Barriers and Facilitators in the Provision of Quality Palliative Critical Care: Critical Care Nurse's Perspectives

by

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Abstract

Intensive care units (ICU) are providing increasing amounts of palliative care. However, a lack of consistency in palliative methods within critical care is reported to create negative end-of-life experiences for patients and their families. Subsequently, there is increasing interest to develop initiatives that improve the quality of palliative care in the critical care setting. The purpose of this qualitative descriptive study was to explore what critical care nurses perceive as facilitators of and barriers to providing quality palliative care in critical care. Eleven critical care nurses working within a general systems intensive care unit (ICU) in a large western Canadian hospital participated in this study. Semi-structured individual interviews were conducted with each participant and data was interpreted using thematic analysis. Key barriers that were identified include ineffective communication, difficulties with end-of-life decision making, not respecting a person's wishes, the lifesaving mentality of critical care, a lack of palliative care education, and barriers related to the critical care environment. Identified facilitators of quality palliative care include advance care planning, effective communication, palliative care education, contributions of the interdisciplinary team, palliative order sets, and promoting an environment that is conducive to quality palliative care. Additionally, key messages that arose include the reality of mortality, moral distress, the components of a "good death," connectedness and the nurse's relational narrative, and the great potential for improvement. These findings point to the importance of promoting advance care planning, early integration of the palliative approach, palliative education, effective communication, palliative care orders sets, critical care environments that are conducive to quality palliative experiences, fostering the nurse-patient relationship, and combatting moral distress. It is anticipated that the results of this study will provide insight into the initiatives and resources that are required to enhance the quality of palliative critical care within the local context.

Preface

This thesis is an original work by Lisa Weisgerber. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Barriers and Facilitators in the provision of Quality Palliative Critical Care, No. Pro00058038, November 17, 2015

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Barriers and Facilitators in the Provision of Quality Palliative Critical Care:

Critical Care Nurse's Perspectives

Chapter 1: Introduction, Literature Review, Research Question

Introduction

Intensive care units (ICU) are providing increasing amounts of palliative care. Studies indicate that the mortality rate in critical care is approximately 20% (Espinosa, Young, Symes, Haile & Walsh, 2010). Accordingly, decisions to withdraw or to withhold life support are common in this environment. Historically, in the critical care setting, death has been seen as a failure (Ferrell, Virani, Paice, Malloy, & Dhalin, 2010). The primary goal of aggressive treatment in critical care is to restore the patient to his/her previous level of functioning (Espinosa et al., 2010); consequently, many patients who die in an intensive care unit do so while receiving invasive and curative treatment (Walling, Fineberg, Brown-Saltzman, & Wenger, 2011). Vanderspank-Wright, Fothergill-Bourbonnais, Malone-Tucker and Slivar (2011) assert that caring for dying patients is an integral component of critical care. However, many intensive care staff report that there are barriers to quality palliative care which negatively affect patients and their families (Ferrell et al., 2010). Additionally, while there are well-established resuscitative methods, there is a lack of consistency in palliative care methods (Nelson & Bassett et al., 2010). These barriers and inconsistencies in the provision of palliative care to critically ill patients can potentially result in negative end-of-life experiences for the patients and their families. In this chapter I will first present my own perspective as a critical care nurse, followed by the literature review and research questions for this thesis.

The Researcher's Perspective

I have spent the majority of my nursing career working in critical care. As such, I have cared for many critically ill patients who are dying. Although I enjoy providing palliative care, I am often disturbed by the ethical complexities that can occur at end-of-life, particularly in critical care. My personal experience in critical care has laid the foundation for my interest in exploring ways to promote and enhance quality palliative care in critical care. The following case study is based on my experience caring for a patient at the end-of-life, and is a significant example of why this topic is of such interest to me.

A patient is admitted to the intensive care unit (ICU) following a cardiac arrest. The patient remains critically unstable and requires ongoing aggressive treatment. He is completely dependent on life support and requires continuous respiratory, inotropic and hematologic interventions. The medical team is in a race against time and physiology to restore this man to health. The family arrives. They are informed of the severity of their loved one's condition and are visibly upset. There also appears to be some family conflict and mistrust towards the health care providers. I hurriedly attempt to keep up with the responsibilities of caring for this patient, but based on past experience, my instinct tells me that the situation will not end well. I urge the physician to engage in further conversation with the family. The medical team wishes to continue aggressive treatment but admits that the chances of survival are unlikely. This prognosis is not clearly articulated to the family and there are no suggestions made to withhold or withdraw treatment. Recognizing the severity of the situation, I attempt to provide family support, but am also actively treating the patient's extreme physiological instability. I am morally distressed and feel helpless in the midst of this very common dynamic of critical care: the simultaneous provision of resuscitative and palliative care.

Background

According to Weidermann, Lehner, and Joannidis (2012) patients who are dying in critical care want to have their wishes respected, be surrounded by their loved ones, and receive adequate symptom management. However, the highly technological atmosphere of intensive care often results in patients experiencing the ICU as an inhumane environment (Hawley & Jensen, 2007**)**. Moreover, the curative and pathophysiological mindset of critical care often results in a patient's values, beliefs and quality of life being overlooked (Zomorodi & Lynn, 2010). Family members of intensive care patients are also subject to difficult situations. As families strive to cope with the stress of their loved ones' fluctuating and unstable health status, they frequently experience loneliness, a lack of involvement in decision-making, and a lack of communication with the medical team regarding withdrawal of care and prognosis (Lind, Lorem, Nortvedt, and Hevroy, 2012). Amidst these struggles, critically ill patients and their families have the following palliative care needs: competent and adequate clinical care, clear communication about goals of care, alignment of treatment with the patient's wishes, and support for the family (Nelson & Puntillo et al., 2010). The primary goals of intensive care are to help patients survive an acute health crisis and restore their quality of life; however, when this goal is no longer feasible, the focus of care transitions from cure to comfort (Troug et al., 2008). Therefore, "the integration of palliative care as a component of comprehensive critical care has been identified as a necessity for all critically ill patients" (Ray et al., 2006, pp. 392). Additionally, Gaeta and Price (2010) state that once end-of-life care decisions have been made, an equal effort should go into ensuring a good death, as went into the resuscitative and curative attempts. However, there are various challenges to providing quality palliative care in critical care (Ferrell et al., 2010).

