nurses described feeling excluded by physicians from EOL discussions (Espinosa et al., 2010; Kisorio

& Langley, 2015; Mani, 2016; Pattison, 2004). Some physicians would go ahead with a family meeting without including the nurse, even though nurses often had valuable information to add to the meeting. The consequences of not being included often left nurses feeling less than satisfied with the decision-making process compared to physicians, especially when nurses viewed treatment as being unsuccessful and contributing to patient suffering (Beckstrand et al., 2006). Additionally, patients' wishes not being respected by the family or the health care team has been identified as a challenge to the provision of a good death. Physicians and family members do not always agree on patients' goals of care and this can lead to confusion and uncertainty for family members. It can also cause pain and suffering for patients when painful interventions are continued unnecessarily (Holms et al., 2014).

Nurses working within constraints can have experiences that are meaningful, however, they are recognized as less positive because of how they can affect the provision of a good death.

2.9 Summary of the Literature

From this literature, we see descriptions of how nurses construct perceptions of good EOLC and begin to appreciate the meaningful and gratifying aspects of their experiences. These experiences often coincide with nurses' perceptions of providing good EOLC. Nurses' provision of a good death is a mechanism through which the perception of a meaningful experience may be viewed in a positive way. According to the extant literature, nurses' perceptions of a good death are one that is pain-free, dignified, without suffering, and one where patients do not die alone. Nurses' insights into the concept of a 'good death' are predominantly consistent with some of the perspectives of patients, family members, and other health care providers (social workers and chaplains) (De Jong & Clarke, 2009; Steinhäuser et al., 2000). Good EOLC was demonstrated through nurses using good communication, providing dignity and comfort care, being there for

patients and families, caring for families, creating a personal space for families, and helping to create meaningful memories and positive experiences for patients and families. The challenges that affect the provision of a good death in the ICU have been well documented in the literature, particularly ineffective communication between physicians and nurses, as well as patients' wishes not being respected. The nurses described these challenges as meaningful but not in a positive way due to how they affected the provision of a good death.

The evidence in the literature suggests that it is entirely possible that nurses have never been asked to describe their meaningful and gratifying experiences with providing EOLC for patients and families. The literature on nurses' encounters with the provision of EOLC tell us stories of experiences that are rewarding, gratifying, and a privilege, however, we need to know more about what these experiences are and what they mean for nursing professionals. A comprehensive exploration of nurses' meaningful and gratifying experiences can contribute to understanding what is required to facilitate these experiences for nursing staff.

Chapter 3: Methods

3.1 Research Design

This chapter provides an overview of the research methodology and the subsequent study design including the sample, eligibility criteria for the participants, the setting, process of data collection, analysis, and methods to ensure rigour. The study setting is described in detail thereby providing a rich description of the context.

3.1.1 Philosophical underpinnings.

According to Guba and Lincoln (1994), a paradigm is a “set of basic beliefs” and “it represents a worldview that defines, for its holder, the nature of the world, the individuals’ place in it, and the range of possible relationships to that world and its parts” (p. 107). To comprehend how this study was constructed, the reader must first understand the underlying philosophical assumptions, namely its ontology and epistemology. In understanding the ontology and epistemology, the reader can have a more thorough understanding of how the study was conceived and how the knowledge was created.

Ontology is beliefs or views of the world concerning the “nature of reality” (Guba & Lincoln, 1994, p. 108). To determine an ontological position, the questions that could be asked are “what is the form and nature of reality and, therefore, what is there that can be known about it?” (Guba & Lincoln, 1994, p. 108). Regarding ontology, two dominant and contrasting perceptions of reality are realism and relativism. Ontological realists describe reality as objective with one truth that exists that does not evolve or change (Guba & Lincoln, 1994). They search for the truth that is measurable and unchanging (Guba & Lincoln, 1994). Ontological relativists, however, describe reality as subjective with multiple realities that exist, and with the truth that evolves and changes (Guba & Lincoln, 1994). Simply put, those who espouse a relativist

perspective acknowledge and value the subjective meaning of experiences and readily acknowledge that many different perspectives exist. This study assumes an ontological relativist perspective.

Epistemology, in turn, is influenced by the ontological beliefs about reality and it elaborates on how this reality can be known (Guba & Lincoln, 1994). Epistemology can be explored by asking “what is the nature of the relationship between the knower or would-be knower and what can be known?”, subsequently determining how knowledge is both created and shared (Guba & Lincoln, 1994, p.108). Epistemological relativists embrace the subjectivity of the researcher and acknowledge that they bring their own values and knowledge into the research process and experience (Guba & Lincoln, 1994). A relativist perspective assumes that knowledge creation is co-constructed between the researcher and others about the phenomenon of interest (Guba & Lincoln, 1994). The latter contrasts with a realist perspective where the researcher is removed from the experience in an effort to eliminate bias. In essence, understanding one’s ontological and epistemological inclinations will influence the types of questions asked by the researcher.

As such, the paradigm of choice for informing and guiding this study is constructivism (Denzin & Lincoln, 1994). Constructivism is congruent with both relativist ontology and epistemology. Premised on the belief that knowledge is constructed as well as co-constructed and that individuals create their own subjective realities (Denzin & Lincoln, 1994), a constructivist perspective was an appropriate choice within which to situate this research methodology. A priori, it acknowledges that there are multiple constructed realities and constructivist approaches that embrace exploring different points of view as well as meaning that individuals have associated with their own experiences (Guba & Lincoln, 1994).

Phenomenology is a research methodology (as well as philosophical tradition) situated within a constructivist lens. Phenomenologists seek to study and understand the world as it is lived and experienced by others (Guba & Lincoln, 1994). There are two main phenomenological traditions or approaches - descriptive and interpretive phenomenology. Edmund Husserl, a German philosopher, in the early 20th century, is credited with establishing the foundations of descriptive phenomenology. Husserl believed that the “lifeworld” is what individuals experience but that an account of this lifeworld is left to description only (Dowling, 2007, p. 132). In fact, Husserl argued that phenomenologists should remove all their prior expert knowledge and experience (bracketing or ‘*epoche*’) to understand the experiences of others (Dowling, 2007). Heidegger, a student of Husserl, challenged his mentor’s perspective by moving beyond description into hermeneutics (interpretation) to uncover the meaning and significance of human experience (Dowling, 2007). In his work, Heidegger (1985) used the term “*being-in-the-world*” (p. 238) to articulate “our everyday being-involved-with the things of our world” (Van Manen, 2007, p. 13). Heidegger believed in sharing narratives and giving voices to humans to support common understandings of the lived experience (Van Manen, 2007). “The goal of a hermeneutic, or interpretive account is to understand everyday skills, practices, experiences; to find commonalities in meanings, skills, practices, and embodied experiences” (Benner, 1994, p. 56), and “to find exemplars or paradigm cases that embody the meaning of everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized, or sentimentalized” (Benner, 1985, p. 5).

During the latter part of the 20th century, Van Manen built on the work of Heidegger. Van Manen’s philosophy is deeply rooted in hermeneutics which incorporates elements of both descriptive and interpretive phenomenology by describing and interpreting peoples’ lived

experiences (Van Manen, 2017). He defined phenomenology as “the study of the lived experiences; the deeper understanding and meaning of everyday practice” (Van Manen, 1990, p. 30-31). According to Van Manen, (1990), phenomenology is concerned with being and “questions the way one experiences the world” (Van Manen, 1990, p. 30). Van Manen’s method is comprehensive and well suited to uncovering the complex realities of nursing work and allows the experiences to be viewed as holistic and made known through the accounts of the participants. He has described interpretive phenomenology in a way that is more explicitly understood for the reader using more simplified text and ideas. According to Van Manen (2017) phenomenological research can be challenging yet it can lead to “experiencing moments of meaningfulness that makes it worth the effort” (p. 779). Interpretive phenomenology was chosen as the method for this study as it facilitates an exploration and deeper understanding of what ICU nurses have described as both meaningful and gratifying within their “lifeworld” of providing care to patients and families at the end-of-life (Dowling, 2007, p. 132).

3.1.2 Assumptions.

As a phenomenological researcher, I have acknowledged using my prior knowledge and experience to facilitate and create openness during the interviews as well as for interpretation of the data (Dowling, 2007; Polit & Beck, 2012). As previously stated, as the researcher, I am a critical care nurse working in the ICU and have had the experience of caring for patients and families at the EOL that I identified as meaningful and gratifying. My prior knowledge helped to determine which probing questions to use to draw out experiences from the participants (Polit & Beck, 2012). Bringing 10 years of ICU nursing (13 years of nursing) knowledge and experience, I acknowledged my own presuppositions and made them explicit before the commencement of the data collection. Recognizing my presuppositions was a way for me to become aware of my

own values and beliefs as well as understand the frame of reference that I brought to the study.

They were documented as:

1. Nurses want to ensure they provide comfort and dignity for patients at the end-of-life.
2. Nurses' experiences with the provision of EOLC can be meaningful and gratifying.
3. The patient's wishes for treatment are not always known by the family or the health care team.
4. Nurses want to ensure patients and families are supported.
5. Nurses want to make sure the experience of end-of-life is optimal for patients and families.
6. Nurses face challenges to providing good EOLC in the ICU.

3.2 Sample

Phenomenological studies often present with a sample of 12 participants or less (Polit & Beck, 2012). A purposive sampling technique was used to recruit ICU nurses. Polit and Beck (2012), defined purposive sampling as "selecting participants who the researcher thinks will most benefit the study" (p. 517). Purposive sampling was chosen because it helped to recruit participants who had knowledge and understanding of EOLC in the ICU. The participants recruited met the inclusion criteria and were representative of nurses in the ICU who had provided EOLC to patients and families. For this study, data collection was stopped after six interviews because there was redundancy in the interview data and no new information was forthcoming. The six participants were considered a homogenous sample based on the inclusion/exclusion criteria. There was both depth and breadth of experiences described within the six interviews and as a result, the thesis committee felt that data collection could cease.

Malterud, Siersma, and Guassora (2016) describe reaching adequate sample size as “information power” (p. 1759).

3.2.1 Eligibility criteria for participants.

Inclusion Criteria

1. Registered nurses who were working part-time or full-time in the ICU;
2. Registered nurses who had provided end-of-life care to a patient/family in the ICU;
3. English or French speaking;
4. Registered nurses who had a minimum of six (6) months’ experience in an ICU.

The justification for including nurses with six (6) months or more ICU experience was that the nurses had sufficient exposure to EOLC in the ICU to have experiences to share (M. Langill, personal communication, September 4, 2014).

3.3 Setting

The setting for this study was a 32-bed medical/surgical ICU located in one of the three campuses of a tertiary care teaching hospital (M. Langill, personal communication, September 6, 2016). There is another ICU located at a different campus of the hospital. At the time of the study, 26 beds were funded and operational. The nurses were all registered nurses (RNs) who had received specialized critical care training from the hospital. At the time of recruitment, the staffing compliment in the unit included, 146 full-time RNs, 14 part-time RNs, two nurse educators (one that was shared between the other ICU on a different campus), one clinical nurse manager, and one clinical care leader.

3.3.1 The physical setting of the study ICU.

The ICU in the study setting is a separate area of the hospital and considered a restricted access area and so visitors must phone in from the family lounge before accessing the unit. There

is usually a volunteer present in the family lounge, which is located outside the main doors of the ICU, who helps facilitate communication for family members and friends who wish to visit a patient. Patient care areas are mostly large, private rooms with glass windows, sliding doors and curtains that can be pulled closed for additional privacy. There are desks with computers situated outside each patient's room so that nurses can easily monitor the patient from a few feet outside the room. There are two main nursing stations at either end of the unit. Each room has a cardiac monitor with the ability to display a patient's heart rhythm and rate, oxygen saturation, respiratory rate, and blood pressure for continuous monitoring as well as other hemodynamic parameters.

3.3.2 ICU patients and end-of-life care in the study unit.

Patients admitted to this ICU have acute, life threatening illnesses such as respiratory failure, multiple organ failure, as well as cancer-related pathologies, and postoperative complications (The Ottawa Hospital, n.d.). These patients often require mechanical ventilation, hemodynamic support, and monitoring on a one to one nurse/patient ratio. Goals of care are patients' wishes for treatment or preferences pertaining to the use of life-sustaining treatment. Ideally, goals of care are discussed on admission (when possible) and subsequently modified throughout the patient's ICU stay. Prior to admission, overarching goals of care are then translated into categories of care.

Categories of care (or code status as it is referred to in the study) are medical directives that refer to interventions that should be conducted by the health care team if the person's heart or breathing stops. There are three categories of care. Category 1 is a "full code" which indicates that all measures will be taken such as CPR (cardio-pulmonary resuscitation), admission to the ICU, and intubation (The Ottawa Hospital, 2009). Category 2 is no CPR but admission to the

ICU is acceptable (The Ottawa Hospital, 2009). Category 3 is do not resuscitate (DNR) and no ICU admission (The Ottawa Hospital, 2009). The decision to transition from curative to comfort care usually implies a change to Category 3. After discussions take place between health care providers and families (and patients when possible), patients who are category 1 may become a category 2 or 3 while in ICU. In the study unit, the transition to comfort care is also reflected in formal comfort care orders being put in place.

Comfort care orders for the withdrawal of life-sustaining treatment. In the study unit, the comfort care order sheet is a pre-written order form signed by the physician to initiate EOLC and the withdrawal of life-sustaining treatments. The orders provide parameters for analgesics and sedation as well as guidelines for the removal of life support (i.e. mechanical ventilation, inotropic and vasopressor support, nutrition, and other pharmacological interventions such as antibiotics). It is routinely used by the nurses as a guideline for pain and symptom management and constitutes standard unit practice for EOLC. These orders are implemented following a decision made by the family and the health care team and can be modified depending on the context.

3.3.3 The family in the study ICU.

Patient and family are considered a unit of care in this ICU. As such, the nurses care for families as well as patients by providing them with support, information, and reassurance. Families have access to the family lounge and the private rooms outside the ICU and they can visit their loved ones at the discretion of the nurses. Visitation is liberal in this unit apart from the beginning of a shift where nurses are doing their shift change report and their first comprehensive head-to-toe assessment. Additionally, the family may be asked to wait before entering the ICU (if family members are already at the bedside, nurses will ask them to step

outside into the family lounge) while procedures (e.g. central line insertions, bronchoscopies) are being done at the bedside. Nurses may also use their discretion during direct patient care (e.g. bathing and repositioning) to ask visitors to briefly step out to respect the patient's dignity with their body being exposed. Multidisciplinary rounding is a unit practice that facilitates family involvement and participation in care by providing families with the opportunity to ask pertinent questions and/or contribute valuable information about their loved one. While families might not participate frequently in the multidisciplinary rounds, they are not precluded from being present and participating. Family conferences (or meetings) also constitute a mechanism for communicating with families. In the majority of instances, nurses are present in family conferences in this unit.

3.3.4 The ICU team in the study unit.

The multidisciplinary team includes nurses, respiratory therapists, physicians, social workers, pharmacists, physiotherapists, dieticians, and spiritual care workers to support and care for patients. The nursing team is made up of one care facilitator, one or two nurse educators, one manager, one clinical care leader, and depending on how many beds are occupied, the number of bedside (staff) registered nurses ranges from 20 to 28 in one 12-hour shift. Of note, nurse educators, managers, and clinical care leaders are usually in the unit during the day. The care facilitator oversees making the daily/nightly nursing assignments, knowing main issues of the patients, deciding which nurse will admit the next patient, and coordinating with physicians about which patients are transferrable to other units as well as the arrival of new admissions to the unit. Care facilitators are present 24 hours a day. The nursing assignment can change from a one to one ratio, to one nurse to two patients if they are considerably more stable (i.e. if they are waiting to be transferred out of the ICU or discharged home). The nurse educator role is to

provide training and education to all the staff nurses in the ICU. They educate and mentor nurse orientees and staff nurses by keeping them up to date with the latest policies, equipment, knowledge, and skills. The manager works closely with the clinical care leader to ensure that safe and quality care is being provided to patients and families in the ICU. Together they provide supervision, assistance, and support to the nursing staff as well as ensuring patient/family satisfaction with care.