Defining Characteristics of Quality Palliative Care

The World Health Organization (2002) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other problems, physical, psychosocial and spiritual "(p.84). Similarly, in the local context, The Edmonton Zone Palliative Care Program (2015) identifies palliative care as the special care of persons with an incurable disease, which is aimed at providing comfort and support to the person and their family. Although there are varying opinions on what constitutes quality palliative care, many experts are attempting to clearly define this component of critical care. For instance Nelson, Mulkerin, and Pronovost (2006), have developed a “bundle of palliative care quality measures for ICU’s.” Similarly, through an informal iterative consensus process, and an examination of literature, The Robert Wood Johnson Foundation Critical Care End-of-Life Peer Working Group identified 18 quality measures of palliative critical care, which are summarized and presented in table 1 (Mularski et al., 2006). These measures lay the foundation for improving palliative care in critical care because they provide a means to measure and report for specific targets of quality palliative care.

Table 1. Quality Measures of End-of-Life Critical Care (adapted from Mularski et al., 2006)

1. Assessment of the patient’s decision making capacity
    - formal capacity assessment within 24 hours of admission)
2. Documentation and identification of substitute decision maker
    - within 24 hours of admission
3. Documentation of an advance directive
    - within 72 hours of admission
4. Documentation of the goals of care
    - within the first 24 hours of admission
5. Timely physician communication with family
    - within 24 hours of admission
6. Timely inter-disciplinary clinician-family conference
    - within the first 72 hours of admission
7. Transfer of key information with patient upon transfer out of the ICU
    - “Documentation that the goals of care and resuscitation status are communicated to the
    - receiving team on transfer of the patient out of the ICU.” (p. 406)
8. Policy for continuity of nursing services
    - “A policy that allows for continuity of nursing care for patients with multiple-day stay in the ICU for patients and family members” (pp. 407)
9. Policy for open visitation for family members
    - 24 hour visitation
10. Documentation of offer of psychosocial support
    - Within 72 hours of admission
11. Documentation of pain assessment
    - Every 4 hours
12. Documentation of pain management
    - “Treatment of pain that is assessed as >3 on a 0–10 scale or greater than mild on other scales, with reassessment after treatment” (p. 408)
13. Documentation of respiratory distress assessment
    - Every 4 hours
14. Documentation of respiratory distress management
    - Plan for and treatment of respiratory distress

Table 1. Quality Measures of End-of-Life Critical Care Continued (adapted from Mularski et al., 2006)

15. Protocol for analgesia/sedation in terminal
    - withdrawal of ventilation
16. Appropriate medications available during withdrawal of mechanical ventilation
    - "Documentation of opiates, benzodiazepines, or similar agents prescribed to manage distress" (p. 409)
17. Documentation that spiritual support was offered
    - Within 72 hours of admission
18. Opportunity for clinicians to review experience of caring for dying patients
    - Debriefing sessions

In addition to the aforementioned quality measures, Troug et al. (2008) assert that family-centered care is also essential to quality palliative critical care. Adding to this notion, several authors suggest that supportive decision-making, open and honest communication, realistic recommendations, and attention to the cultural and spiritual values of patients and their families are all necessary aspects of quality palliative critical care (Gaeta and Price, 2010; Toug et al., 2008). Moreover, many claim that once the transition from cure to comfort has been made, it is crucial to adequately assess and manage distressing end-of-life symptoms. For instance, Weidermann, Lehner, and Joannisdis (2012) assert that quality improvements in palliative critical care should focus on adequate symptom management with open-ended orders of analgesia and sedation, second opinions for complex symptoms, discontinuation of treatments not congruent with palliation, and checklists for withdrawing life support. Despite these suggestions for improving care, many challenges hinder the medical team's ability to provide consistent and quality palliative care to critical care patients and their families.

Literature Review

For the initial research proposal, a comprehensive literature review, using the CINAHL and MEDLINE databases, was conducted to explore what is known about the barriers to and facilitators of quality palliative critical care. Key search terms were entered into each search engine (Table 2) and over 300 articles were identified in the search. Following a review of abstracts and titles, 42 articles were selected for review. Literature was eligible for inclusion if it was published in English between 2005 and 2015, and if it focused on the barriers and facilitators of palliative care for adult patients in a critical care setting. A thematic analysis of the selected articles was performed to identify common themes. The following themes were identified: (a) the nurse perspective, (b) the physician perspective, (c) barriers to quality palliative critical care, and (c) facilitators of palliative critical care.

Table 2. Literature Search Terms

Term	With	Term	With	Term
Palliative Care Or End-of-Life Care		Critical care Or Intensive Care		Barriers or Facilitators

The Nurse Perspective

For the initial literature review, 11 articles were found that examined palliative critical care from the critical care nurse perspective. Methodologies that were used in these studies included three general qualitative designs, four descriptive qualitative designs, two phenomenological studies, one mixed qualitative-quantitative survey method, and one ethnographic design. The researchers employed various methods of data collection including one-on-one interviews, focus groups, and surveys. Sampling sizes ranged from five to 35 participants for one-on-one interviews, 18-84 participants for focus groups, and up to 277 participants for surveys. Five studies were conducted in hospitals in the United States (US), three were conducted in Australia, one was conducted in Egypt, and two were conducted in Canada (Ontario and Quebec). The main themes that emerged from these studies are the critical care nurse's general experience of providing palliative critical care and the barriers encountered while providing this care.

General experience. Nurses are in an opportune position to improve the comfort of palliative patients and their families because they are more involved in direct patient care than any other health care provider (Badger, 2005). Critical care nurses appear to have a clear understanding of what constitutes “a good death” in the ICU (Sorensen & Iedema, 2006). For instance, in one ethnographic study in which 84 nurses were interviewed, the following elements were reported as essential components of a good death: the patient and family know the prognosis and have been involved in decision-making, the patient is comfortable and free of pain, the patient is able to die in peace with a do-not-resuscitate order in place, and family members are present with the patient (Sorensen & Iedema, 2006). Additionally, in another qualitative study, there was a consensus among the 22 nurses interviewed, that quality palliative care in critical care includes the following components: providing support of patients and families, breaking bad news, and enduring stressful situations (Popejoy, Brandt, Beck, & Antal, 2009). Moreover, in a phenomenological study, critical care nurses reported that the essence of providing quality palliative care is “trying to do the right thing” for the patient and their family (Vanderspank-Wright, Fotherfill-Bourbonnais, Brajtman, & Gagnon , 2011).

Barriers. Overall, from the perspective of nurses, the main barriers to quality palliative critical care include a lack of communication (Aslakson et al., 2012), minimal support and knowledge (Crump, Schaffer, & Schulte, 2010), and personal and relational factors (Zomorodi & Lynn, 2010). Gelinas, Fillion, Robitaille, and Truchon (2012) identified that nurses who provide palliative critical care struggle with many organizational, professional and emotional stressors. For instance, in their descriptive exploratory study, McCallum and McConigley (2013) found that intensive care nurses often struggle with moral and ethical dimensions of decision-making regarding withdrawing life support. Additionally, in one phenomenological study, 18 nurses reported that they faced barriers with regards to a lack of involvement in planning care, disagreements among physicians, inconsistent orders, internal conflict, and difficulty developing effective coping strategies (Espinosa et al., 2010). Furthermore, after interviewing 70 nurses in their qualitative descriptive study, Attia, Abd-Elaziz, and Attia-Kandeel (2012) identified that nurses face barriers regarding family conflict, environmental constraints, personal attitudes towards dying, and ambiguous treatment policies.

The Physician Perspective

While 11 studies were found that explore the perspective of critical care nurses in the ICU, only three studies were found that examine palliative critical care from the physicians' perspective. All three were conducted in Europe, employed qualitative methods, and highlighted the general experience of critical care physicians. For instance, in one qualitative study in which 13 physicians were interviewed, Coombs, Addington-Hall, and Long Sutehall (2012) identified that there are three stages of the trajectory of a stay in the ICU: (a) admission with hope of recovery, (b) transition from interventions to end-of-life care, and (c) a controlled death. Of these three stages, it was reported that the second stage (transitioning to end of life) is the most difficult transition for families and the medical team (Coombs et al., 2012). In another qualitative study, there was an overall consensus among the 15 physicians interviewed, that there are many negative aspects to providing palliative care in the ICU (McKeown, Cairns, Cornbleet, & Longmate, 2011). These include the intense and artificial environment of critical care, treating patients aggressively for too long, difficulties in identifying palliative patients, minimal continuity of care once a patient is deemed palliative, and difficulties with consulting palliative care teams (McKeown, Cairns, Cornbleet, & Longmate, 2011). Additionally, in their study, Jensen, Ammentorp, Erlandsen, and Ordings (2011) conducted a survey in seven hospitals which yielded 776 responses, 135 of which were intensivists. This study identified that there is a potential collaboration gap between nurses and physicians, as the nurses in their study reported being unsatisfied with the level of collaboration between physicians and nurses in providing palliative care, while physicians reported being satisfied with the level of collaboration (Jensen, Ammentorp, Erlandsen, & Ordings, 2011).

Barriers to Quality Palliative Critical Care

Several research endeavours have highlighted the barriers to providing high quality end-of-life care in the critical care setting. Many of the studies in this literature review were qualitative studies exploring the perspectives of nurses, physicians, and families. The most frequently reported barriers include communication gaps, inconsistencies in end of life decision-making, psychosocial aspects of care, ethical concerns, and minimal access to education.

Communication gaps. High quality communication with families and patients in critical care is one of the most highly valued aspects of end of life care (Spinello, 2010). However, it has been reported that communication and decision-making with family members in crisis can be difficult (Crump, Schaffer, & Schulte, 2010). Moreover, end-of-life care communication deficits and decision-making are frequent sources of conflict in critical care (Weidermann, Lehner, & Joannidis, 2012). Barriers to adequate communication include logistics of care, inadequate skill and training, inability to identify an end-of-life situation, and cultural differences related to end-of-life care (Aslakson et al., 2012). Additionally, due to prognostic uncertainty, health care professionals are often uncomfortable engaging in end-of-life discussions with families and, in turn, they inadvertently deliver ambiguous and misleading information (Adams, Bailey, Anderson, & Thygeson, 2013). Seaman (2013) suggests that early and honest communication with patients and their families is essential to exploring patient-specific goals of care, and to clarify the risks, benefits, and alternatives to life-sustaining treatment. Although communication has been identified as a crucial component of palliative critical care, few guidelines exist to support and direct clinicians and family members in this process (Wiedermann, Lehner, Joannisids, 2012).

Inconsistencies in end-of-life decisions. Although some critical care patients die suddenly, most die following the decision to withdraw or withhold treatment (Ranse, Yates, & Coyer, 2012). Decisions to withdraw or withhold care are complicated by an uncertain clinical course, a lack of advance care planning, and misinterpretations of a person's expressed wishes (Weidermann, Lehner, & Joannisdis, 2012). Up to 95% of patients in the ICU are unable to make decisions for themselves; as such, decision-making is often the responsibility of the family (Troug et al., 2008). However, studies have shown that it is common for family members to disagree about treatment decisions and often they find it difficult to come to a consensus (Badger, 2005). Additionally, it has been identified that inconsistent care orders and physician variability in end-of-life decisions pose a significant barrier to providing quality end-of-life care (Espinosa et al., 2010). Wilkinson and Troug (2013) report that physician variability is indeed an ethical concern that arises from variations in setting, personal values, age, race, religion, attitude to risk, and personality factors. They argue that although physician-related variability cannot be eliminated entirely, strategies to promote consistency in palliative care methods should be developed (Wilkinson & Troug, 2013). These inconsistencies arise most commonly with regard to symptom management and withdrawal procedures. For instance, Jensen, Ammentorp, Erlandsen and Ording (2011) found that lack of continuity among intensivists is a common reason for changing or withholding therapy decisions. Additionally, studies have shown that decisions to withdraw therapy are most often postponed due to varying professional/personal opinions and a lack of guidelines (Jensen et al., 2011).

Psychosocial aspects of care. Palliative critical care creates many challenges for health care professionals as they attempt to address the psychosocial needs of patients and families. For example, environmental factors such as noise and technology often inhibit the quality of comfort provided to patients and their families (Zomorodi & Lynn, 2010). Nurses frequently described a need to alter the environment by removing invasive lines, machines, and masking noises in order to enhance comfort; they described this as acting to “set up the death scene” (Zomorodi & Lynn, 2010). Additionally, some health care professionals report that they struggle with maintaining a balance between becoming too emotionally involved versus distancing themselves entirely from patients and families. For instance, in one study nurses described caring for dying patients as an ordinary and a matter-of-fact routine task (Badger, 2005) This emotional distancing occurs most often when there is ambiguity in the care direction and an inability to obtain knowledge about the patient (Zomorodi & Lynn, 2010). Overall, it is challenging to provide psychosocial support to families with high expectations and a lack of medical knowledge (Badger, 2005). Additionally, assisting families in coping with a situation is particularly difficult when families do not understand or accept a poor prognosis, do not understand the significance of aggressive life-saving measures, override the patient’s wishes, and fight amongst each other over end-of-life decisions (Crump, Schaffer, & Schulte, 2010).