The composition of the ICU team is multidisciplinary. The ICU medical team is led by 20 intensivists between the two hospital campuses. Intensivists are staff physicians that have received specialist training with a focus in critical care. There are typically two ICU fellows on at one time who are training to become intensivists over a two-year period. Residents are medical doctors who are still in training and being taught by the fellows and the intensivists. The residents, fellows, and physicians are part of the ICU health care team. There are always two residents in the unit 24 hours a day. There are two intensivists and two fellows on each week with residents and medical students changing over every month. After a week, the intensivists rotate to a different campus ICU or an off-service. The transfer of responsibility of care for ICU patients is done with physician handover. Information is communicated from staff physicians to other staff physicians, fellows and/or residents to help with the delivery of safe and effective care as well as continuity of care. The type of information that is typically transferred between physicians is clinical conditions, potential problems, investigations and treatments, family dynamics, goals of care, and ongoing plans of care. Handover allows for physicians to have discussions, find out information, and ask questions about patient's ongoing plan of care.

3.4 Data Collection

At the outset of the study, the researcher met with the unit manager to discuss the study and the recruitment process. Following research ethical approval, recruitment posters (see Appendix A and B) were placed in the ICU with permission from the clinical manager and were e-mailed to staff nurses. The researcher visited the ICU on several different days and presented the study to individual RNs working on the unit. While speaking to individual RNs who expressed interest, the researcher used a recruitment script (see Appendix C) to ensure a consistent message in communicating with them. The researcher explained details of the study and answered questions. Aside from the unit visits, interested participants also contacted the researcher through e-mail and set up a time for an interview.

3.4.1 Interview process.

Data was collected through face-to-face unstructured interviews. The interviews were scheduled at a mutually agreed upon time and were conducted in a quiet, private interview room at the hospital. The purpose of the study was reiterated and questions/clarifications from study participants were addressed. Informed consent (See Appendix D and E) was obtained before the start of each interview. The interviews lasted 45 minutes to one hour in length and were audio recorded. The principal investigator (H.S.) conducted all the interviews. Each participant completed a demographic questionnaire (see Appendix F for English and G for French) before the start of the interview. Each interview began with a broad question from an interview guide (see Appendix H): “Tell me about a meaningful or gratifying experience where you provided end-of-life care for a patient and family in the ICU?” Probing questions were used to generate more in-depth responses. The probing questions included: “Tell me about any challenges that you have encountered to having meaningful and gratifying experiences with end-of-life care?” and “Tell me about the facilitators to have meaningful and gratifying experiences in providing

end-of-life care?” Field notes were taken during the interviews as the participants talked, to document observations such as the participants’ body language, any pauses, and/or facial expressions. The participants also consented to participate in a second face-to-face interview for the purpose of member checking.

3.4.2 Characteristics of the participants.

There were six ICU nurses who participated in the study. All participants were female and ranged in age from 26 to 58 years old (median age of 37 years) and were English speaking. Of the six participants, five nurses had received a Bachelor of Science in Nursing and one nurse had a diploma in nursing. The years of experience as an RN ranged from three years and nine months to 36 years (median of 12.5 years). Their ICU experience in that specific unit ranged from four years to 23 years (median of 7.5 years). None of the participants identified that they had any additional education in end-of-life/palliative care. Three participants had received a Critical Care Certificate, three indicated that they had taken critical care courses and one had Canadian Nurses Association certification in adult critical care.

3.5 Data Analysis

Audio recorded interviews were transcribed within 12 hours of the interviews being conducted. The transcripts were verified for accuracy by the researcher who listened to the audio recording for a second time. The qualitative interview data were analyzed using Van Manen’s (1990) three step approach. These steps include the holistic approach, the selective approach, and the detailed (line by line) approach (Van Manen, 1990).

The first step was the holistic approach where I attempted to capture the meaning of the text as a whole (Van Manen, 1990). I read and re-read the data until I became very familiar with it. Then I met with my thesis supervisors to discuss the transcribed data. At this stage, I started

asking myself analytic questions such as: what is the story being told here and what does it mean? The second step was the selective approach whereby I identified meaningful, significant statements and phrases that were important to the study (Van Manen, 1990). I color coded (i.e. highlighted) these significant statements, phrases, and words to help organize the data. The different color codes were then organized into different categories. I started thinking about possible themes with these categories and I met regularly with my thesis supervisors to discuss the coded data and the developing categories.

The third step as per Van Manen (1990) was the detailed approach whereby multiple readings were done and every sentence of the interview data was examined. The revealing statements from step 2 were pulled out of the data and re-examined until they started to develop into themes and subcategories. I met regularly with my thesis supervisors to discuss the development of the themes and subcategories. After reflecting on these themes and subcategories, I constructed appropriate titles for these themes and found suitable quotes to support the themes. The themes and subcategories were analyzed, including the relationships among them and between them, until an underlying essence was discovered. Follow-up interviews (member-checking) were conducted with the participants during which they verified the themes and interpretations.

3.6 Methods to Ensure Rigour

Credibility, dependability, confirmability, and transferability were used to ensure rigour of the study (Lincoln & Guba, 1985). In the following paragraphs, I explain how I established trustworthiness by elaborating on these criteria.

3.6.1 Credibility.

Credibility is the degree of confidence that a reader has in the truth of data and interpretations (Lincoln & Guba, 1985; Polit & Beck, 2012). Members of the research team had expertise in critical care and qualitative methods which brought credibility to the study. Credibility was also achieved by completing member checks with the participants (Polit & Beck, 2012) which entailed providing a summary of the data to the participants and completing follow-up interviews to verify the interpretations and main themes of the study.

3.6.2 Dependability.

Dependability refers to the reliability of the data over time and conditions (Lincoln & Guba, 1985). If the same process were to be repeated, would it lead to the study's findings? (Polit & Beck, 2012). To ensure consistency and accuracy of the process, I maintained a "decision trail" to increase the dependability of the study (Noble & Smith, 2015, p.35). The "decision trail" was done in order to document decisions made throughout the study as well as decisions related to the data analysis such as how I interpreted the findings and reported the results (Noble & Smith, 2015, p. 35).

3.6.3 Confirmability.

Confirmability is "the degree to which study results are derived from characteristics of participants and the study context, not from researcher's bias" (Polit & Beck, 2012, p. 175). Although the perspective of the researcher is fundamental to understanding interpretation in qualitative research, it is important not to take authorship away from the participants. Thus, I made my presuppositions explicit before the start of gathering the data to keep them in check and to show that the findings came from the participants' narratives and not my own assumptions. I used a reflective journal to record my thoughts, experiences, opinions, assumptions, and feelings throughout the entire study process. In addition, my thesis supervisors, who are both experts in

critical care and qualitative research, read every interview and discussed the interviews with me. Further, the thesis committee, also experts in qualitative methods, reviewed themes and subcategories. Quotes were extracted from the interview data and were used to explicate each theme and represent the participants' experiences in their own voices.

3.6.4 Transferability.

Transferability is facilitated through a detailed description of the study setting, contextual information, and participant characteristics (Lincoln & Guba, 1985). It is the reader of the research who compares the research findings to another situation, environment, or context. If descriptions of the findings are thick and they are well described, it is then easier for readers to compare it to other research findings or their own research (Lincoln & Guba, 1985). I have provided a detailed description of the study unit, EOLC within the unit, and the characteristics of the participants in order to facilitate transferability of the findings.

3.7 Ethical Considerations

Ethical approval for the study was obtained from the Ottawa Health Science Network Research Ethics Board and the University of Ottawa Research Ethics Board. All participants were provided with the consent form that contained an explanation of the study. When it was clear that there were no questions or clarification required, the consent forms were signed by the participants and they each received a copy. Participants were under no obligation to participate and could withdraw at any time or refuse to answer any question.

Anonymity and confidentiality were maintained by not including names of participants or other identifying data in the interviews. An identification number and a pseudonym was assigned to each participant that was attached to the data. The audio recorded interviews were stored in a locked filing cabinet in the thesis supervisor's office at the University of Ottawa. Any identifying

data was stored separately from the coded data with a password protected file to protect the participants' privacy and confidentiality. Data from this study will be conserved for a period of 10 years and then destroyed as indicated in the REB proposal.

Chapter 4: Findings

4.1 Reflections on the Findings

For this study, I chose to use a phenomenological approach to explore nurses' meaningful and gratifying experiences providing EOLC for patients and families in the context of the ICU. The idea for this study was based upon research findings that had identified a need for further knowledge and understanding of nurses' meaningful and gratifying experiences with providing EOLC. At the outset of this study it was unclear how nurses would describe 'meaningful' and 'gratifying' within their own accounts and what a phenomenological approach would reveal about these experiences. According to Zayed (2009), "as researchers, we must remain explicitly willing to alter our manner of studying phenomena, and allow them to evolve and adjust to the phenomena we are examining to fully capture their meaning" (p. 559). As is consistent with a phenomenological approach, I used open-ended, unstructured questions which enabled the participants to discuss their experiences with EOLC more liberally. In the beginning stages of analyzing the data, it became apparent that I needed to interpret what was meaningful for the participants. Through immersion in the data, I came to the realization that what the nurses were describing to be meaningful was how they created a good death for patients and families in the ICU. Participants gave in-depth, detailed descriptions of their everyday lived experiences using expertise, skills, and knowledge in their practice of how they provided a good death. The three main themes that materialized from the researchers' interpretation of the data were '*Creating a Good Death*', '*Navigating the Challenges*' and '*Making it Work*'. While exploring each of these themes, '*Being Able to Make a Difference*' emerged as the essence of ICU nurses' meaningful experiences.

4.2 Being Able to Make a Difference – The Overarching Theme

For the participants, *'Being Able to Make a Difference'* reflected their efforts to create a good death for dying patients and their families in the ICU. In situations that they described as positive in nature, knowing they could make a difference in the care they provided to patients and families helped them (the participants) to find meaning. They also described situations where they had to navigate their way through challenges that affected the provision of a good death. The challenges of coming in cold, not knowing the patient or the family, and not connecting with the family created situations that were described as uncomfortable and difficult for both the nurses and the families. These experiences still had meaning for the participants but were not described in a positive way because of how they affected the provision of a 'good death'. Even though the work was difficult and demanding at times, they found ways to make it work through building relationships with families quickly, taking care of themselves, and recognizing EOLC as a privilege, in efforts to create a 'good death'. Knowing they had made a difference in the provision of EOLC kept the nurses coming back, day in and day out, to their nursing work. One participant summed up the essence of their meaningful experiences: *"As long as you feel that you've made a difference and you've made things a little bit easier in such a hard situation. You go home and you feel like you've done your job, you've done the best that you can both as a nurse and as a person."*

4.3 Creating a Good Death

This chapter provides insight into how participants created a good death in the context of the ICU. By exploring and understanding what was meaningful to the participants through a phenomenological approach, it allowed for a deeper understanding and insight into the lived experiences of ICU nurses providing EOLC. Through interpretation of what was meaningful for

the participants, the researcher found their descriptions were intricately woven around the concept of creating a good death. The participants described how they created a good death through: respecting wishes, facilitating comfort, being there, preserving dignity and peacefulness, and connecting with families.

4.3.1 Respecting wishes.

All the participants believed that respecting patients' wishes was an important aspect of creating a good death in the ICU. In what was considered the most 'ideal' EOL circumstances, patients could make their physical and/or emotional needs known to their care providers (namely ICU nurses and physicians). When the patient had, for example, provided advanced health care directives or had discussed their wishes ahead of time with the family, it was identified to be much easier for everyone involved. Goals of care and EOL decision-making became less complicated because there was no guessing or supposing what the patient would want. However, due to the often unpredictable nature of critical illness, it was also entirely possible that patients were admitted to the ICU and their wishes were not known a priori. Yet, regardless of the circumstances, getting to know and then ultimately respecting patients' wishes required good communication and teamwork amongst the family and the health care team. Good communication and open dialogue created an atmosphere much more conducive to a) getting to know what the patient's wishes were or might be; and b) structuring goals of care in ways in which patients' wishes were respected. Amy elaborated upon teamwork and communication:

The teamwork, the good communication, the understanding among the teams, the ICU team, the nursing team, the doctors, the palliative care [team]. And everybody that's involved... that's the way to make the patients comfortable and die with dignity and respect their wishes.

Amy stated: *"When you give...end-of-life care to a patient who dies with dignity and you feel that his wishes and values were respected...I mean this is a meaningful death in my eyes."*

Seeing the patient's wishes being fulfilled at the EOL was described as both important and meaningful by the participants. Margo reflected: *"If we can abide by people's wishes and do what honours them and how they would have liked to live their life...to be able to honour someone's wishes is the biggest compliment that you can show them."*

When patients could communicate their wishes for EOLC then it was easier for everyone involved because the patient was the one making all the decisions regarding their own goals of care. If the patient was conscious, the physician and/or the nurse would ask them their preferences for EOL (e.g. category status, values, beliefs). Angela reflected: *"I feel like once the patient has a say it makes it so much easier on the family and the team in general because it's their choice and no one has to live with that other than them."* Although the pressure is taken away from the family for having to make the ultimate decision regarding goals of care, the participants acknowledged that despite knowing the patient's wishes, it could still be a very difficult experience for the families because they were imminently facing the death of their loved one. Tracey explained:

I mean it's so wonderful when a patient can provide their family with enough information to make the decision...when the family knows that they're doing the patient's wishes no matter how hard the decision is, it's easier for them and that in itself makes our job easier cause the family is in agreement because they are following the patient's wishes.

Additionally, if a patient admitted to the ICU was unable to communicate but had advance care directives coming in to the hospital, then treatment plans, goals of care and category status were more easily decided. Angela described the latter as a facilitator to knowing and respecting the patients' wishes:

Facilitators like...category status, having that coming in to the hospital to prevent any...unwanted CPR or ventilation or dialysis or whatever people consider an extreme measure to keep someone alive. Having that clarified really helps just to figure out what our goals of care would be. And I think that makes it easier in the end as well.

However, within the context of critical illness, which by nature can be sudden and unexpected, patients' wishes are often unknown. On one hand, the onus falls on the family to act as a substitute decision maker for their loved one and on the other hand, responsibility also falls upon the health care team to explore with the family what the patient's wishes might be. In these situations, communication and teamwork between the family and the health care team are imperative to creating a comprehensive plan of care.

Nurses in this study described themselves as mediators between the physician and the patient/family, relaying information back and forth with the goal of getting everybody on the same page regarding goals of care. They found themselves in a unique position to initiate these types of discussions with family members or substitute decision makers because of their continuous bedside presence. Their presence allowed them to spend quality time with the family, provide the family with information about the patient's health status and address their questions or concerns regarding patients' prognosis and/or plan of care. Additionally, as part of their role, nurses facilitated the planning and execution of family meetings (note – family meetings and family conferences were terms used interchangeably by the participants). Participants described the family meetings as spaces where open dialogue between the family and the health care team focused specifically on learning more about the patient (i.e. what kind of person they are, what they value in life and at the EOL) in order to establish goals of care that would best reflect the wishes of the patient.