Ethical concerns. Three ethical principles shape end-of-life decision-making in critical care: (a) withholding and withdrawing life support are equivalent, (b) there is an important distinction between killing and allowing a patient to die, and (c) the doctrine of double effect (Troug et al., 2008). The doctrine of double effect assumes that when an action has both a negative and positive effect it is permissible if (a) the action is morally good or neutral, (b) the good effect is not the direct result of the foreseen negative result, (c) the negative result is not directly intended, and (d) there is no way to accomplish the desired end without the negative effect (Oneshcuk, Hagen, & MacDonald, 2012). Despite these guiding standards, end-of-life decisions in critical care remain complex and enmeshed in ethical dilemmas. For example, many physicians report that they are more comfortable withholding treatments than they are withdrawing treatments (Troug et al., 2008). Troug et al. (2008) warn that this reluctance to withdraw treatment often results in premature decisions to withhold other treatments that the patient would consider beneficial. Additionally, these inconsistencies often result in the provision of medically futile care (Moscovici, Camalionte, & Caruso, 2015). There is no universally accepted definition of medical futility; however, some believe that care is considered futile when the goals of treatment are not attainable or when there is an extremely low chance of a meaningful recovery (Chow, 2014). In one study, participants identified that the most common reasons for engaging in medically futile care are related to demands from family or designated decision-makers, a lack of timely and skilled communication, and a lack of consensus among ICU team members (Chow, 2014). The legal dimensions of hastening death versus the act of withdrawing or withholding treatment are also common sources of concern for health care professionals working in critical care (Kuschner, Gruenwald, Beal, & Ezeji-Okoye, 2009).

Browning (2013) found that ICU clinicians reported a high level of moral distress. Moral distress is a significant barrier to quality end-of-life care (Zomorodi & Lynn, 2010). Medical futility, aggressive treatment, and concerns over hastening death are common sources of moral distress for health care professionals working in critical care. Critical care professionals frequently express concerns over providing aggressive care to patients despite their poor prognosis (Crump, Schaffer, & Schulte, 2010). Nurses in intensive care report that there are fates much worse than death in critical care and that they often experience emotional conflict while "prolonging the inevitable" (Badger, 2005). In one qualitative study, participants reported that they have often felt fear and guilt after the death of a patient (Vanderspank.Wright, Fothergill-Boubonnais, Malone-Tucker & Silvar, 2011). Despite these ethical dilemmas, many ICUs do not have guiding policies and procedures to direct end of life care decision-making (Kuschner et al., 2009).

Minimal access to education. According to Spinello (2011), the three pillars of comprehensive critical care training are: (a) evidence-based patient care, (b) proficient procedural skill, and (c) compassionate end-of-life management. However, varying levels of inconsistencies in training across institutions and professions create ambiguity regarding appropriate delivery of palliative critical care (Walling, Fineberg, Brwn-Saltzman, & Wenger, 2011). Overall, critical care staff are rarely trained in palliative care (McKeown et al., 2010). In one study, ICU clinicians reported that they are required to learn the principles of palliative care on the job, by trial and error and from their own experiences (Zomorodi & Lynn, 2010). Many critical care health professionals report a need for education on palliative symptom management (Aslakson, Curtis, & Nelson, 2014). The most common palliative symptoms experienced by critical care patients are pain, delirium, dyspnea, and death rattle (Maxwell & Pope, 2006). Palliative symptom management is often difficult because most critically ill patients are not able to self-report these distressing symptoms (Mularski et al., 2009). Moreover, achieving adequate symptom management requires knowledge and skill in behavioural, social, and pharmacological strategies (Mularski et al., 2009). Other palliative learning needs that have been identified by critical care staff include culture, ethnicity, religion, recognizing potential palliative ethical challenges, and sharing the burden of ethical conflict (Crump, Schaffer, & Schulte, 2010).

Facilitators of Palliative Critical Care

Based on what I have observed in the literature, in many countries, efforts have been underway to improve the quality of palliative critical care. For instance, a notable example of a successful initiative is the “Improving Palliative Care in the ICU” project, which provides practical evidence-based frameworks, tools and guidelines (Sihra, Harris, & O’Reardon, 2011). Many of these initiatives are focused on facilitating palliative critical care by providing palliative education to critical care staff, supporting useful models of care, and introducing palliative critical care pathways, guidelines and tools into practice.

Education. Advances in technology have resulted in the ability to prolong life beyond what was previously possible (Vanderspank-Wright et al., 2011). As such, ICU health care professionals provide palliative care to patients admitted for a variety of conditions including trauma, chronic illness, and age-related illness. Crump, Schaffer, and Schulte (2010) assert that critical care staff require more knowledge, skill, and cultural competency in communicating with patients and families about prognosis, life-saving measures, and limits of aggressive treatment. Furthermore, many intensive care health professionals report that they do not have the experience or education to adequately assess and respond to the symptom management and support needs of palliative care patients (Vanderspank-Wright et al., 2011). Some institutions have developed programs to enhance critical care health care providers' end-of-life-care knowledge. For instance, The End-of-Life Nursing Education Consortium is a national education initiative to enhance the quality of palliative care (American Association of Colleges of Nursing, 2015). To date, this program has been responsible for furthering the end-of-life education of more than 19,000 critical care nurses (American Association of Colleges of Nursing, 2015). Overall, it is clear that critical care health care professionals would benefit from formal palliative care training (Browning, 2013), but there are few education initiatives that have been evaluated and successfully implemented, and those that exist are geared mostly towards nurses (Robley & Denton, 2006).

Models of care. There are two main models used in North America to integrate palliative care into the critical care context: the consultative model and the integrative model (Nelson & Bassett et al., 2010). The consultative model focuses on increasing the involvement of the palliative care consult team, particularly for those patients and families that are expected to experience the poorest outcomes (Mosenthal et al., 2012). At times, optimal palliative care for a critically ill patient may require more advanced palliative care skills, in which case a consultative approach is the best manner to ensure high quality care (Aslakson, Curtis, & Nelson, 2014). Alternatively, because mortality is quite high in critical care, some professionals believe that palliative care principles should be integrated into daily ICU practice (Integrative Model) (Nelson & Bassett et al., 2010). Research suggests that both models of care can improve palliative critical care; however, a mixed approach promotes the highest quality of care because it allows for a straightforward palliative approach while providing opportunity to consult palliative care specialists for more complex problems (Aslakson, Curtis, & Nelson, 2014).

Palliative critical care protocols and guidelines. Numerous suggestions for palliative critical care protocols are presented in the literature. Gaeta and Price (2010) assert that the purpose of such protocols is to prevent patient discomfort and that the protocols should focus on aspects such as withdrawal of life support, successful symptom management, and the provision of emotional support (Gaeta & Price, 2010). Troug et al. (2008) suggest that acts of withdrawal and symptom management should be guided by pre-existing protocols and procedures to ensure that nothing is overlooked during these processes. Bradley and Brasel (2009) emphasise the need to develop guidelines for the early identification of critical care patients who would benefit from palliative care services. Nelson and Basset et al. (2010) suggest using clinical criteria to identify palliative patients, such criteria include baseline characteristics (age > 80, previous functional dependence), acute diagnosis (multiple organ dysfunction, global cerebral ischemia post cardiac arrest), and/or specified healthcare-use criteria (prolonged ICU stay, ventilator dependence, decisions to withhold life-sustaining treatment). Lind et al. (2012) recommend developing protocols that address the communication needs of critical care patients' family members. Ferrell et al. (2010) suggest the need for tools that improve critical care health professionals' palliative care knowledge. Some attempts have been made to incorporate palliative care guidelines and protocols into critical care. For example, in one study a guideline for withdrawing and withholding critical care therapy was found to enhance end-of-life care by enabling more prompt end-of-life decision-making for patients who were not expected to survive (Jensen & Ammentorp, & Ordin, 2013). Other examples of palliative care guidelines include the Liverpool Care Pathway, which has been used in various ICUs in the United Kingdom (Walker & Read, 2012), and the Embrace Hope intervention, which has been implemented in an Ohio ICU (Yeager et al., 2010). While staff have provided positive feedback, limited evidence exists to support the protocols' adequacy and success in enhancing palliative critical care (Walker & Read, 2012).

Gaps in the Literature

In my literature search there appeared to be extensive amount of information about integrating palliative care into critical care. However, only 11 studies were found that explore nurses' perspectives of palliative critical care, and only three were found that examine the perspectives of other members of the critical care team. Additionally, many studies provided insight about the barriers to palliative critical care; however, few studies identified the facilitators of this care. Many authors suggested using guidelines, protocols, and tools to enhance palliative critical care; however, there is minimal evidence to demonstrate the effectiveness of such tools. While many of the articles identified in this review examined palliative critical care in the context of the US, Australia, and Britain, few studies have been conducted in Canada. The American and Canadian health care systems operate very differently from one another, as such, the current literature on palliative care in critical care may not reflect the ICU experience of ICU health care professionals working within Canada.

Research Question

The literature suggests that there is a need to improve the quality of palliative care provided in critical care settings. However, in order to implement interventions that improve and enhance this care, it is necessary to gain an in-depth understanding of the current state of palliative critical care from the perspective of critical care health care professionals (Espinosa et al., 2010). The Canadian Association of Critical Care Nurses states that “critical care nurses have an important and integral contribution to make in the provision and enhancement of end-of-life care” (pp.1). However, to date, there is a minimal amount of literature that examines the perspective of Canadian critical care nurses. In this context, my **research question** was: “What do critical care nurses perceive as barriers and facilitators in the provision of quality palliative care in the critical care setting?” As the purpose of this study was to explore what hinders and what facilitates quality palliative critical care, the two **research objectives** were: 1) to explore the barriers in the provision of quality palliative care in critical care from the perspective of ICU nurses, and 2) to examine the facilitators in the provision of quality palliative care in critical care from the perspective of ICU nurses.

Barriers and Facilitators in the Provision of Quality Palliative Critical Care:

Critical Care Nurse’s Perspectives

Chapter 2: Research Methodology

Research Methodology

A research methodology influences decisions regarding the research design, methods, sequencing, and processes (Kramer-Kile, 2012). It must stem from the research problem (Streubert & Carpenter, 2011), and must provide the capacity to adequately address the research question (Loiselle & Profetto-McGrath, 2011). To address my study purpose and aims, I used Sandelowski's qualitative descriptive methodology to describe the barriers and facilitators in the provision of quality palliative critical care from the perspective of the critical care nurses. According to Farrelly (2013), qualitative methods are critical when researching phenomena that are difficult to quantify. A qualitative method is appropriate for this study because it was an exploration of the subjective experiences of critical care nurses, which are difficult to describe in a quantitative ordinal manner (Guest, MacQueen, & Namey, 2012). As such, a qualitative inquiry enabled the generation of greater insight into the provision of end-of-life care in critical care, from the perspective of ICU nurses (Sim and Wright, 2000).

More specifically, I used qualitative description, which is an approach that provides an opportunity to describe "the facts, and the meaning participants give to those facts," and then convey them in a coherent and useful manner (Sandelowski, 2000, pp. 336). In accordance with the goal of this study, descriptive qualitative methods are ideal when pure description of a phenomenon is the goal (Walker, 2012). Researchers who choose this method are interested in describing an experience or an event from the perspective of those experiencing it and in the context within which it occurs (Sandelowski, 2000). Although no description is entirely without interpretation, qualitative description is the least interpretive of all qualitative methodologies (Sandelowski, 2010). Sanelowski (2000) explains that "researchers conducting such studies seek descriptive validity, or an accurate accounting of events that most people (including researchers and participants) observing the same event would agree is accurate" (p. 336). As such, the strength of a qualitative descriptive approach is the knowledge that is produced from findings that are more representative of the original data and data source (Sandelowski, 2010).

Research Design

A research design is the overall research plan; it determines how the methodology will be applied to answer the research question (Loiselle & Profetto-McGrath, 2011. The research design of a qualitative descriptive approach is focused on: recruiting participants with experiences that are information rich; directing data collection towards discovering the who, what and where of the research topic through modernly structured individual interviews, focus groups, or observation; and engaging in data analysis that reveals a straight forward descriptive summary of the informational content that is unveiled during data collection (Sandelowski, 2000). As such, the steps involved in developing a qualitative descriptive research design include choosing a setting, sampling method, data collection method, data analysis technique, and attention to rigor (Tracy, 2013).

Setting. Overall, qualitative research designs are often emergent in that the design unfolds throughout the course of the study (Loiselle & Profetto-McGrath, 2011). I had initially planned to conduct this study in two intensive care units (ICUs) within two western Canadian hospitals: The Royal Alexandra Hospital Adult Intensive Care Unit and the Grey Nuns Community Hospital Intensive Care Unit. Due to challenges with participant accrual at one site, participants of this study consisted entirely of the critical nurses from the Royal Alexandra Hospital Intensive Care Unit. This unit is a 27 bed general systems ICU that "provides intensive care to all adult patients with illnesses that affect more than one body system" (Alberta Health Services, 2018).