In the study unit, family meetings were typically held in a quiet, private room away from the bedside. Members of the health care team who were often the participants of family meetings included the attending ICU physician, the ICU nurse, and the family members. On occasion, the unit's social worker and spiritual care worker also participated in family meetings. The social

worker and the spiritual care worker were invited to the meetings based on the needs of the patient and family as well as their availability. For the nurses, being active participants in family meetings provided a sense of both personal and professional gratification. Being an active participant was described as when the physician would ask the nurse for information or when the nurse would readily provide input regarding the patient during a family meeting. In these instances, ICU nurses found it meaningful to engage in good communication with other members of the health care team as well as the family. Nurses also found it meaningful to engage in dialogue about goals of care and to share their professional insight about the patient. Amy stated: *“You feel good as a professional, as a person.”*

However, good communication was also necessary beyond the context of more structured family meetings. Participants explained that families were often overwhelmed during these meetings because of their loved one’s critical illness but also because they were not always able to understand or retain all the information that was discussed. The nurses found meaning in providing the family with a space to seek more information, to seek clarification, and to bring forward other questions or concerns after the family meeting. Participants also found meaning in moving forward with comfort care when the family’s informational needs had been met. Tracey described the value added when both the family and the health care team were on “the same playing field”:

Having that conversation is really important I think. It really helps the nurses who then have to start the comfort measure orders... move forward with family, it sort of puts everybody on the same playing field that we know what we're doing and why we're doing it...that their questions have been asked.

4.3.2 Facilitating comfort.

All the participants described comfort as an essential part of providing a good death for patients and families. Providing comfort included pain and symptom management through both

pharmacological and non-pharmacological means. Within this study's context, physical comfort and pharmacological management of symptoms common at the EOL including dyspnea and anxiety, were facilitated using a standardized protocol for comfort care. The comfort care orders provided parameters for analgesics and sedation as well as guidelines for the removal of life support (i.e. mechanical ventilation, inotropic and vasopressor support, nutrition, and other pharmacological interventions such as antibiotics). The prescriptive/algorithmic nature of the protocol provided a particularly useful guideline for novice nurses or those who had limited experience initiating comfort measures and treatment withdrawal. It was routinely used by the nurses as a guideline for pain and symptom management and was standard unit practice for EOLC.

However, it was also noted that while there was a prescriptive/algorithmic approach to the comfort care orders, the ICU nurses used their discretion and judgment and found flexibility within the protocol to ensure patient comfort. For example, the protocol incorporates orders to wean the patient from the mechanical ventilator. Terminal weaning ultimately results (according to the protocol) in the removal of the endotracheal tube. Participants, however, experienced discord with regards to extubating and its place in facilitating patient comfort. Several participants felt patients 'looked' more comfortable when the endotracheal tube was left in place rather than if the tube was removed. They felt that when the endotracheal tube was removed it could cause the appearance of the patient being in respiratory distress. Tracey explained:

Sometimes we take the ventilator off, sometimes we don't. It really depends on how involved the lungs are...I find that always difficult because [extubating] can cause some...discomfort. I find when we take the breathing tube out or even sometimes take them off the vent they can gasp a lot...whereas you don't notice that on the vent when they have that little bit of positive pressure I find they don't really gasp and we can control that better.

Removing the endotracheal tube was not always discussed with family.

Sherri affirmed:

I find a lot of the times when I come in and a patient isn't extubated not because the family didn't want to but because the family was never asked...and if you look at the protocol really, they should be extubated unless the family has a real objection to it we should be extubating them and providing that symptom management afterwards.

Additionally, while nurses' management of patient's symptoms was guided in part by the ICU comfort care protocol, they also routinely incorporated other non-pharmacological comfort measures including repositioning, mouth care, and bathing patients. These non-pharmacological comfort measures were clearly situated in the nurses' accounts as important for two key reasons: for the provision and maintenance of physical comfort but also because they demonstrated to the family that the nurses were still providing care to their loved one until their death and beyond post-mortem care. They were still *caring* for the patient. Sherri described:

Knowing that I'm there to provide symptom management and make sure that the drips don't run out and you know that sort of stuff...we still provide...mouth care and you know checking, providing that little bit of care to make the family not just believe but that *I actually am caring for their loved one*.

Physical comfort for the patient also provided comfort for the family and the ICU nurses alike. For example, when there were no signs of suffering or discomfort, the nurses felt like they had done their job. Kathy illustrated what providing comfort care meant to her:

Normally a patient comes in the ICU really sick and then they become too ill and there's nothing else we can do and then we go into comfort care which is basically providing comfort...for my shift comfort care really means making the patient comfortable, and the family comfortable.

Amy reflected:

A good death for me in the ICU, from my experience is when you make the patient comfortable.... if I think from the beginning of the process till the end...the patient...becomes more and more comfortable and no shortness of breath...and it's just the patient going towards a good death, no suffering, comfortable, this is a very good death for me in my eyes when [they are] going gradually.

Furthermore, consulting the palliative care team was mentioned by one of the

participants as an added resource to give the nurses more information on how to enhance patient comfort. The palliative care team is a multidisciplinary team with specialized training in palliative care to provide support and guidance with pain and symptom management of patients with advanced disease or at the EOL. They can offer suggestions for combinations of medications that can help to increase patient comfort and relieve symptoms. Angela explained:

I took care of a lady and we started giving her dilaudid because she was in pain, she had terminal breast cancer.... we have a team in the hospital who is the specialist in palliative care, they know exactly how to function...then we called them...and I heard the palliative care team came and they prescribed other medication...and she...died comfortably and peacefully and I was relieved. This was a very meaningful example.

These different approaches suggested that each patient's EOL situation in the ICU was considered unique. The nurses found meaning in ensuring comfort at the EOL and when they did, they felt they were able to make a difference for patients and families.

4.3.3 Being there.

The participants frequently expressed their belief that nobody should die alone and that 'being there' for patients was essential to meaningful engagement. They all believed that family presence at the bedside during EOLC was both important and integral to a good death. In situations where the family couldn't be there on time or the patient didn't have any family, some participants felt it was imperative that they as ICU nurses, be there for the dying patient. All of the participants preferred that family be there with patients when they were dying and they described the efforts they made by calling the family to come to the ICU and be at the bedside with their loved one.

However, within the context of the ICU several scenarios could contribute to the possibility that the patient might die without family or friends at the bedside. First, there were instances where the patient was imminently dying and the family members were on their way to the hospital but they did not make it on time. Second, there were reports of family members

choosing not to be present for the death. A third scenario also existed where the patient had no family or next of kin. The participants described these situations, elaborated upon their role, and discussed how being there for the patients both physically and emotionally was meaningful for themselves as nurses.

Sherri, for example, reflected on an experience where family members were in transit to the hospital but were unlikely to make it there before the patient died. Sherri provided both an emotional and physical presence at the patient's bedside. She described speaking softly to the patient with words of comfort and reassurance that they were not alone. Sherri told her patient "*it was ok to go and that she would tell her family that she went peacefully*". She explained further:

I went in the room and sat down next to her and held her hand...I don't like anybody to die alone. I don't care if they have family or not or they're the homeless Joe from down the street...nobody should go alone as far as I'm concerned... so I was there for her last moments, her last breaths but it left me with a very heavy heart because I knew her family was coming in and they weren't going to be there.

Sherri described how she attempted to provide comfort to the family:

The curtains were all closed and I had to tell them I'm very sorry that...his wife had passed away so sort of the shock and you know that really wasn't what he was expecting when he came in...I was able to provide comfort to the family...saying that it was peaceful, she wasn't alone. Karen our spiritual care was here, she spoke to the family briefly and each of the doctors spoke to the family, and that's sort of the best that I could do but it left me with a heavy heart because I prefer to have families there.

Aspects of nurses' physical presence included gestures such as sitting with the patient and holding their hand while they were dying. Angela described a situation where the patient was dying and the family was not coming in right away even with her efforts of calling to get them there. She found out from the family that he was a very religious man and she described being there for the patient both physically and emotionally by holding the patients hand and praying with him. She described the meaningful experience she had with this patient:

I wanted to give him more medication to help him be more comfortable but I wanted the family to be there you know...I felt bad...It was a very emotional day but it was really meaningful to me, just kind of more the spiritual aspect of it...I was able to be there for him when no one else really was and I felt that peacefulness in him.

The nurses were present with patients without having to speak any words. Being there for the patients at the EOL was described as both a meaningful and rewarding aspect of the ICU nursing role. Some participants described them as experiences they would never forget. Kathy recalled her memorable experience:

The patient doesn't actually have any family members around and I was there for 2 days with the patient and I was actually able to be there when the patient was passing away holding the patient's hand so that was a total different experience.... very meaningful and I don't think I'm ever going to forget that...I've done what I was supposed to do that day like I was supposed to be in that room and supposed to hold that patient's hand when he took his last breath.

4.3.4 Preserving dignity and peacefulness.

The nurses in this study described preserving dignity and promoting peacefulness as significant elements in the creation of a good death. The participants ascribed meaning to their efforts in preserving human dignity and further recognized this as one of their professional nursing values. For some nurses, spirituality and religion were also connected to peacefulness and were described as important aspects of a good death. Participants referred to the 'little things' they did to preserve patients' dignity which, like other aspects of the nursing role such as incorporating non-pharmacological comfort measures, demonstrated to the family that they were caring for their loved one. One participant added that she strove to treat patients and their family members how she would treat her own family. Tracey explained:

I always try and treat my patients like they're my family or like I would want my family treated. Whether that be combing hair while they're dying, putting their hands on the top of their sheets so that family members can feel like they can hold them.... making sure their face is washed and they're clean...it shows care.

In attempts to preserve patient dignity and to bring the focus back to the individual, participants spoke of how they removed unnecessary technology and equipment in an effort to make the patient look more like the person they were before they got sick. Sherri elaborated:

Removing some of those tubes and bringing back their humanness, their dignity...but to provide the visual of less tubes, less mechanical, less machines beeping, less tubes in the body, just to normalize it, make it more human looking versus the tubes and the beeps and everything...you sort of take out the tubes, make it... a little bit less cold and hospital like.

Removing the equipment also brought the patient into focus. Again, Sherri explained: *“I want them to be able to focus on knowing their loved one and not necessarily focusing so much on the tubes and the machines and so I really try to get rid of as much as I can.”* She wanted families to remember the patient and *“focus on their memories when they were healthy versus the image in the bed.”*

The nurses also considered the importance of a ‘look’ of peacefulness and calm on the patient’s face (i.e. no evidence of physical suffering such as facial grimacing or dyspnea) as important. The preferred appearance which was suggestive of a ‘good death’ was when the patient had the appearance of having a peaceful/restful sleep. This appearance contributed to ease of the family but also the ICU nurses themselves. Angela reflected:

I had known her when she was conscious, before, so I kind of knew what kind of person she was before. It was nice... what was gratifying to me or meaningful was just things went really smoothly in terms of her physical death... her heart stopped and she stopped breathing and it was just very peaceful. I felt peaceful with her and it just wasn't tragic, that was one of my first comfort care/palliative care patients...I felt really good about it.

Participants also suggested that a good death could be facilitated by accommodating and meeting the religious and spiritual needs of the patient and family. The ICU nurses played a key role in ensuring that requests were made for spiritual care workers, priests, and/or other religious leaders. One participant described an experience where she had discovered, from conversation

with the family, that the patient was a very religious man. Consequently, she got permission from the family to contact a priest to visit, read the patient his last rights, and pray for the patient. It was meaningful to Angela when she brought the priest to the patients' bedside and she prayed with the priest while holding the patients' hand as he lay there dying. She elaborated:

I was really glad that we were there for him at that moment because as soon as we said that prayer. We were probably in there for 20 minutes, like it was the longest prayer ever and just the things she was saying to him...then we said amen and it was almost like...I felt this release of him....it was like I felt his spirit leave after that because his face just calmed and his body...he wasn't tense anymore, he didn't look like he was struggling anymore, he just looked at peace.... she [the priest] basically told him it's okay to just go and I felt like he did.

Spiritual and/or religious experiences were described by some participants as important aspects of a good death but also as very meaningful for the nurses themselves. Some nurses found that when the family had found peace and comfort through either their spiritual or religious beliefs, they (the nurses) themselves were comfortable and at peace with the situation. Tracey felt that when the patient was peaceful, the family was peaceful as well. She described the situation to be as "perfect as death could be." She recalled an experience that had a profound influence on her:

They were very peaceful...at one point the sun came into the room in just this ray of sun right on her, and it was so incredible and they all noticed it and they all commented on how just all of a sudden, this ray of sun came into the room on their mother and wife. It was incredible... it was just this optimal withdrawal [of treatment] where the family agreed she was passing peacefully, comfortably, it was just perfect...she was peaceful. I'll never forget that.

4.3.5 Connecting with families.

Families comprised an integral part of the participants' experiences in providing care to patients within the context of EOLC in the ICU. Nurses described connecting with families as fundamental to creating a good death. Connecting with families required two essential elements: Making time to build relationships and creating a space for family within the ICU. Building and

fostering relationships with families allowed for the establishment of trust and facilitated the creation of a physical space where everyone was more comfortable.

4.3.5.1 Making time to build relationships

Participants explained that time spent with families was about getting to know them, getting to know the patient through them as well as keeping the family informed and involved with the patient's goals of care. Within the busy and often hectic ICU environment, the nurses were readily aware of the need to spend quality time with the patient and their family. When the nurses did not have the time, they expressed having more difficulty with building relationships. Building a trusting relationship with family takes time. In spending time with families, nurses were often silent and spent these moments simply being there and listening to their stories.

Margo explained:

Time allows you to be there for the family and explain things...[but] mostly to be there. I find a lot of times people just want to have someone to listen to them talk about things whether it be about how frustrated they are that things got this way or how happy they were with the lives that they had with the person whatever it is. You know sitting there talking to the people. It makes you feel good and makes you feel you've done your job and it makes them feel understood and they're able to do some of the grieving ahead of time with you as opposed to going home and just dealing with it there.

Participants described their priority as spending time at the bedside getting to know the family and getting to know more about the patient through the family members. Time was spent talking to families about what the patient was like before they became sick and learning about the life they shared together. The participants described these experiences as sometimes emotional, particularly when they really got to know the family members well. Margo expressed:

While we were waiting for the children, we talked about them and their lives and how much he meant to her...I got to know her and she at least had someone there that she could talk to not just about dying but about the life that they had together and you could tell it meant a lot to her, even though she was having a hard time talking about it but it was nice to be involved in their life and get to know him as a person.

The nurses acknowledged and reflected upon the fact that each patient and family was unique and as a result the provision of EOLC was always slightly different. Because of the nature and complexity of critical illness, participants like Sherri explained that since each situation was unique, it was extremely important to avoid a “cookie cutter approach” to care. She noted that because families were all different it was necessary to: “*gauge the family dynamics*”, to evaluate the interactions between family members and learn what information families already had in order to determine what they needed or wanted to know. Sherri would then personalize the information to meet the specific needs of the family members. She added that it was also part of the nursing role to “*give them the information that they want without giving them too much information and burdening them, it’s hard to tell.*”

The benefits of working consecutive shifts assigned to the same patient and family were described by the participants. Having this opportunity provided consistency in care, facilitated communication, and provided a foundation for getting to know both the patient and family well - all of which contributed to building a rapport and connecting with the family. Participants described feeling a sense of privilege when they had already established a good relationship with the family and they were the nurse who was there with the patient when they died. They recognized the importance of the relationship and the comfort it provided for the family. Tracey explained:

When I used to work full time and you're doing that third or fourth stretch...you've got to know the family...you get to know that relationship with the family and you get to be the one, you get to be the person there when their family [member] dies.