Sampling. After receiving ethical approval from the University of Alberta and operational approval from Alberta Health Services, purposive sampling was used to recruit participants for this study. Purposive sampling is an appropriate qualitative descriptive method (Sandelowksi, 2000) that entails choosing participants who meet the parameters of the study's purpose, goals, and questions (Tracy, 2013). It results in an aggregate of participants who have knowledge and experience of the research topic (Clearly, Horsfall, & Hayter, 2014), which ultimately leads to data that is information-rich (Sandelowski, 2000). The accrual procedure involved placing recruitment posters (Appendix A) and participant invitation letters (Appendix B) in the ICU. Additionally, one key contact person circulated an e-mail with an attached invitation letter among the critical care nurses in the participating unit. I was also invited to visit the ICU staff room to informally present my study to the ICU nurses. I recruited participants with varying levels of experience and knowledge, using the following inclusion criteria: a critical care nurse (Registered Nurse or Nurse Practitioner) who had at least one year of experience in critical care and had cared for a dying patient in critical care. The rationale for the "one year of experience" requirement is based on the assumption that after one year of working in ICU, it is highly unlikely that a nurse has not cared for a palliative patient. Unlike quantitative studies, adequate sample size is difficult to determine in qualitative inquiries (Loiselle & Profetto-McGrath, 2011). Additionally, the sample size for qualitative studies is generally smaller than that for quantitative studies (Trotter, 2012). Sample size is largely determined by the purpose of the inquiry, the quality of data, and the sampling method (Loiselle & Profetto-McGrath, 2000).However, there is a point when data becomes redundant and repetitive (Walker, 2012). As such, the sample size of this study was determined by the point at which no new ideas were evident in the transcripts. This resulted in a sample size of 11 participants, four of whom are Nurse Practitioners and seven who are Registered Nurses. The participants' critical care experience ranged between one and 15 years.

Data collection. The data collection activities included conducting interviews, recording field notes, keeping a reflexive journal, and member checking. Each participant contacted me through my University of Alberta email, and arrangements were made to meet in person at a time and location that was convenient for the participant. Prior to beginning each interview, I reviewed the consent form (Appendix B) with the participant, and provided them with time to ask questions. Once I completed the data analysis, I engaged in a process of member-checking in which I sent email invitations to nine of the participants, inviting them to provide feedback on the final themes that emerged (the two other participants did not give me permission to contact them for feedback). Four of the participants responded and provided positive feedback. Their feedback is summarized in table 6 in Appendix D.

Interviewing. One semi-structured, in-depth, face to face, audiotaped interview was conducted with each participant. Interviewing is the main technique used in qualitative methods when exploring an individual's perceptions and experiences (Farrelly, 2013). Semi-structured interviews require using a list of guiding questions, but the interviews are flexible enough to allow for in-depth story telling (Streubert & Carpenter, 2011). Open-ended questions give participants the opportunity to answer in their own words (Farrelly, 2013), eliciting subjective experiences and viewpoints (Tracy, 2013). To develop the interview guide for this study, I used some of the qualitative interview questions I had found in studies in my literature review as a reference. I examined the interview guides from these studies for content and wording of open-ended questions and used the guides to inform the categories and content of my interview guide. The open-ended questions for this study were developed to explore the research question (Appendix C). Each interview occurred at a time and location that was preferable to the participant, and lasted between 35 and 60 minutes. The interviews were digitally recorded and transcribed verbatim by a transcriptionist. The files were stored on the Health Research Data Repository (HRDR) of the Faculty of Nursing at the University of Alberta.

Field notes. Field notes are the notations that researchers use to document their observations in terms of what they heard, saw, thought, or experienced, which become a part of the data analysis

(Streubert & Carpenter, 2011). Following each interview I recorded any pertinent information that may not have been captured in the audio recording in my field notes.

Data analysis. I began analyzing the data as soon as I completed the first participant interview. According to Streubert and Carpenter (2011), the goal of qualitative data analysis is to highlight a person's lived experiences and to "bring to life particular phenomena" (p. 47). Information gained during ongoing data analysis often guides the researcher to adapt the sampling and collection plan to meet the study's needs (Loiselle & Profetto-McGrath, 2011). Therefore, the data analysis phase of this project occurred concurrently with the data collection. I entered the data from each interview in the software program NVivo©. The purpose of this program is to facilitate the organization of data for data analysis. Using Sandelowskis' qualitative descriptive design, I used thematic analysis to identify themes and patterns among the narrative data. According to Guest, MacQueen, and Namey (2012), thematic analysis moves beyond "counting explicit words or phrases and focuses on identifying and describing both implicit and explicit ideas within the data" (pp. 13). Thematic analysis is a common qualitative descriptive method which is used by researchers who seek to identify and report patterns within data while maintaining a low level of interpretation (Vaismoradi, Turnunen, & Bondas, 2013). Additionally, I diligently reviewed each transcript line by line searching for key revealing phrases or statements. The ultimate goal was to reveal the themes that were embedded in the clinicians' rich descriptions (Santos Salas & Cameron, 2010).

Rigor. The purpose of rigor in qualitative research is to demonstrate trustworthiness by accurately portraying participants' experiences (Streubert & Carpenter, 2011). Additionally, rigor offers the means to replicate a study in a different setting with a different sample (Thomas & Magilvy, 2011). Lincoln and Guba (1985) present four criteria for establishing trustworthiness: (a) dependability, (b) confirmability, (c) credibility, (d) and transferability. I utilized strategies to enhance these qualities in this study.

Dependability. Dependability refers to data stability over time and conditions (Loiselle & Profetto-McGrath, 2011). Strategies that were employed to enhance the dependability of this study included keeping an audit trail and exercising reflexivity. An audit trail is a systematic collection of documentation that reflects the decision-making processes of data analysis (Loiselle & Profetto-McGrath, 2011). The NVivo program enabled me to keep a comprehensive record of data analysis decisions. Reflexivity is a process of engaging in self-reflection to identify personal biases that could influence data collection and interpretation (Loiselle & Profetto-Mcgrath, 2011). To offset the potential for personal bias, I kept a reflexive journal in which I recorded my feelings, insights, and biases that arose during the interviews and as I analysed the data.

Confirmability. Confirmability is the neutrality and objectivity of data to the extent that two or more individuals can come to similar conclusions in data interpretation (Loiselle & Profetto-McGrath, 2011). Confirmability is closely linked with dependability, in that the processes for establishing both qualities are similar (Houghton et al., 2013). Techniques such as reflexivity and maintaining an audit trail are strategies that assisted in enhancing the confirmability of the research data.

Credibility. Credibility is established by ensuring that the data accurately represents and reflects the experiences of those who are describing it (Thomas & Magilvy, 2011). I used the strategies of peer debriefing and member checking to enhance the credibility of my findings. Peer debriefing consisted of conducting a review of the research data with objective peers (such as my supervisor) to explore and critique my interpretation and analysis of the data (Loiselle & Profetto-McGrath, 2011). As such, I met with my supervisor on a regular basis to discuss and examine the identified themes. Member checking involves reconnecting with study participants to confirm the accuracy of data interpretation and data analysis (Thomas & Magilvy, 2011). Once themes were identified through data analysis, I sent an email invitation to all of the participants (who had given prior consent), inviting them to provide feedback on the findings. The initial identified themes were summarized in a research poster for the Edmonton Palliative Care Conference. Sending this poster to each participant, I asked each of them to consider whether the themes accurately reflected palliative care in the ICU, if anything was missing, and if anything needed to be altered. The four participants who responded to the feedback request confirmed that the identified themes were accurate.