The participants described how a good connection or rapport with the family facilitated the transition from curative to comfort care. They discussed families often not knowing what to expect and having misconceptions about EOLC. For example, families had misconceptions that

the withdrawal of life support also meant withdrawal of “care” or that the provision of comfort care, including pain and symptom management, would hasten death. Misconceptions could be addressed by spending time with the family and providing clarification to meet their informational needs. The participants acknowledged that their role was to walk them through the transition from curative to a comfort care focus, and from life to death. Sherri reflected:

It’s really a thinking on your feet type of process because you have to gauge what they’ve been told...what they know, and what more information they need to know about the symptoms that I’m looking for...when I would give them extra medication, why I’m giving them extra medication and to really stress that I’m not giving them medication to make their loved one die, I’m giving them medication to prevent any sort of suffering, we don’t want pain, we don’t want suffering, so looking for those symptoms you know gasping or muscle use or gurgling sounds...and providing privacy, providing education and you are actually showing them that you are taking care of their loved one.

The participants felt the families’ primary concerns at the EOL stemmed from whether their loved one was comfortable and if they were receiving the best care possible. As such, participants like Kathy, encouraged open dialogue with family members that focused on patient comfort. However, in turn, she felt that focusing on patient comfort also strengthened relationships with families and helped to develop bonds with them. Kathy liked to include the family in the patient’s care by asking about their comfort. She explained:

I like asking... "Do you think your family member; do you think your father looks comfortable right now?" ...I often ask that throughout the whole process ...you definitely want to make sure you have that relationship because family members have a lot of say in terms of what's going on during the process so it's good to have those questions come out and make sure that they feel that their loved one is comfortable.

Furthermore, one participant emphasized that connecting with the family also allowed the nurses to encourage the family to take time for, and care for themselves and each other. Sherri explained: *“I did my best to show the family that not only do I care about their loved one in the bed, I care about their well-being.... I try to get them to take care of each other and to take care of themselves.... I try to tell them that it’s a rollercoaster, that there’s back and forth steps....*

they have to remember to take care of themselves because it often is a very long process.” Sherri would remind the family to support each other and that there was no right or wrong way to grieve. She described how sometimes families needed that reassurance to enable them to let go of any anger or stress from home in order for them to focus on their loved one.

4.3.5.2 Creating a space for family

The participants also reflected on how they manipulated the technologically complex ICU environment to create an intimate and personal space wherein families could spend time with their loved one. They personalized the ICU environment to make it more home-like where patients and their families could experience comfort, memories, and final moments. The nurses discussed how private rooms in the ICU helped them to create a space where families could grieve and mourn. If the patient was conscious they could grieve and mourn with their family in privacy. The large, private rooms had enough space for family members to be present at the bedside and closing the sliding doors and curtains allowed for additional privacy and reduced the outside noise. Sherri emphasized the importance of space and privacy: *“Providing privacy [is important] because it tends to be an extremely emotional time and all families deal with it differently, some people argue, some people cry, some people wail.”*

Sherri encouraged families to focus on their loved one and not on the technology by reminding them to remember “the good times.” She would ask about what the patient did for a living and she would tell them about the symptoms they might see. Sherri said: *“I truly try to get them to talk...and reminisce with their loved one or with each other rather than focus on the monitor because it could be minutes, it could be hours, and it could be three days”.*

Participants spoke of creating a space where family could bring in music, pets, and/or photos to create comfort, familiar surroundings, as well as personal experiences and memories.

In this personal space, families honoured their loved one whether it was through playing music, singing, and/or prayer. Margo recalled a memorable experience where she had created an intimate space for the patient and their family:

We'll have some families that will bring in whatever kind of music, some of them its prayer and they'll put their favorite music on, some of them it's even been hard rock. It's nice that they are looking at you know what my mom would have liked or what my dad would have liked...even though they might not be conscious of the fact that it's there...I still believe that people can hear and feel even though they might not be outwardly conscious and you can just think that it's like a gift to them you know.

Tracey described a similar experience:

He brought his guitar in and they sang and they sang while she died...they knew that she loved it when he played guitar, it was really wonderful, it was odd to hear guitar in the unit. But not inappropriate, we just closed the door and they you know played guitar, and talked and reminisced. It was really lovely... they knew her that well and they were that comfortable with themselves that it didn't matter that they were playing guitar while their aunt died, that she would like that.

Creating a good death emerged from participants' descriptions of what was meaningful with the provision of EOLC. The participants described how they created a good death by respecting patients' wishes, providing comfort, being there for patients and families, preserving dignity and peacefulness, and connecting with families. However, while creating a good death was a priority of the participants, they often had to navigate their way through challenges in order to create what they perceived a good death to be.

4.4 Navigating the Challenges

In their stories, the participants reflected on the challenges they experienced that ultimately affected the creation of meaningful experiences wherein a 'good death' was possible. They identified these challenges as being multifactorial and they described how they attempted to navigate their way through them. The challenges that were identified could be clustered under three subthemes: '*Coming in cold*', '*Not connecting*' and '*Not being on the same page*'. The first

subtheme, *'Coming in cold'*, reflected participants not having the time to build a relationship with the family prior to them entering the room to either initiate or provide EOLC. The second, *'Not connecting'*, involved situations when the participants were not able to connect or establish a relationship with the family. The last subtheme, *'Not being on the same page'* represented the challenge of the family, patient, nurses, and/or physicians not agreeing with the plan of care which was commonly due to a lack of communication and/or teamwork.

4.4.1 Coming in cold.

'Coming in cold' described the experience of the nurses stepping into a situation where they were assigned to care for the patient without having a prior relationship with either the patient or their family. The latter posed an immediate challenge because there was no pre-existing relationship, let alone a trusting relationship between the nurse and patient/family. In these types of situations, the participants had to find ways to quickly establish a level of comfort and trust with the family in order to create a 'good death' and meaningfully engage with them. Importantly, as Sherri explains below, these scenarios are not necessarily outliers and can happen frequently in the ICU. Sherri explained:

Often times I come in and it's a family and a patient I don't know. I get report and then I have to say hi my name is and I'm going to be with you this evening or this day and you know it's sort of like the elephant [i.e. unspoken] in the room that your loved one is dying....and you know that they're dying and I'm here to help everybody sort of cope with it and watch what's happening and all that. The hardest is when you don't know the family, you don't know the situation, you're coming in cold...you don't know anything about the patient and internally I feel like sometimes "I'm here to be the person that's going to help your loved one die" which can be difficult...those are the hardest because it's really hard to sort of build that relationship with the family.

A different type of 'coming in cold' was described by one participant as coming in to a scenario where the patient and family had been in the ICU for a long period of time (over several months or even a year) where the family was familiar and comfortable with some of the nurses

and the physicians and they had established several trusting and close relationships. In this instance coming in cold was described as a situation where a nurse had not worked with the patient and family but were assigned to the patient on the day when the decision was made to withdraw life-sustaining treatment. Kathy described feeling uncomfortable and felt like she was being compared to other nurses in the unit who already had a 'good' relationship with the family because the other nurses had worked with the family in the past. She described it as difficult for the family and for the nurses to build comfort and trust quickly especially with a patient/family that had been in the ICU for such a long time. The nature of this difficulty is more about the nurses' discomfort with the situation since the family's perspective is unknown. Kathy elaborated:

If you don't actually have a good relationship with them...if you're just coming on to your shift and you don't know them previously and they compare you to the other nurses they've had so there's already this expectation that comes on to the nurses when they walk in if they haven't seen or been with this patient.

4.4.2 Not connecting.

Some participants found it challenging to create a good death when they did not 'connect' or establish what they perceived to be a good relationship with the family. These types of situations could be perceived as affecting the provision of a good death. The participants explained that some families were more difficult to build a connection with, particularly if there was discord either within the family or between the family and the health care team regarding the patient's goals of care. In other instances, the participants mentioned that some families were more closed off to building close and trusting relationships with the nurses but they did not explain how or why this occurred. With respect to the latter, participants explained that even when they had gotten to know the family, it did not necessarily ensure there was a connection between them. As Margo explained:

Sometimes you just don't feel that connection with the person and sometimes there's no reason, sometimes you know it's just a vibe that they don't get along with you or you don't get along with them. Sometimes it just doesn't click...I guess sometimes it's just hard to build a relationship with people, it might be part of something with me or something with them but sometimes it just doesn't come together.

The acuity of the unit (i.e. busyness of the nurses' work) did not always allow the participants enough time to spend getting to know the patient and the family for whom they were providing care. The participants explained that when the unit was particularly busy, it could be difficult to balance treating critically ill patients who, for example, can have care requirements that extend beyond the normal one to one or one to two nurse-patient ratios. This type of busyness could result in nurses, who were assigned to patients receiving comfort care, to be pulled from their bedside to help their colleagues. As a result, this took away from the time they needed to spend getting to know the family and providing good EOLC and subsequently a good death. As Margo explained:

Time in terms of busyness of the unit...if it's really busy in the unit and someone's critically ill and we can potentially save them, sometimes it does take away from the time where we can sit there and have time to deal with the family.

In the end, not connecting with families often left the participants feeling that they had not done enough for the patient and family despite how hard they had worked. As a result, they did not feel as though they had created a good death for the patient and the family. These situations had meaning but were not associated with positive experiences.

4.4.3 Not being on the same page.

Participants described 'not being on the same page' as situations where there was discord and lack of consensus (i.e. agreement) about the plan of care or goals of care. Ultimately not being on the same page was interpreted by the participants as affecting the creation of a good death. The participants described three different types of scenarios that could contribute to the

sense or even reality of not being on the same page: when the family and the physician were not on the same page, when the health care team were not on the same page with each other, and when the family was not respecting the patient's wishes. The common denominator across all of these scenarios appeared to be lack of communication and teamwork.

The participants described scenarios involving physicians and families where they were not in agreement regarding the plan or goals of care. For example, when the physician had recommended to the family that they start comfort measures, because curative medical treatments and therapies had not been effective, families sometimes wanted to continue with aggressive treatment measures. Kathy explained: *“When the families aren't really in agreement with what the physician has to say about the whole situation sometimes that's a big challenge...if the family isn't in agreement...that this is...the end of the patient's life.”*

Conversely, participants also described instances where the family was ready to transition to comfort care and the physicians were not on the same page. In this type of scenario, the physician and the family were not communicating effectively pertaining to the patient's goals of care. For Angela, the latter led to an experience where she felt the patient died a “traumatic death.” She explained:

The biggest thing is when the family and the doctors and the team, and the patient are not all on the same page...I've had a situation where a doctor may have given them undo hope...that I felt they shouldn't have and I felt like the family was asking to stop doing this, cause the son was saying he wouldn't want all this, why should we keep doing this. And the doctor said, “well I think we should keep going, we should give it a few more days you know, see where he's going” and it just went downhill from there.

Further, ICU patients due to their critical illness, are often left unable to communicate on their own behalf either due to a decreased level of consciousness due to being intubated and sedated for airway management. As such, when a patient is still able to decide his/her own goals of care for EOL, this presents a unique situation in the ICU. Kathy described an experience that

was emotionally difficult for everyone involved because the patient was dying and he could still advocate for himself. The patient wanted to pursue active treatment whereas the physician wanted him to make the transition to comfort care. She explained:

It was probably one of the hardest family meetings because the patient had input. The mother was there and the wife was there but it was the patient speaking for himself and you don't see that very often here because they are all intubated and it's all about the family, but this time it was mainly the patient speaking and telling us that he didn't agree with what the physician was saying so that was hard.

Not being on the same page occasionally occurred during physician hand-over (when physicians and residents hand-over a report about each patient to the new residents and physicians coming on for the next rotation). Ideally during the hand-over, medical information and background information about patient-family dynamics are communicated. However, the on-coming team may have differing perspectives concerning the situation which can result in changing the goals of care. This can be very confusing for the family and may cause conflict among family members as well as a lack of trust in the health care providers. The nurses may have to rebuild that trusting relationship with the family all over again. Tracey explained:

You can have a family who is just about ready to do withdrawal of care, we've got a family meeting tomorrow, that just happens to be the day that the doctors switch, there's two or three of our docs who... [Tracey is quoting the perspectives of two or three different ICU physicians] "oh no I don't know this patient...we're going to continue with this...we're not going to withdraw...we're going to keep going, I'm not going to walk in that meeting, I don't know the patient. There's no reason to withdraw...we can continue the antibiotics; they might pull through this pneumonia yet.

Not being on the same page also occurred when physicians and nurses had conflicting perspectives about goals of care. Nurses spend more time at the bedside than the physicians do and they are often the ones who recognize that treatment is unsuccessful and/or causing suffering before anyone else does. Yet, communication between the ICU nurse and attending physician could be strained. Kathy elaborated:

I find it sometimes challenging if you're not on the same page as some of the residents ...you get a new admission and you're clearly thinking in your head "wow what are we

doing right now, all these tests and all these things and yet we haven't actually talked to the family, we haven't asked them what they want. I know that they're a category one on here but let's re-evaluate all these things." So that's sometimes one of our biggest challenges in terms of for me as a nurse, not just as a unit but in terms of being on the same page. "Is this necessary, does the patient actually want this?"

Lastly, one of the most difficult situations described by participants was when families disregarded their loved one's wishes. Participants described situations where families completely reversed the patients' wishes for comfort care and made the decision to continue with aggressive curative treatment. This was very difficult for the ICU nurses because they wanted the family to respect the patients' wishes and this led nurses to providing care that they felt was unethical. When family members were divided in their opinions about the patients' wishes for EOL, it could drive them apart. Margo elaborated:

When families don't agree on decisions and that happens quite often.... either that they don't value the decisions made by the person that's dying or just between themselves families sometimes don't get along, they don't see eye-to-eye and it makes it tough. When you know one person is like "oh I totally agree end-of-life should be happening to this person", the other person is very focused on a cure, "I'll just give them one more chance." And it ends up causing rifts between the family and instead of bringing the families together to support their loved one it drives a rift and it just makes it uncomfortable and unhappy and makes it a terrible experience for everyone.

The participants identified the challenges of coming in cold, not connecting, and not being on the same page as affecting the creation of a good death.

4.5 Making it Work

Despite the identified challenges, nurses described how they navigated their way through these challenges and made it work in order to be able to provide a good death by 'Building Relationships', 'Taking Care' and 'Recognizing it as a Privilege'. As the participants navigated through these challenges they reflected on their role as ICU nurses and ultimately derived meaning from their nursing work and in the end continued to strive towards the creation of a good death for dying patients and their families.

4.5.1 Building relationships quickly.

Participants described situations where they were coming in cold to provide EOLC and they portrayed these types of experiences as awkward and uncomfortable. However, despite these situations being recognized as challenging and awkward, the participants worked towards establishing relationships and trust with the family as quickly as possible. Sherri explained:

You have to build that relationship very quickly and whether they know my name doesn't matter. All they know is that there was a nurse there that provided care and made them feel safe, that's all that matters to me at the end of the day.

Participants described meeting the family where they were at and providing the information they needed. Sherri explained that she would “feel it out with the families” by finding out what stage they were at in the end-of-life process and then she would provide them with the information they needed accordingly. She would “gauge” families to assess the situation and find out if they were ready for the next step or if they were not ready to accept their loved one dying. Sherri would try to be perceptive by determining what works best for the family, for example, if the family wanted continuous nursing presence at the bedside or if they needed more privacy. She described how she would ask the family what they needed to know about the dying process (i.e. what they knew about symptoms) and she individualized the information to meet their needs, while trying not to give them too much information that it would burden them. Providing the family with information and showing she cared about their loved one helped to foster and build relationships in less than ideal situations. She elaborated on working with families that she did not know well: *“I try and assess where they are...the ones that are the hardest [are] the ones that are really angry that this is happening...but trying to show them I care about their loved one.”*

4.5.2 Taking care.

In analyzing the interview data, it also became apparent that whether the participants were caring for patients and families in the most ideal situations or not, they were cognizant of the need to care for themselves to manage the challenges. '*Taking care*' described how self-care enabled the participants to continue to work in and through difficult situations. The participants described the various ways in which they would care for themselves including taking care of their mental health, grieving with the family, practicing religious beliefs, being supported at home, receiving support from colleagues, and/or self-reflection. Amy explained different ways that nurses could take care of their mental health to provide better care for dying patients:

In order to take all this stuff from all these challenges, nurses need to take care of themselves and if it's necessary we can ask for counseling, we can talk to the clinical manager, and outside the job we can meditate. We can have a good life, we can read books, we can forget that we are nurses for a certain period of time until we come back and then it's easier or take stretches and not work overtime....we need mental health. We can do whatever it takes outside of work not to think about our patients and the challenges we have and [when] we have stretches, days in between our shifts, then it's easier to come back and take care of...a dying patient... we are more patient to give explanations, to use our professional knowledge.

Participants described situations where they allowed themselves to become emotionally vulnerable at the bedside in front of patients and families. They allowed themselves to grieve for the loss of the patient and demonstrate compassion for the family through the sharing of sentiments and by crying with the family. This was how some participants coped with death and dying. Sherri, who had the most experience out of all the participants, had witnessed a high number of deaths in the ICU and she still allowed herself to become emotionally invested in the patient and family. She expressed her feelings and emotions explicitly at the bedside. Sherri referred to the fact that some nurses become "stone cold" where they become more task

orientated and don't allow themselves to open-up and become emotionally invested. She took care of herself so she would not become "stone cold." Sherri explained:

There are times where there's so much emotion in a room that you can't help but be emotional. And I'm one of those nurses who I'm not afraid to cry in front of families...if I have to wipe a tear, I have to wipe a tear. I think that shows that I'm not stone cold yet, that I still have that part of me that this is a person.

Other participants spoke of how they would navigate the emotional challenges associated with providing EOLC by bringing it home with them. Those participants discussed how important it was to receive support from their own family to help them manage the challenges of witnessing so many deaths. Tracey described her personal experience:

I think when you see so much dying as we see here...the way you see dying is different. It's heartbreaking but I guess there's a little broken part of me that is able to leave it here [at work]. For years and years, I [would] go home and I have my husband, he's a big guy...and I'd sit on his lap and sob... I think to survive in an environment where there is so much death you do have to have perspective or you [would] burnout.

Having support from colleagues also played a role in helping the participants navigate the challenging aspects of providing EOLC. Kathy had experiences that she described as "difficult deaths" and she readily acknowledged how important it was to her to have emotional support from her colleagues. She explained:

That's my job...I go in to work and I see patients passing away on...a daily basis so it's been a great help and a great support to be able to have them [colleagues] around me and to help me go through this cause it's not easy...we do debrief between each other at work after all that, we do talk about it at work because you have to, that's how you're able to let go and that's our main grieving ways here as an RN, you just debrief with your peers and your co-workers and they help you through it.

None of the participants mentioned that they felt a need for more education and training in EOLC. They were confident in the care they provided and when the patient was dying comfortably, peacefully and with dignity, they felt like they had done a good job and made a

difference for patients and families. The participants described learning from experience and becoming the “specialists.” Amy elaborated:

Nurses in ICU are not specialized in end-of-life care.... we don't get training for end-of-life but we learn to do it so well in collaboration with everybody else who's involved that.... we are the specialist in giving the end-of-life care but we actually don't get courses, we don't get refreshers, we don't get anything, we just do it and we do it well, we do it very well.

Some participants also reflected upon their own spiritual and religious beliefs which helped them to manage the challenging aspects of experiencing death and dying within the ICU. The participants described having a belief in something facilitated the provision of EOLC. For Tracey, her religious beliefs were an important aspect of how she managed with seeing so many deaths. Tracey expressed her thoughts on her religious beliefs: *“Part of me being Christian....is to just believe it's going to be a whole lot better...having a higher power whatever it is, whatever it is for you. I think you have to believe in something outside of here.”*

The process of self-reflection and being introspective about their experiences also helped the participants to learn things about themselves and become more aware of the way they provided EOLC. Amy talked about how she could imagine herself in the place of her patients at the EOL and she explained that while these thoughts were difficult to experience, she reflected on her own death and dying and her wishes for EOL. However, she did not elaborate further on what her personal wishes were. Other participants, like Margo for example, spoke openly about what it meant to her to witness patients being honoured by their families. She described an experience where the family had brought in members of the community and they performed a cultural ceremony with music and dancing in honour of the patient. She reflected: *“I hope that for my own life, I hope that...people that love me will support me and honour me in the same way that they get honoured.”*

Similarly, Tracey described herself as being very self-aware of her personal thoughts and feelings about EOL. She knew what her own wishes were and she was also aware of her family member's wishes. She stated that she always tried to treat her patients how she would want herself or her family members to be treated. She reflected:

I think I have perspective...I appreciate everything I have in my life more because of it. I know exactly everybody's wishes in my family...should they ever be in the situation, I know exactly what each one of them would want and where to stop and my family knows that...I think to survive in an environment where there is so much death you do have to have perspective or you [would] burn out.

'*Taking care*' illustrated how participants took care of themselves to be able to manage the challenges associated with death and dying in the ICU. When the nurses took care of themselves they could function better both professionally and personally. Some participants described it as part of their job to care for themselves and when they did they were more capable of creating a good death for patients and families and in return they had meaningful experiences.

4.5.3 Recognizing it's a privilege.

Ultimately, the participants reflected upon how the provision of a good death and working with patients and families, despite the challenges (e.g. coming in cold, not connecting and not being on the same page) was both rewarding and a privilege. While it was noted to be both difficult and demanding work, they navigated these challenges to provide optimal EOLC and to be able to ascribe meaning to their work. Tracey described: "*Sometimes I feel...privileged to be a part of it. I mean it's a pretty intimate part of somebody's life, their death.... for the patient and the family...a really big part of that is a privilege. The better I can make it for them. It can be hard.*"

The participants discussed how they enjoyed certain aspects of providing EOLC such as supporting families, building connections with families, and ensuring patient comfort. They

embraced their role of providing EOLC and described being satisfied with their job, despite being faced with many deaths. Sherri described providing EOLC to a high number of patients: *“I’ve participated and provided end-of-life care to easily 20 to 25 people a year or so...plus lots of other...[they] weren’t my patients but I was around so it happens...it’s...part of my job.”* ICU nurses have unique opportunities within their role to have an impact on the last moments of patients’ lives and help facilitate memorable experiences for the families. When the family thanked them for the care, the nurses knew that they had made a difference with the care they had provided. Participants described intimate moments with families that were emotional and memorable for them and they perceived it to be memorable for the families as well. Amy recalled:

These are moments you never forget, when the daughters...just lost their mother and they come to the nurse and they will hug the nurse and say thank you for the care you gave and my mom died peacefully and we are happy. These are sad moments and you have tears in your eyes and they are happy that their mom is in a better place and I remember the family specifically.

Sherri revealed: *“They [family] came back in, they stayed with their loved one for a while, had some more tears, some more laughs and I got a big wet, slobbery hug and kiss from everybody in the family...it was a privilege to bear witness to.”*

Recognizing it’s a privilege was how participants could navigate their way through the challenges. They described experiences with EOLC as ‘rewarding’, ‘meaningful’, ‘a privilege’, ‘a gift’ and ‘an honour’. Tracey elaborated: *“I generally find it rewarding...you get to know that relationship with the family and you get to be the one, you get to be the person there when their family dies.”* Margo was tearful during the interview describing an experience where she felt honoured and privileged to witness a final moment at the EOL. She reflected:

He [the husband] said “I just wanted some time to see the woman that I love for the last time and...how beautiful she was.” It still makes me tearful cause it’s just pure

love...everybody wants that for themselves in life...he went up to her and kissed her and gave her a hug. It was just really touching you know?

Chapter 5: Discussion and Implications

5.1 Introduction

This chapter provides a discussion of the study findings integrated with relevant literature. The implications for Advanced Nursing Practice will also be discussed within the context of EOLC in the ICU. Recommendations for future research are provided as well as the limitations of this study.

The research question that led this study was, *what are ICU nurses' meaningful and gratifying experiences with providing end-of-life care in the context of the ICU?* The answer to this question was found within the comprehensive exploration and understanding of nurses' lived experiences. At the outset of the study, it was unknown what the participants would perceive as meaningful with respect to the provision of EOLC. The use of unstructured, open-ended questions allowed for the participants to tell their stories and speak liberally about what it was like to provide EOLC for patients and families. A constructivist lens was used to help guide this study, which acknowledges that multiple realities exist and that individuals create their own subjective realities (Guba & Lincoln, 1994). While participants were reflecting on past and present experiences with EOLC, they were constructing an account of their experiences. Their stories were windows into everyday nursing actions, experiences, skills, values, and beliefs (Benner, 1984) and revealed that what was meaningful to the participants was providing a good death for patients and families.

5.2 Making a Difference – The Essence of Nurses' Experiences Providing EOLC

The essence of ICU nurses' meaningful experiences with providing EOLC was 'being able to make a difference'. There were many reasons why the nurses could keep coming back to their role day after day, despite being faced with many challenges. The participants worked

through these challenges and ultimately felt comfortable and confident in their provision of EOLC. They perceived EOLC to be ‘good’ when patients’ wishes were respected, good pain and symptom control was provided, when families and the health care team were on the same page, and when the participants provided dignified care. Participants’ perceptions of having made a difference in the provision of EOLC for patients and families created meaning for these ICU nurses.

5.3 What is Meaningful?

The participants did not explicitly explain or define ‘meaningful’, however, it was the language used by the participants throughout the interviews. The findings of this study clearly demonstrated that caring for patients and families at the EOL was not only an important aspect of ICU nursing practice, it held meaning for the participants. The participants illustrated what was ‘meaningful’ to them by describing how they created good deaths within the context of the ICU. Studies by Bratcher (2010) as well as Silva and colleagues (2015) have highlighted how ICU nurses have defined and perceived what constitutes a good death. Some of the same elements were echoed in this current study: providing dignity and comfort, respecting patients’ wishes, good communication between families and health care providers, and building relationships with families. However, the current study went beyond simply listing what constitutes a good death – it ultimately explored how nurses actively participated in this experience of working towards the creation of a good death in the ICU. This current study also revealed how these ICU nurses connected the creation of a good death as a meaningful experience. The researcher has attempted to explicitly explore nurses’ meaningful and gratifying experiences and to overtly describe them with respect to EOLC in the ICU. This study has moved our understanding beyond previous research like that of Vanderspank-Wright et al. (2011) in that it has purposefully explored the

perceived privilege of providing EOLC. Importantly, however, this study does not disregard that participants also described difficult and challenging experiences – challenges affecting the provision of a good death in the ICU continue to be a reality in this clinical context.

Meaningful practice for nurses is developed over time by acquiring a nursing identity that is comprised of both personal and professional experiences (Fagermoen, 1997; Malloy et al., 2015; Pavlish & Hunt, 2012). According to Fagermoen (1997), “professional [nursing] identity refers to nurses’ conception of what it means to be and act as a nurse; that is, it represents his/her philosophy of nursing” (p. 435). The “development of the professional identity of nurses could be understood as professional and personal growth in caring, which implies moral maturity” (Ohlen & Segesten, 1998, p. 726). Nurses’ values and beliefs guide their practice and become part of their professional nursing identity (Fagermoen, 1997). Their nursing identity and how they find meaning in their work (i.e. through establishing relationships, providing compassionate care, feeling passionate about their work, and being mentored) continues to evolve over time (Malloy et al, 2015).

When nurses decide to work in the ICU, they eventually become part of the ICU team and develop their own nursing identity by learning the language used in the ICU and developing knowledge and an experientially based practice (Vanderspank-Wright, Fothergill-Bourbonnais, Toman, & McPherson, 2015). Once they are socially integrated as part of the ICU team, they develop a level of competence and experience that can allow them to understand meaningful practice (Vanderspank-Wright et al., 2015). Nurses’ meaningful practice is derived from developing relationships with patients, families, and colleagues and from providing compassionate care (Fagermoen, 1997; Malloy et al., 2015; Pavlish & Hunt, 2012). Malloy et al., (2015) stressed the significance of nurses’ connections with colleagues in order for meaningful

practice to occur. When nurses discovered meaning in their work, it also facilitated them managing stressors (Malloy et al., 2015). In the current study, while it was evident that nurses valued the development of important relationships with patients and colleagues, the nurses recognized the meaning and importance of relationships formed with the families. Relationships were created through spending quality time with families, providing them with information, support, and showing the family that they were caring for their loved one. Pavlish and Hunt (2012) support the finding that when nurses have the time to be with family, they listen and learn more about them. The participants in the current study described how they provided care for the families of dying patients. When family members have recognized nurses for their work, it has also been associated with meaningful practice (Pavlish & Hunt, 2012). In this current study, participants described being acknowledged by the family for the work they did through kind words, hugs, kisses, and cards - participants described these as moments they will “never forget”.

While participants readily described experiences that they identified as *meaningful* they did not refer to or use the term *gratifying*. To understand why this had occurred, the participants were asked in follow up interviews why they chose to focus solely on the term meaningful. The participants expressed that gratifying was a problematic word. They felt it was not an appropriate word to describe their experiences of caring for patients and families at the EOL and was associated too closely with being satisfactory and feeling better about themselves for a job well done. It was problematic because while a good death may be provided, they did not feel happy about providing EOLC. The term meaningful on the other hand reflected what they do, being able to make a difference, providing meaning, and making connections with family. The ‘meaningful’ experiences were also described as ‘positive’, ‘rewarding’, and ‘a privilege’ by some of the participants – but these descriptions were not associated with self-gratification or

happiness. Thus, this study sheds light on what was meaningful (and not gratifying) for the nurses, which revealed how nurses create a good death in the ICU.

5.4 Creating a Good Death

The ideal of a ‘good death’ has not only been socially constructed more broadly within various healthcare landscapes, but it has also been constructed by nurses in the ICU. Personal influences often shape nurses’ perceptions of a good death such as core values, beliefs, religious views, cultural influences, and worldviews (Silva et al., 2015). Attributes of a good death have been identified as providing safe and dignified care, relief of pain and suffering, providing emotional support, respecting patients’ goals, and communicating with the family (Bratcher, 2010; Silva et al., 2015). Nurses’ insights into what constituted a good death were not always made explicit in the literature. In the current study, when participants were asked to share stories about their meaningful experiences, they explicitly spoke of what they perceived to be a good death and described how they provided it in the ICU. This study makes explicit how nurses create good deaths in the ICU through communication and team work, ensuring patient comfort, spending time with families, being there for patients/families, and creating a space for families.

5.4.1 Communication and teamwork.

Good communication and teamwork are necessary in all settings of nursing practice, and particularly within the context of EOLC in the ICU. Participants in this study recognized the importance of teamwork and communication between patients/families, nurses, and physicians. According to the CACCN (2009), communication is an essential element of EOLC and every patient/family member has a right to have clear and concise information. In this study, the participants spoke of how they wanted to ensure they provided family members with the information they needed in a manner that was clear, concise and could be easily understood.