Transferability. Transferability refers to the extent to which a study's findings can be transferred to other settings (Thomas & Magilvy, 2011). The transferability of this study may be limited because it was conducted at only one site. However, by including in the research report a thick description about study processes, context, and participant qualities, I attempted to enable the reader to make an informed decision about whether the findings are transferable to other settings(Cope, 2014). In addition, participants' rich descriptions of their experiences provide insights into the nature of palliative care in the critical care setting, which has solid potential to inform other critical care contexts in a reflective manner .

Ethical Considerations

The history of ethics in human research has a dark past; it is laden with examples of research endeavours that have been harmful to participants, and in some cases fatal. The Tri-Council Policy Statement of Canada outlines mandatory principles for ethical conduct in research involving humans. The underlying core value of this statement is respect for human dignity (Canadian Institutes of Health Research (CIHR)**,** Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC), 2014). Respect for human dignity requires that researchers seek to uphold the inherent worth of each individual, and is expressed in the following principles: respect for persons, concern for welfare, and justice (CIHR, NSERC, & SSHRC, 2014). This study received ethics approval (Pro00058038) through the University of Alberta Health Research Ethics Board on December 12, 2015. The approval has been renewed twice.

Respect for persons. Respect for persons in research requires that the researcher protect the interests of the participant (Loiselle & Profetto-McGrath, 2011). It necessitates that the researcher uphold the participants rights to self-determination, autonomy, and free and informed consent, (CIHR, NSERC, & SSHRC, 2014). I maintained these principles in my study by presenting each participant with an invitation and consent form that comprehensively presented the study's purposes and objectives the importance of the research project; participant selection, voluntary participation; potential harms and benefits of participating in the study; and how the data will be used, stored and disseminated. Prior to each interview I reviewed this form with each participant, stressing that consent is ongoing, and that strict methods will be used to maintain confidentiality. I gave the participant an opportunity to ask questions, and asked each to sign the consent form before beginning the interview.

Concern for welfare. Concern for welfare requires that the researcher consider the impact that participation will have on the participant's physical, psychological, spiritual, and social health (CIHR, NSERC, & SSHEC, 2014). Additionally, it entails protecting the participant's determinants of health and privacy (CIHR, NSERC, & SSHEC, 2014), protecting vulnerable populations, ensuring a favourable harms-benefit ratio, and acting on the principles of beneficence and non-maleficence (Loiselle & Profetto-McGrath, 2011). I took strict steps to ensure confidentiality by giving participants coded names, disseminating their data in a manner in which they cannot be identified, and keeping audio files and transcripts in a password-protected secure data server (HRDR). Signed consent forms have been kept in a locked filing cabinet. One negative effect that participants may have experienced from participating in this study is the unearthing of difficult emotions as they talked about their end-of-life care experiences; however, talking about these situations may also have been beneficial in that it allowed them time to reflect and understand how these experiences have influenced their practice. I made it clear to each participant that if the interview triggered difficult emotions, they could stop the interview at any time if they felt uncomfortable.

Justice. "Justice refers to an obligation to treat people fairly and equitably" (CIHR, NSERC, & SSHEC, 2014, pp. 8). It requires the burdens and benefits of a research project be divided equitably among participants (Loiselle & Profetto-McGrath, 2011). Although some variation is unavoidable, each participant was treated equally in that all were exposed to the same interview questions and received similar treatment with regard to informed consent, voluntary participation, confidentiality and anonymity, and dissemination of results. Additionally, all clinicians who met the inclusion criteria had an equal chance to participate in the study.

In what follows, I present research findings for this study. I endeavour to portray what end-of-life and palliative care look like in the ICU setting from the Critical Care Nurse's perspective. In the interviews, nurses shared their wealth of knowledge and experiences to convey their views. Their stories are loaded with a wide range of patients' and family situations that reveal the urgency as well as the significance of providing humane and knowledgeable end-of-life care. In an effort to honour their experiences and stay true to their perspective, I have kept many of their stories and inserted extensive quotes. The Findings chapters are thus very descriptive, yet organized in way that follows a careful analyses of these experiences. I discuss these findings in the context of the literature and I outline the practice implications in the final chapter.

Barriers and Facilitators in the Provision of Quality Palliative Critical Care:

Critical Care Nurse’s Perspectives

Chapter 3: The Barriers to Quality Palliative Care in Critical Care

The Barriers to Quality Palliative Care in Critical Care

The participants interviewed for this study clearly identified and articulated the barriers to quality palliative care in critical care. The most salient barriers identified were related to ineffective communication, difficulties with end-of-life decisions, not respecting a person's wishes, the lifesaving mentality of critical care, lack of formal palliative care education, and specific characteristics of the critical care environment.

Ineffective Communication

"It seems like talking about death is a faux pas." (P8)

Several nurses identified that conversations related to palliative and end-of-life care in the intensive care unit (ICU) are often avoided and not addressed early enough in a patient's illness trajectory. As one nurse observed, "I don't think we talk about end-of-life nearly soon enough" (P1). Another nurse shared, "the process of being palliative and becoming palliative is very fast, and sometimes it can be very poorly explained to the families" (P8). Accordingly, many participating nurses noted that communication between the patient, family, and health care team is often ineffective and inconsistent:

> I had a lady who had a thyroidectomy done. She had a massive tumour – she was in her eighties. But she had a tremendous amount of pain from the tumour... And they did this thyroidectomy. They put a trach in her. And she was never told that she would need a trach during her surgery. So she ended up in ICU, because she had a trach and had to be ventilated. Her pain was never well-controlled, even when we got her in ICU. She was back and forth between ICU several times before she finally passed away. And I think there was a real miscommunication; the whole reason she agreed to do the surgery was because she thought she would get pain control by having the surgery done…And I'm pretty sure that if you would have

> asked her, if you would have actually given her all of the facts and said, “you’re gonna have a tracheostomy. It’s going to hurt a great deal,” all of these different things, she probably wouldn’t have agreed to the surgery…It’s just that real miscommunication with all the different services. (P3)

One nurse recounted a specific negative end-of-life experience that had been plagued by inconsistent communication between two medical specialties:

> And the perspective of Surgery, was that the surgery was a success. And it was a success in terms of what they expected to happen was happening. So it didn’t necessarily mean the patient was actually going to recover, or that it did him any good. Just that what they expected to happen, was happening. And it was horrible. He was essentially rotting from the inside out, and he was in tremendous amounts of pain…And Surgery was just pleased as punch that his ostomy was putting out stool…When everything else was falling apart. And I remember, the ICU resident went in and spoke to the family and said, like, “we need to change the focus of care.” And the family seemed like they were kind of on board with that…. But every once in a while, a surgeon would walk in and be like, “Oh, yeah. We’re really pleased with how this is going.” And then they’d be confused, and they’d be like, “Well, but ICU is saying something very different.”...So then they would feel guilty, because, “We don’t wanna give up hope prematurely. And we don’t wanna write him off.” So when they kept getting all these mixed messages, that was really horrible for them. (P3)