They were also confident in educating family members about what to expect regarding the withdrawal of life-sustaining treatment, what the dying process might look like, and other information pertaining to families' needs. The participants described how good communication was required in all aspects of nurses' practice with the provision of EOLC: building relationships with families, patients' wishes being respected, being there for patients, providing comfort for patients, and nurses supporting each other. This finding echoed similar results in a study conducted by Cook and Rucker (2014) and a literature review by Efstathiou and Clifford (2011) where good communication during the provision of EOLC was associated with family satisfaction and good patient outcomes. When there was clear communication between family/patient and members of the health care team, it facilitated everyone getting on the same page with patient's goals of care – essentially, it implied teamwork in creating patient's plan of care/goals of care.

Participants described good teamwork as collaboration between nurses and physicians and with other members of the health care team (social workers, chaplains, spiritual care, and others) as well as patients and families. The nurses in this study identified their role as 'mediator' by relaying health care information back and forth between the physicians and the family. Nurses have often been the first ones to acknowledge the patient was dying and would facilitate communication between the health care team and the family so that discussions might begin around a transition to comfort care. The transition to comfort care can be challenging with conflicts arising between the family and the health care team, therefore, communication and teamwork are essential. In the hospice context, Wright (2012) conducted an ethnographic study on exploring delirium and the good death. In his study, hospice caregivers used the same language of "getting (family) on that page" (Wright, 2012, p. 145) as ICU nurses used in this

current study. It was evident that communication was of equal importance in both settings and when everyone was on the same page with patient care, it made good deaths possible in both settings.

When good communication does not occur between physicians and nurses, teamwork becomes fragmented. Ineffective communication has been acknowledged in the literature as a barrier to nurses providing a good death. The participants in Weinberg, Miner and Rivlin's (2009) study, for example, attributed challenges with nurse-physician communication to their different styles of communication, the lack of time they spend communicating with each other, the absence of understanding regarding their different roles, and not always sharing information with each other. As previously mentioned, nurses often initiate communication regarding EOLC including initiating family meetings, however, they are still not always included by physicians in the family meetings or EOL discussions (Baliza et al., 2015; Weinberg et al., 2009). In this current study site, nurses often mentioned initiating family meetings and EOLC discussions but this is not consistently reported in the literature and across contexts. Despite these identified challenges with communication, some physicians do respect the information that nurses provide and they want to increase the amount of time they collaborate with nurses and become more inclusive of them in EOL discussions (Weinberg et al., 2009). End-of-life decision making should be prefaced by both good communication and teamwork and, as such, needs to include the perspectives of both physicians and nurses for optimal patient care (Hamric & Blackhall, 2007). In this current study, some participants described being included by physicians as active participants in family meetings during EOL discussions. Participants found it meaningful to engage with other members of the team as well as the family. Positive work environments can

foster nurses' satisfaction and confidence in their work and can contribute to optimal patient outcomes (Malloy et al., 2015; Pavlish & Hunt, 2012).

Discrepancies arose in the decision-making about patients' goals of care that involved families, nurses, and intensivists. Sometimes goals of care were re-examined with the change-over of the ICU intensivists. The participants described how this affected their work of building trust with families. Families in this situation might start to question the motives of the physicians as well as other members of the health care team. Participants spoke of how they had to start over with establishing a relationship with families to gain back their trust and confidence. This was also a finding in Vanderspank-Wright and colleagues' (2011) study, where intensivists changing over was perceived to affect the patients' plan of care and as a result, weakened relationships and trust between families and health care providers.

5.4.2 Promoting patient comfort.

Facilitating comfort for the patient through pharmacological and non-pharmacological means was an important aspect of creating a good death. The nurses described the ICU comfort measures protocol as a facilitator to providing physical comfort and pharmacological management in the creation of a 'good death'. Protocols and guidelines helped to guide nurses on procedures related to the withdrawal of life support. Jensen, Ammentorp, and Ording's (2013) study found that protocols and guidelines improved EOLC through enabling quicker decision making by nurses with the provision of comfort for dying patients. Quick decisions can be made by referring to the protocol when deciding which medication to use and the appropriate dosing to treat patients' symptoms. In this study, the nurses described the protocol as having the necessary tools to evaluate symptom management strategies and help make decisions to provide patient comfort and alleviate distress. Downar and colleagues (2016) recommended that all ICUs should

use protocols for the withdrawal of life-sustaining therapies because they can increase the quality of EOLC provided to patients and families. These protocols do not preclude addressing the specific patient situation. According to Mark, Rayner, Lee and Curtis (2015), there is an absence of policies on EOLC as well as a high level of inconsistency in the withdrawal of life-sustaining treatment across countries, between ICU health care providers, and in different ICUs.

This study found that some participants experienced discomfort with the ICU comfort care protocol when it came to extubation. The protocol indicates that patients should be weaned off oxygen and extubated; however, it is usually at the discretion of the physicians and should be discussed with the family. One participant believed that all patients should be extubated because it is cited on the ICU comfort care protocol and that keeping the patient intubated could prolong death unnecessarily. She described situations that occurred where families were not informed of the possibility of extubation. Even though extubation might not be appropriate in some circumstances, this participant felt that families should be provided with all the information necessary, including the decision to extubate. Another participant held the belief that patients should remain intubated for the appearance of comfort for the family because if the tube were removed, the patient may have the appearance of dyspnea (respiratory distress) and discomfort. She felt that patients' breathing usually 'looked terrible' once they were extubated and it caused families undue discomfort and distress. These differing views raised the question 'should the nurse prioritize the needs of family over patients' own needs?' In other words, should the decision to extubate or not be based solely on patient comfort or comfort for the family? This question requires further exploration. Efstathiou and Ives (2017) study, in a secondary analysis of ICU nurses' experiences of treatment withdrawal, also found that there was a question of nurses considering the family's needs and comfort over the patient's.

Papadimos, Maldonado, Tripathi, Kothani and Rosenberg (2011) who explored patient issues with EOLC in the ICU, found that there was no right or wrong way when it came to the protocol with regards to extubation; the patient could either be kept on the mechanical ventilator with the oxygen being weaned or they could be extubated. The participants in the same study described one of the key aspects being the discussion of these options with family with the goal of reducing patients' suffering and promoting comfort. Downar and colleagues (2016) also supported and recommended that family members and patients (where possible) be informed about the withdrawal of life-sustaining measures including what the dying process might look like with physical symptoms they might see and how patients' symptoms will be treated. Downar et al. (2016) recommend that the withdrawal of life support goal is for comfort and that each case should be personalized.

5.4.3 Spending time with families.

In this study, participants described spending the time to establish trusting relationships with families as a necessary component in the creation of a good death. They portrayed relationships with families as a central aspect in the provision of EOLC and described how they built upon those relationships. The nature of those relationships helped to foster comfort for families and nurses alike. Many studies have found that nurses establishing a trusting relationship with family can lead to good patient outcomes in the ICU (Ciccarello, 2003; Efstathiou & Walker, 2014; Fridh, 2014; Vanderspank-Wright et al., 2011). When nurses had the time to really connect with families, they did so by listening, talking, and simply being present at the bedside. In a study by Kirchhoff and Kowalkowski (2010), they suggested that staffing should be arranged to accommodate nurses so they have only one patient when they are

providing EOLC and this would allow nurses more quality time to spend with patients and families.

Additionally, in the current study, participants described that continuity of care occurred, with nurses being assigned the same patient over several consecutive days/nights. Several studies have identified how continuity of care during EOLC also helps to foster relationships between nurses and families (Efstathiou & Clifford, 2011; Truog et al., 2008; Vanderspank-Wright et al., 2011). It allowed nurses more time to spend engaging with families and providing compassionate care. Continuity facilitated the provision of EOLC for nurses and was perceived by nurses to have increased family satisfaction during the dying process. While several studies have identified the importance of the nurse-family relationship for the provision of EOLC, this study has made explicit the establishment of the nurse-family relationship as a significant component of how nurses create a good death in the ICU.

5.4.4 Being there.

For the participants, being there was about how they were present at the bedside and how they communicated with dying patients and their families to create a good death. Some participants described being there as part of a sense of obligation and duty to patients while they were dying. Being present and making the time to listen and get to know the family is important for establishing a connection with the family (Ciccarello, 2003; Fridh, 2014). Finfgeld-Connett (2006) described presence as “an interpersonal process that is characterized by sensitivity, holism, vulnerability, and adaptation to unique circumstances” (p. 710-711). In this current study, participants used nursing actions such as holding the patient’s hand, praying with patients (when they were religious), talking to them about everyday matters, and providing them with reassurance. The use of touch in EOLC was a major finding in Hov and colleagues’ (2007)

study. In their study, the participants described in detail how they used non-verbal communication (with their hands-on patients' bodies) to demonstrate safety, dignity, comfort, and compassion to dying patients (Hov et al., 2007). Being present also supported families. Nurses in the current study supported families by letting them know there were different ways of being there. For example, one participant encouraged family members to talk to and touch their loved one in the bed. She provided support to families through reassurance and validation with the decisions they made whether it was being present in the room with their loved one or not being there because it was too difficult.

Some of the participants felt strongly that family members should be present and they experienced discomfort when the family could not be there. One participant described herself as having a *heavy heart* when the family could not be present because *she* preferred them to be at the bedside. When the family could not be there, the participants were present with the patient and they described it as meaningful. All the participants shared the belief that 'nobody should die alone'. The literature supports nurses' perceptions that patients should not die alone, thus, nurses are often present when patients are dying (Bach et al., 2009; Beckstrand et al., 2006; Bratcher, 2010; Efstathiou & Walker, 2014; Fridh et al., 2009; Hov et al., 2007). However, Finfgeld-Connett's (2006) study, found that some patients did not want the presence of a nurse and in those circumstances the nurses respected their wishes. The participants in the current study did not mention any situations in which patients were not accepting of their presence, however, in some cases patients were described as unconscious and would not have been able to communicate their wishes. The findings in this study raise awareness that nurses should be vigilant that they are not imposing their beliefs and values in situations where they might not be accepted or shared by the patient/family. As such, there is a need for further exploration into

whether nurses' perceptions of a good death are congruent with patients and family members' perceptions of a good death.

5.4.5 Creating a space for families.

The participants created a space that was more aesthetically pleasing and home-like for the family by manipulating the ICU environment to make a space where the family could mourn, grieve, and have cherished private moments with their loved one. Participants in the current study discussed families bringing in music, pets, and photos to make special memories. Several research studies have supported the intervention of nurses modifying the ICU environment to create a space that generates comfort and peace for the family/patient and one that fosters positive memories (Arbour & Wiegand, 2013; Bratcher, 2010; Efstathiou & Ives, 2017; Pattison, Carr, Turnock, & Dolan, 2013; Ranse et al., 2012). Ranse and colleagues' (2012) study suggested that altering the ICU environment can help facilitate meaningful end-of-life experiences for patients and their families" (p. 10). When the participants removed the technological equipment from the room, it allowed for a more 'natural' death to occur (Efstathiou & Ives, 2017). Johnson, Cook, Giacomini and Willms (2000) also found that removing the technology promoted a more natural death and one that was "more dignified and aesthetically pleasing" (p. 284). In the current study, participants felt they had made a difference for patients and families by creating a space wherein a good death could occur. The nurses removed the technology and equipment in order to make the patient appear peaceful and more aesthetically pleasing for the family and to show them that they were still providing care for their loved one.

Nurses in the current study were all experienced nurses ranging from 4 to 23 years ICU nursing and they were competent with EOLC. They described their experiences of the 'good'

nursing care they provided to patients and their families in the ICU and spoke minimally about the technology. The participants in this study had achieved a level of comfort and experience whereby they were able to prioritize caring over technology. Taking away the technological equipment of the ICU created comfort for families, patients, and the nurses alike and restored patients' dignity. This study makes it explicitly known how the participants created good deaths in this clinical milieu.

5.4.6 A palliative approach to care.

A joint position statement created by the Canadian Nurses Association, the Canadian Hospice Palliative Care Association, and the Canadian Hospice Palliative Care-Nurses Group (2014) defines a palliative approach to care as: “using palliative care principles (i.e., dignity, hope, comfort, quality of life, relief of suffering) with people facing chronic, life-limiting conditions at all stages, not just at the end of life. It reinforces personal autonomy, the right for persons to be actively involved in their own care and a greater sense of control for individuals and families” (p. 2). The palliative approach “does not link the provision of care too closely with prognosis”; rather, it focuses (more broadly) on “conversations with [people] about their needs and wishes” (Stajduhar, 2011, p. 10). The Way Forward is an initiative managed by the Canadian Hospice Palliative Care Association (2014) who recognized the need for a palliative approach to care across all health care settings because of the ever-increasing complexities of patient illnesses, ageing populations, and patients with limited access to hospice palliative care. Patients have a need to access palliative care services earlier on in their illness trajectory and not just at the EOL or only in palliative care settings (Canadian Hospice Palliative Care Association, 2014). A palliative approach to care can improve patient symptoms, decrease caregivers stress, enhance patient quality of life, increase patient satisfaction, decrease the number of patients being

hospitalized, and reduce the amount of unsuccessful treatments being used in the ICU (Canadian Hospice Palliative Care Association, 2014). Critical care literature has identified the main challenge to implementing a palliative approach to care in the ICU as the curative culture of this clinical setting (Canadian Hospice Palliative Care Association, 2014; Papadimos et al., 2011; Truog et al., 2008; Zomorodi & Lynn, 2010).

5.4.7 A palliative approach to care in the ICU.

This study affirms that a palliative approach to care already exists and the participants in this study felt they had the knowledge and competence to provide good EOLC and a good death – these nurses provide care that 1) meets critical care competencies and 2) readily embraces and enacts a palliative approach to care. While they do have to navigate through some challenges to provide a good death, these challenges are some of the same challenges that nurses face in other areas of practice. According to the CNA, CHPCA, and CHPC-NG (2014), management in different health care settings (including ICU's) need to promote and support an environment that fosters a palliative care approach to care, yet, as this study portrays, the ICU environment is already supporting this approach. Educational opportunities can help nurses to recognize, reflect, and articulate the connections between what they already do and the values of a palliative approach.

5.4.8 A supportive environment for meaningful practice.

Pavlish and Hunt's (2012) study found that the support of colleagues and the work environment contributed to meaningful practice. According to the participants in Pavlish and Hunt's study, meaningfulness could occur if nurses had quality time to spend with patients, good teamwork and communication, good management, and an environment that facilitated learning. The conditions of nurses' work environments were also important for fostering relationships and

connections for improved patient outcomes and collaboration among health care providers (Malloy et al., 2015; Pavlish & Hunt, 2012). When nurses had favourable work environments, they demonstrated engagement in their work, they experienced job satisfaction, and positivity (Pavlish & Hunt, 2012). Nurses' work was described as difficult and stressful at times, however, meaningfulness facilitated their work and created a positive outlook on their nursing practice (Malloy et al., 2015). If nurses are not able to engage with EOLC meaningfully then they are at risk for reduced levels of job satisfaction, decreased engagement in their work, and decreased quality of patient/family care (Pavlish & Hunt, 2012).

5.4.9 EOLC is rewarding and a privilege for nurses.

Despite having to navigate through challenges, the participants in this study recognized caring for patients and families at the EOLC as rewarding and a privilege. The participants knew they were in a unique and privileged position within their nursing role to share in and have an impact on patients' (and their families) final moments of life. They described doing the best they could with providing good EOLC and creating a good death, and when they did, they felt like they had made a positive difference for patients and families. The participants described their actions of fostering the creation of a good death as being a privilege - when they made emotional connections with families, when they were present for patients, when comfort was provided, when they could respect patients' wishes and when they created a space for families. Other studies have also likened nurses' perception of the provision of good EOLC to being a privilege in the ICU (Calvin et al., 2007; Fridh et al., 2009; Ranse et al., 2012; Vanderspank-Wright et al., 2011). This was also a finding in a study by Oliveira and colleagues' (2016), where participants working on a medical unit described their experiences of providing EOLC to patients and families as a privilege. Wright (2012) found that hospice caregivers described feeling privileged

by creating what they (the caregivers) perceived to be a good death as well as being part of such an intimate and emotional time with patients and families. The hospice caregivers portrayed feelings of pride and satisfaction with their work of helping patients and families at the EOL (Wright, 2012). These studies (Oliveira et al., 2016; Vanderspank-Wright et al., 2011; Wright, 2012) revealed that nurses across different health care settings have described feeling a sense of privilege with the provision of EOLC for patients and families. This study reinforces that ICU nurses' meaningful EOL practice is rewarding and a privilege.

5.5 Implications for Advanced Nursing Practice

Graduates of the Masters of Science in Nursing program at the University of Ottawa are prepared to function as advanced practice nurses. Therefore, the relevance of the findings for this study are discussed in this section as they apply to nursing practice, education, and research within the context of advanced nursing practice. The Canadian Nurses Association (2008b) defines advanced nursing practice as “an umbrella term describing an advanced level of clinical nursing practice that maximizes the use of graduate educational preparation, in-depth nursing knowledge and expertise in meeting the health needs of individuals, families, groups, communities, and populations” (p. 9). According to the Canadian Nursing Association (2008b), there are five core competencies: expert clinician, leadership, consultation/collaboration, research, and education.

5.5.1 Expert clinician.

The findings of this study emphasized how experienced critical care nurses are pivotal to the provision of good EOLC and the creation of a good death in the ICU. Advanced Practice Nurses (APNs) are expert clinicians and can engage with critical care nurses and nursing practice through coaching, role modeling, and acting as consultants. Critical care APNs can link

experienced and novice nurses to improve knowledge and skill related to EOLC. APNs can also participate in the care of patients by assisting nurses with implementing palliative care interventions as well as preventing complications (Canadian Nurses Association, 2008b). They can be a constant resource and source of support for critical care nurses.

Critical care APNs can promote continuity of care by following patients/families throughout their hospitalization from the time of their admission until death or discharge from the ICU. In an environment where continuity of care is important and it is not always possible (with physicians and nurses rotating often), the role of the APN can provide that continuity. The building of a relationship with the family was of utmost importance to the participants in this study. However, APNs can help to increase communication and teamwork by becoming a liaison between the family and the health care team. They can facilitate open dialogues with families where they can collaborate with family regarding, for example, patients' goals of care and advanced care planning. APNs, without having direct patient obligations, may have the time to spend with families to help establish trusting relationships. Kisorio and Langley (2015), found that it would be helpful if a designated person provided support and caring for families of dying patients. APNs could fill this role by supporting patients and families and working with frontline staff during the transition from curative care to comfort measures, developing relationships, assessing family's needs, and educating them.

5.5.2 Leadership.

The leadership role of an APN can include assessing learning needs of nurses, mentoring nurses, advocating for patients and families, and advocating for development of organizational policies. APNs can assess the educational and learning needs of nurses in order to find out what programs or resources they can access to help meet their needs. ICU nurses need more informal

and formal support thus, the APN can facilitate debriefing with other members of the interdisciplinary team (physicians, social workers, spiritual care workers, and other team members) after the death of a patient. APNs can influence organizational policies in order to implement unit rounds once a month with members of the interdisciplinary team to discuss topics about what has been working and what needs to be improved with the provision of EOLC in the ICU.

APNs are mentors and role models to critical care nurses and can provide guidance to nurses in their role with EOLC. They can empower and support nurses to have a voice during interdisciplinary rounds (to be actively involved in discussions and collaboration), with educating patients and families about EOLC, and with initiating family meetings and EOL discussions (to be actively involved in these discussions with families). APNs can work towards affecting change to organizational policies in order to implement regular family meetings starting with admission and occurring throughout the ICU stay, as well as facilitating nurses in being able to attend meetings in settings where this does not currently happen. This policy would support early and continuous communication with patients, families, and health care providers and could help to avoid future conflict and misunderstandings with families in the ICU. Nurses in this current study valued being meaningfully engaged with families and having a voice at family meetings.

5.5.3 Consultation/collaboration.

Another important characteristic of the APN role is acting as a consultant to nursing colleagues and patients/families, and as a collaborator with the interdisciplinary team to enhance EOLC for patients/families. They can be consulted informally by nursing colleagues at the bedside who might have questions or need advice about starting the withdrawal of life-sustaining

treatment. APNs can often identify the need for a referral for patient/family to another health care service such as a social worker, spiritual care worker, palliative care APN, and/or dietician. APNs can promote family-centered care in the ICU by collaborating with the interdisciplinary team on ways to improve and include families in interdisciplinary team rounds as part of a routine practice. They can encourage family members to become more actively involved with interdisciplinary rounds by educating them on the benefits of family-centered rounds and what to expect during rounds. Collaboration can lead to higher quality care and more positive patient outcomes (Hamric, Hanson, Tracy, & O'Grady, 2014).

5.5.4 Research.

An important aspect of the APN role is being actively involved in research. They must be able to “critique, interpret, apply, and disseminate evidence based findings” (Canadian Nurses Association, 2008b, p. 24). APNs can assess current unit practices with EOLC and bring in new knowledge through the identification and evaluation of evidence based practices (Canadian Nurses Association, 2008b). They can present and share knowledge on EOLC through formal routes such as presentations (in-services, journal clubs, staff meetings, conferences, and peer reviewed publications) and informal routes such as discussions with colleagues. APNs can facilitate and encourage frontline nurses to initiate journal club meetings where they can present their own research, other research studies, protocols, and/or guidelines pertaining to EOLC. They can lead the discussions at the journal club meetings and encourage participation, sharing of experiences, and questions from staff nurses. All these activities can facilitate nursing staff in actualizing their nursing care as incorporating a palliative approach.

APNs can become principal investigators to conduct research and/or to support research studies conducted by other members of the health care team to explore interventions to improve

EOLC for patients and families. They can conduct research on whether staff feel supported when trying to help families of dying patients. Another example where APNs could conduct research studies is exploring the communication between nurses and families. Nurses in this current study valued their connection with families. Such studies could help foster an increase in positive and trusting relationships between critical care nurses and families.

5.5.5 Education.

APNs can assist with the development, training, and mentorship of novice nurses and experienced nurses who are new to the ICU. Mentorship programs can be improved with more of a focus on socializing novice nurses into the ICU (Vanderspank-Wright et al., 2015). APNs can explore methods for nurses to help them build stronger social support networks that would offer them support on an emotional level by improving communication skills and connecting as a group. The socialization of novice nurses is crucial in helping them to gain confidence and develop a comfort level to perform as an ICU nurse (Vanderspank-Wright et al., 2015). APNs can be a constant resource and source of support for nurses to bring forth any issues they might have with their socialization into the ICU and/or their nursing practice.

APNs can teach and educate critical care nurses, especially novice nurses, effective ways to manage death and dying and how to navigate challenges that affect the provision of a good death. They can assist novice nurses in building upon personal resources, skills, and confidence to effectively care for patients at EOL. APNs can foster awareness about the Employee Assistance Programs to help provide nurses with assistance and formal counselling if needed. They need to become more involved in influencing and creating policies to promote staff well-being and health. For example, they can work towards implementing a policy that when a patient dies it is mandatory that nurses have some time to themselves (i.e. a break before the next

admission or assignment). APNs can create a safe place for nurses by designating a quiet, private room for nurses to spend time reflecting on situations when they occur. They can work with managers and staffing personnel to implement changes to policies to ensure there are adequate workloads to accommodate the time required for the integration of palliative care and ICU care. This policy would support the philosophy of patient and family-centered care within the hospital.

The role of the APN could help with the promotion and support of a palliative approach to care in the ICU. APNs can support and foster this culture by educating members of the health care team as well as families (and patients if possible) about the palliative approach to care, the language used in practice, and how the nurses are already meeting palliative care competencies.

5.6 Limitations

The purpose of the study was to explore ICU nurses' meaningful and gratifying experiences with providing EOLC for patients and families. The findings of this study may not be transferrable to different types of hospital environments due to the specialized nature of the ICU setting and they may not relate to other types of critical care settings such as the emergency department, the trauma unit, or other ICUs. Nurses who have experience providing EOLC or who were very comfortable and confident with the provision of EOLC may be overrepresented in this study and the sample may not reflect novice nurses in the ICU. Additionally, nurses who do not feel comfortable with EOLC may not have responded to participate in this study. The sample was recruited from one ICU and therefore transferability to other ICUs should be assessed by the research consumer. The sample was made up of female participants only and therefore it did not reflect the opinions of male ICU nurses. Another limitation may have been that the participants were all Caucasian, English speaking. Further research with a culturally diverse sample is encouraged. The study described how ICU nurses provide good EOLC and

create a good death, however, we do not know if it is also perceived as a good death by patients and family members. Future studies will need to be conducted to explore this topic.

5.7 Conclusion

At the outset of this study, it was unknown what nurses would perceive as meaningful and gratifying experiences with the provision of EOLC in the ICU and what a phenomenological approach would illuminate. Phenomenology led me to discover that meaningful EOL practice for nurses was how they provided good EOLC and created good deaths for patients and families in the ICU. The essence of the nurses' experiences was 'being able to make a difference.' When nurses felt like they had made a difference with the care they provided for patients and families, it created meaning for the nurses and it is what kept them coming back to their nursing role day after day. The participants' stories went beyond simply listing what they perceived as a good death to describing how they created good deaths in the ICU. They portrayed how communication and teamwork was a key element to creating a good death because it facilitated getting everyone on the same page with goals of care, building trusting relationships with families, being there for patients and families, providing comfort for patients, and creating an intimate and home-like space for patients/families. EOLC was also described as difficult and challenging work and the participants described how they navigated their way through the challenges that affected the creation of a good death and good EOLC. Despite the challenges, the participants made it work by building relationships quickly, taking care of themselves and recognizing EOLC as rewarding and a privilege. It is important to make explicit that while the specific focus of this thesis is on what is 'good' and 'meaningful' for the nurses, it does not take away from the fact that there is still much work to be done in improving the many challenges nurses face in the ICU for the provision of good EOLC and good deaths to occur.

This study has helped me to reflect on my own nursing practice as a critical care nurse providing EOLC in the ICU and it has changed the way I provide EOLC to patients and families. Since this study, I have become more engaged and compassionate in caring for dying patients and their families. I devote more time (when possible) getting to know families through building emotional connections with them and by getting to know their loved one. I strive to do my utmost to make it a positive experience for families by helping and encouraging them to create positive memories and experiences. I have educated other nursing colleagues on how they are already meeting palliative care competencies with the provision of EOLC in the ICU. Through listening to the participants' stories, I have become more aware of my own values and beliefs about death and dying. I hope that my study will create awareness for other nurses to reflect on their own nursing practice and recognize their personal values and consequences with EOLC. Perhaps it will inspire them to share meaningful stories and experiences with their colleagues of how they provide good EOLC and create good deaths for patients and families in the ICU.

The participants' stories are invaluable windows into the everyday, lived experiences of nurses providing EOLC in the ICU. The essence of nurses' experiences was summed up by Margo: *"you just want to feel that you've made a difference and I think as long as you feel that you've made a difference and you've made things a little bit easier in such a hard situation...you go home and you feel like you've done your job, you've done the best that you can both as a nurse and as a person."* Nurses are the expert providers of EOLC in the unique context of the ICU. They have meaningful experiences with the provision of EOLC for patients and families. This study sheds a much-needed light on how ICU nurses provide good EOLC and create good deaths for patients and families.

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Appendix A: Recruitment Poster (English)

ARE YOU AN RN WHO WORKS IN THE ICU?



Interview Participants Wanted

Hello Nurses;

I am a Registered Nurse in the ICU and a Master's of Science in Nursing student at the University of Ottawa. I am doing a study to explore the lived experiences of ICU nurses who perceive end of life care as meaningful and gratifying.

I would like to interview nurses who have provided end of life care to patients/families in the ICU.

You must be an RN working full time or part time in the ICU to participate. You must also have a minimum of 6 months experience in an ICU.

This study has been approved by the Ottawa Health Science Network Research Ethics Board.

If you are interested in participating, please contact me at the email below.

Thank You

Heather Stokes, RN



Version 1 - 2015-01-09

Appendix B: Recruitment Poster (French)

ATTENTION INFIRMIER(ÈRES) À L'UNITÉ DES SOINS INTENSIFS,



Participants(tes) pour une étude recherch 

Bonjour infirmier( res);

Je suis une infirmi re dipl m e qui travaille dans l'Unit  des Soins Intensifs et une  tudiante   l'Universit  d'Ottawa prenant une maitrise en Sciences Infirmi res.

Je fais une  tude visant   explorer les exp riences v cues par les infirmi r(e)s de soins intensifs qui per oivent soins de fin de vie gratifiant et enrichissant.

Je recherche des Infirmier( res) dipl m e qui travaillent   temps plein, ou   temps partiel, dans l'Unit  des Soins Intensifs pour une dur e minimum de six mois qui ont pris soins de patient en situation de fin de vie.

Cette etude a  t  approuv e par le Conseil d' thique de la recherche du R seau de science de la sant  d'Ottawa.

Si vous  tes int ress s, contacter moi   l'adresse de courriel ci-dessous,

Merci

Heather Stokes, RN



Version 1F - 2015-01-09

Appendix C: Recruitment Script

Recruitment script for staff meeting

My name is Heather Stokes and I'm in the Masters of Science in Nursing program at the University of Ottawa. I have been a nurse for 13 years and have worked in the ICU at the civic hospital for approximately 7 years. I am currently in the beginning stages of developing my thesis. The title of my thesis is "Intensive Care Nurses' Meaningful and Gratifying Experiences in Providing End-of-Life Care". When I started working in the ICU I felt unqualified and unprepared to provide "good" end-of-life care to patients and families. After years of working in the ICU, I had several experiences with end-of-life that were meaningful and gratifying. I realized it was the little things that nurses do while providing EOLC that were meaningful and memorable for the patient/family and also rewarding for myself as a nurse. When I listened to other nurses talk about their rewarding experiences I thought about how I could make the next experience meaningful for the patient/family. The focus in the literature has been on the need for improvement in how dying patients are cared for in the ICU. This study is concentrated on the positive aspects and what we as nurses do that make our experiences meaningful and gratifying. Understanding these experiences can facilitate the development of knowledge and skill specific to end-of-life care. This can lead to enhanced end-of-life care for patients and families in the ICU.

The proposed research aims to explore the lived experiences of ICU nurses who perceive EOLC as meaningful and gratifying. The objectives are: to describe and seek to understand ICU nurses meaningful and gratifying experiences providing end-of-life care; to identify barriers to nurses having meaningful and gratifying experiences with end-of-life care and to identify facilitators to nurses' having meaningful and gratifying experiences with end-of-life care.

The research design is qualitative using a phenomenological approach with unstructured interviews to capture the lived experiences of ICU nurses' who perceive end-of-life care as meaningful and gratifying.

My inclusion criteria is nurses who are presently working part-time or full-time in the ICU, nurses who have provided end-of-life care to a patient/family in the ICU, nurses who are English or French speaking, and nurses who have a minimum of 6 months experience in an ICU.

Unstructured interviews will be done with each nurse individually. Interviews will be conducted in a quiet, private interview room at the Ottawa Hospital and scheduled at a mutually agreed upon time identified as convenient by the participant. The interviews will last approximately one hour in length and will be audio recorded. The principal investigator will conduct all the interviews. Each participant will complete a demographic questionnaire before the start of the interview.

You can identify if you are interested in participating in the study by talking to me after the meeting or by sending me an e-mail as advertised on the recruitment poster. All participants will receive an informed consent sheet with an explanation of the study and a consent form. Prior to the interview, the consent forms will be signed by the participants and they will receive a copy. Participants will be under no obligation to participate and may choose to withdraw at any time or refuse to answer any question.

Anonymity and confidentiality will be maintained by not including names of participants or other identifying data in the interviews. An identification number will be assigned to each participant that will be attached to the data (Polit & Beck, 2012).

Follow up interviews with the participants will be done in order to verify themes and interpretations identified by the researchers. The interviews will be done face to face individually and will last approximately 30 minutes in length.

Appendix D: Combined Info Sheet / Consent Form (English 1 of 4)



PARTICIPANT INFORMED CONSENT FORM

Title of Study: *Intensive Care Nurses' Meaningful and Gratifying Experiences in Providing End-of-Life Care.*

Local Site Principal Investigator (PI): Heather Stokes

Email:

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

Why am I being given this form?

You are being asked to participate in this research study because you are a nurse who works in the ICU who has provided end-of-life care to patients and families and are being asked to share your meaningful and gratifying experiences.

Why is this study being done?

ICU nurses perceive caring for dying patients as rewarding and a privilege. Little is known about the meaningful and gratifying experiences that ICU nurses have while providing end-of-life care. The purpose of this study is to explore the lived experiences of ICU nurses who perceive end-of-life care as meaningful and gratifying. The objectives of the study are to describe and seek to understand ICU nurses' meaningful and gratifying experiences in providing end-of-life care and to identify facilitators and barriers to nurses having those experiences.

We estimate that 6 to 10 participants will be enrolled in the study.

How is the study designed?

The research design is qualitative using a phenomenological approach with unstructured interviews to capture the lived experiences of ICU nurses' who perceive end-of-life care as meaningful and gratifying.

What is expected of me?

You will be asked to complete 1 demographic questionnaire, prior to the first interview session. The questionnaire is to assess the demographics of the participants. It will take approximately 5 to 10 minutes to complete. You will be asked to participate in 1 interview, at a convenient date and time decided by you and the Principal Investigator. The interviews are to discuss your meaningful and gratifying experiences with end-of-life care. The interviews will be

Appendix D: Combined Info Sheet / Consent Form (English 2 of 4)

approximately 60 minutes in length. There will be a face to face follow-up interview approximately 30 minutes in length to verify themes and interpretations done by the researchers. You may skip any questions that make you uncomfortable or that you do not wish to answer. The sessions will be audio recorded. You can opt out of the audio recording and still participate.

How long will I be involved in the study?

The entire study will last approximately 12 months. Your participation in the study will last approximately 6 months. Over this time, you will be required to visit the Ottawa Hospital twice. The study will be done on your own time.

What are the potential risks I may experience?

The risks for this study are no greater than those encountered in everyday life.

Interviews:

You might find the interviews upsetting or tiring based on the questions being asked about end-of-life care. You might not like all of the questions that you are asked. You do not have to answer any questions that make you uncomfortable.

If the PI believes the participant's life or another person's life is at risk, information may need to be disclosed and the participant will be provided with help.

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

You may not receive any direct benefit from your participation in this study. Your participation may allow the researchers to understand your experiences with end-of-life care. This may benefit future nurses by adding to nursing knowledge and skill specific to the provision of end-of-life care in a critical care setting. You may benefit from participating in this study by being able to share your experiences with others.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the employment or other services to which you are entitled or are presently receiving at this institution.

If you choose to withdraw your consent, the study team will no longer collect your personal identifying information for research purposes. Participants can choose to have their data withdrawn from the study completely.

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

The cost of parking/transportation will be paid for any extra visits related to the study.

How is my personal information being protected?

Appendix D: Combined Info Sheet / Consent Form (English 3 of 4)

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your name, address, etc.
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents or samples leaving The Ottawa Hospital will contain only your unique study number. This includes publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed under the supervision of Heather Stokes's staff by representatives from:
 - the Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - The University of Ottawa.
- Research records will be kept for 10 years, after this time they will be destroyed.

Will I be informed about any new information that might affect my decision to continue participating?

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study. You may be asked to sign a new consent form.

Who do I contact if I have any further questions?

If you have any questions about this study, please contact Heather Stokes by e-mail at

The Ottawa Health Science Network Research Ethics Board (OHSN-REB) has reviewed the plans for this research study. The Board considers the ethical aspects of all research studies involving human participants at the Ottawa Hospital. If you have any questions about your rights as a study participant, you may contact the Chairperson at 613-798-5555, extension 16719.

Appendix D: Combined Info Sheet / Consent Form (English 4 of 4)



uOttawa



Intensive Care Nurses' Meaningful and Gratifying Experiences in Providing End-of-Life Care

Consent to Participate in Research

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

I agree to be audio taped. Yes No Initials ____

Participant's Printed Name

Participant's Signature

Date

Investigator or Delegate Statement

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

Investigator/Delegate's Printed Name

Investigator/Delegate's Signature

Date

Appendix E: Combined Info Sheet / Consent Form (French 1 of 4)



FORMULAIRE DE CONSENTEMENT ÉCLAIRÉ À L'INTENTION DU PARTICIPANT

Titre du projet de recherche: Les expériences vécues par les infirmier(e)s de soins intensifs qui perçoivent les soins de fin de vie comme une expérience gratifiante et enrichissante.

Chercheur principal : Heather Stokes
Courriel:

Votre participation à ce projet de recherche s'effectue sur une base entièrement volontaire. Veuillez lire ce formulaire de consentement soigneusement avant de décider si vous souhaitez participer. Posez à l'équipe responsable de l'étude autant de questions que vous le souhaitez.

Pourquoi me remet-on ce formulaire?

Vous êtes invités à prendre part à cette étude de recherche parce que vous êtes un infirmier(ère) diplômé(e) qui travaille à temps plein, ou à temps partiel, dans l'unité des soins intensifs depuis au moins six mois et qui a pris soins de patients en situation de fin de vie.

Pourquoi effectue-t-on ce projet de recherche?

Les infirmières/infirmiers de soins intensifs perçoivent les soins de fin de vie comme une expérience gratifiante et un privilège. Les expériences enrichissantes des infirmières/infirmiers qui ont pris soins de patients en situation de fin de vie sont peu reconnues et documentées dans la littérature. Le but de cette étude est d'explorer les expériences vécues par les infirmier(e)s de soins intensifs qui perçoivent les soins de fin de vie comme une expérience gratifiante et enrichissante. L'objectif de cette étude est d'explorer le vécu des infirmières/infirmiers et de tenter de bien comprendre la nature de leurs expériences gratifiantes et enrichissantes eu égard les soins de fin de vie et d'identifier les éléments qui ont facilité ou entravé ces expériences. Nous anticipons inscrire environ six à dix participants provenant de l'hôpital d'Ottawa.

Quelle est la méthodologie de ce projet de recherche?

Le cadre de ce projet repose sur une approche qui est qualitative et phénoménologique utilisant des entrevues non structurées pour explorer les expériences vécues par les infirmier(e)s de soins intensifs qui perçoivent les soins de fin de vie comme une expérience gratifiante et enrichissante

Que serai-je appelé à faire?

Vous serez invité à remplir un questionnaire démographique avant la première séance d'entrevue. Le but du questionnaire est d'évaluer les caractéristiques démographiques des participants. Il faudra environ 5 à 10 minutes pour le compléter. Par après, vous serez invité à participer à une entrevue à une date et une heure mutuellement établie entre vous et le chercheur principal. L'objectif des entretiens est de discuter de vos expériences enrichissantes et gratifiantes des soins

Appendix E: Combined Info Sheet / Consent Form (French 2 of 4)

de fin de vie. Les entretiens dureront environ 60 minutes. Finalement il y aura une seconde entrevue de validation, face à face, d'environ 30 minutes dont l'objectif est de valider la compréhension des chercheurs relatif aux thèmes et interprétations découlant de la première entrevue. Vous avez la pleine liberté de refuser de répondre aux questions qui vous rendent mal à l'aise ou que vous souhaitez tout simplement éviter. Les sessions seront audio enregistrées. Par contre, si vous le désirez, vous pouvez refuser l'enregistrement audio et quand même participer aux entrevues.

Quelle sera la durée de ma participation à ce projet de recherche?

Le projet de recherche au complet durera environ douze (12) mois. Votre participation sera d'environ six (6) mois. Pendant cette période, vous devrez visiter l'hôpital d'Ottawa deux (2) fois. L'étude se fera sur votre propre temps.

Quels sont les risques potentiels que je peux rencontrer relatifs à cette étude?

Les risques pour cette étude ne sont pas supérieurs à ceux rencontrés dans la vie quotidienne.

Questionnaires :

Il est possible que vous trouviez, troublantes ou épuisantes, certaines questions traitant des soins de fin de vie et qui sont comprises dans l'entrevue ou le questionnaire. Il est possible que certaines des questions posées vous rendent mal à l'aise. Vous ne serez pas tenu de répondre à toutes les questions qui vous rendent mal à l'aise.

Si le chercheur principal (CP) estime que la vie du participant ou la vie d'une autre personne est à risque, l'information peut avoir besoin d'être divulgués et le participant sera muni d'aide.

Puis-je m'attendre à retirer des bienfaits en lien avec ma participation à cette étude de recherche?

Il est possible que vous ne retiriez aucun avantage direct en prenant part à cette étude. Par contre, votre participation à cette recherche pourrait aider les chercheurs de comprendre vos expériences avec les soins de fin de vie. Vos expériences peuvent bénéficier aux futures infirmières en ajoutant à la connaissance générale des soins infirmiers et des compétences spécifiques à la prestation de soins de fin de vie dans un contexte de soins intensifs. Vous pourrez également bénéficier de participer à ce projet de recherche de par le partage de vos expériences avec d'autres personnes.

Suis-je tenu de participer? Quelles sont mes autres options?

Votre participation à cette étude s'effectue sur une base entièrement volontaire. Vous pouvez choisir de ne pas prendre part à cette étude, d'y prendre part maintenant, ou de changer d'idée plus tard, sans que votre décision n'influence votre emploi actuel ou futur à l'hôpital d'Ottawa.

Si vous choisissez de retirer votre consentement, l'équipe de recherche cessera de recueillir vos renseignements d'identification personnels pour les fins de cette recherche. Les participants peuvent choisir d'avoir leurs données retirées de l'étude complètement.

Appendix E: Combined Info Sheet / Consent Form (French 3 of 4)

Serai-je payé pour ma participation ou assujéti à des coûts supplémentaires?

Les coûts de stationnement /transport seront payés pour les visites supplémentaires liés à l'étude de recherche.

Comment assurera-t-on la protection de mes renseignements personnels?

- Tous les renseignements recueillis dans le cadre de votre participation à cette étude seront identifiés par un numéro unique d'étude et ne contiendront aucune information permettant de vous identifier, par exemple votre nom, adresse, etc.
- Le lien entre votre numéro unique d'étude, votre nom et les coordonnées, sera stocké de manière sécurisée et séparée de vos dossiers d'étude sans pour autant quitter ce site.
- Les documents ou échantillons qui devront quitter l'hôpital d'Ottawa contiendront uniquement votre numéro d'étude unique. Cela comprend des publications ou des présentations issues de cette étude.
- La divulgation de vos renseignements personnels ou toute information qui vous identifie ne sera permise que si requise par la loi.
- Aux fins de vérification seulement, vos dossiers d'études d'origine peuvent être examinés sous la supervision du personnel de Heather Stokes par des représentants de:
 - Le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa (CÉR-RSSO),
 - L' Université d'Ottawa.
- les dossiers de recherche seront conservés pendant 10 ans, après cette période, ils seront détruits.

Vais-je être informé de tout nouveaux renseignements qui seraient susceptibles d'influencer ma décision de continuer à participer à cette étude?

Nous vous informerons dès que possible de tout nouveau renseignement qui serait susceptible d'affecter votre volonté de continuer à prendre part à l'étude. Il est possible que vous soyez alors appelé à signer un nouveau formulaire de consentement.

Avec qui dois-je communiquer si j'ai d'autres questions?

Si vous avez des questions relatives à cette étude, s'il vous plait rejoindre Heather Stokes au courriel suivant:

Le Conseil d'éthique de la recherche du Réseau de science de la santé d'Ottawa (CÉR-RSSO) a examiné ce protocole et cette étude de recherche. Le Conseil est chargé de l'ensemble des aspects éthiques de toutes les études de recherche menées auprès de sujets humains effectuées à l'Hôpital d'Ottawa. Si vous avez des questions sur vos droits en tant que participant à l'étude, vous pouvez contacter le président, au 613-798-5555, poste 16719.

Appendix F: Demographic Form (English)

Demographic Questionnaire

Circle the correct answer and write short answer in the space provided

1. What is your age?

2. What is your gender?

- Male
- Female

3. What is your primary language?

- English
- French
- Spanish
- Other

4. What is the highest level of nursing education completed?

- College Diploma
- Bachelor's Degree
- Master's Degree
- Doctoral Degree
- Other

5. What is the highest level of non-nursing education completed?

- College Diploma
- Bachelor's Degree
- Master's Degree
- Doctoral Degree
- Other

6. How many years of experience do you have as a Registered Nurse?

7. How many years of experience do you have in the current Intensive Care Unit?

8. How many years of experience do you have in a different ICU (if any)?

9. What education do you have in end-of-life/palliative care (if any)?

10. What education do you have in critical care (if any)?

11. Do you have any specialty certifications in Critical Care?

- CNCC
- CCRN
- Other

Appendix G: Demographic Form (French)

Questionnaire Démographique

Entourez la bonne réponse et écrivez la réponse courte dans l'espace prévu

1. Quel âge as-tu?

2. Quel est votre sexe ?

- mâle
- femelle

3. Quelle est votre langue maternelle ?

- anglais
- français
- espagnol
- autre

4. Ce qui est le plus haut niveau de scolarité en soins infirmiers ?

- diplôme d'études collégiales
- baccalauréat
- une maîtrise
- doctorat
- autre

5. Ce qui est le plus haut niveau d'études de soins infirmiers|non terminées?

- diplôme d'études collégiales
- baccalauréat
- une maîtrise
- doctorat
- autre

6. Combien d'années d'expérience avez-vous comme infirmière?

7. Combien d'années d'expérience avez-vous dans l'unité de soins intensifs actuels ?

8. Combien d'années d'expérience avez-vous dans une unité de soins intensifs différent (le cas échéant) ?

9. Quelle éducation avez-vous dans les soins de fin-de-vie/soins palliatifs (le cas échéant) ?

10. Quelle éducation avez-vous en soins intensifs (le cas échéant) ?

11. Avez-vous des Certificats de spécialisation en soins intensifs ?

- CSI-C
- CCRN
- autre

Appendix H: Interview Guide

Interview Guide

1. Tell me about a meaningful or gratifying experience where you provided end-of-life care for a patient and family in the ICU?
2. Tell me about any challenges that you have encountered to having meaningful and gratifying experiences with end-of-life care?
3. Tell me about the facilitators to having meaningful and gratifying experiences in providing end-of-life care?