Participating nurses expressed a concern that communication among the health care team is often characterized by a lack of consistent palliative symptom and care orders. The nurses explained that this makes it very difficult to provide consistent and quality palliative to patients and their families. For instance, one nurse recalled the following experience:

> And it was very clear what the goal was….And so everyone was there that needed to be there, to say their good-byes…. But Doctor ___ [the attending physician] didn't actually write any orders for me. He basically said, "just leave everything as is." So then every time something changed, I felt obligated to talk to him about, "okay so, you don't want me to do anything about this?" Because he didn't write any clear parameters for what he wanted to do. And this lady was on Prisma. She was still on vasopressors. We weren't increasing what we were using, but then of course, it's like, "okay, so you don't want me to do blood work." But then we had blood work from the morning that was abnormal. And normally, you would treat it. But because he didn't write anything, it just made it very difficult. It's the continuity, right? Usually you have orders that are written, you have parameters that you're following, and I guess an understanding of what the end goal is. But when they don't write anything, you just have to keep charting, "physician aware, physician aware." "This is abnormal, physician's aware." Whereas if he would have just written the orders of what he was okay with and not okay with, I wouldn't have had to just continually be checking in. (P3)

Many nurses also said that communication can be hindered by discontinuity of care related to nursing assignments and physician change over. As one nurse said, "I find that the lack of continuity of care can sometimes be a barrier. Both with the physicians and the nurses…sometimes I feel like the families could benefit more from having one nurse with them for longer stretches. (P7) Another nurse said,

> I think the conversations that the physicians are having really influence what the families are deciding. When the physician the week before has laid it out that this person is not recovering, they'll make plans to withdraw, and then the [new] physician coming on Monday changes

> things. And it leaves the family very confused and frustrated, scared because they think that there was a mistake that happened. (P7)

Ineffective and inconsistent communication was clearly identified as a significant barrier to quality palliative care in critical care. The profound negative impact that these communication-related barriers can have on palliative patients and their families was apparent in each of the nurses' stories. Moreover, these barriers appeared to be closely associated with identified barriers related to end-of-life decision making.

Difficulties with End-of-Life Care Decisions

> People think of critical care and ICUs as a do-everything, to save my loved one and my family no matter what. And while that's true for some part of people's trajectory in ICU….a lot of the patient-care trajectories turn into palliation. (P4)

The nurses reported that many of the discussions between patients, families, and the health care team in critical care focus on making decisions related to withdrawing and withholding life-sustaining treatment that result in a patient's imminent death. They also said that families are often heavily involved in making these final decisions. One nurse explained, "You know, the trend is to move away from paternalism in terms of deciding those medical decisions, and being more inclusive of family and patient wishes. So, there's sort of this reluctance to just be paternalistic" (P11). However, several nurses suggested that this decision-making responsibility can be a great burden on families, often leaving them with feelings of guilt and doubt. As one nurse said, "I do feel that sometimes family members hold a lot of guilt when it comes to withdrawal of care" (P9). Another nurse said, "Some families are in denial. And they think that everything hasn't been done yet. So, there's still a chance. It's almost like there's a guilt component. Some families feel guilty at saying, "okay, let's stop." (P7). A third nurse confirmed this: "I think that's what gives family distress and I think it causes some guilt, too. Like, what could have been done? What if I had just said this, you know: those “what ifs” that will just drive you crazy.” (P6). Moreover, several nurses suggested that sometimes too much pressure is placed on families to make a final decision. One nurse explained, “I’ve had doctors that say things like, you know, basically, ‘you let me know whether you think your family member should live or die.’ Like who wants that burden on them? You know, and then they feel like they’re the ones pulling the plug, so to speak” (P10).

The nurses interviewed for the study made it clear that this burden of decision-making is often further compounded by unexpected crisis situations. For instance, one nurse observed, “End-of-life in ICU, I find, is quite hard sometimes, because patients don’t come in there expecting to be palliative. They come in expecting to be resuscitated and survive. So, when they find out that the decision’s made for them to become palliative, it’s quite hard on the staff I find, especially because it’s hard on the family. It’s usually extremely unexpected” (P8). Another nurse observed:

> The family is left to make the decision of whether or not we persist in caring for this patient or do we stop aggressive measures and palliate and provide comfort measures to the patient. This is a conversation where people are caught off guard, because one minute their loved one is completely functioning in life without any known underlying disease and the next minute they’ve just received a phone call that their loved one has been in a motor vehicle collision and now they come into hospital to find out that they have a devastating head injury, and despite the best care, the best intervention, their loved one will never be the same person that they were before in life. (P9)

Many nurses suggested that end-of-life discussions and decision-making can be thwarted by disagreements regarding directions of care, particularity when the disagreement is between the medical team and the patient's family. Many nurses reported that some families have unrealistically high expectations and an inability to accept the gravity of their loved one's condition:

> Families' expectations of what we can and what we should do is one aspect. And of course, there's the emotional attachment, and certainly I get that people don't – they're not ready to let their loved ones go, most of the time. (P4)

One nurse noted that these disagreements can impede the health care teams' ability to provide quality palliative care:

> When the family is wanting to pursue aggressive care when the team feels that that might not be in the patient's best interest or under the circumstances of a poor prognosis. Those situations are challenging; you're not actually able to provide palliative care when you feel like that would be most appropriate." (P11)

Another nurse described the situation this way:

> We've got a few controversial patients. You know, in the sense that we know in the end they will be palliative. But the family is so unaccepting of that, that you still are doing things that are not palliative, that are just distressing for the patient, its uncomfortable for the patient. And you're doing it… not for them. Right? It's not about what is best for them. So I guess that would be contradictory to palliative care." (P3)

One nurse said that these disagreements can create significant problems for all members of the health care team:

> Definitely I've had those situations where I have felt a certain amount of moral distress over it. And it often usually comes when there is disagreement between either the physician and the nursing staff, or the physician and the family. Or even within the family itself. (P9)

One nurse recalled a particularly distressing confrontation with a patient's mother: "His mother was like, shaking me. "You can't pull the plug on [him]!" And it was awful. I felt so bad for them, but they had to understand, right? Like, there's nothing we can do" (P2). Another nurse said that one of the worst situations she found herself in was with a comatose patient who had metastatic cancer in his esophagus. He could not be taken off the ventilator, and his family didn't grasp the seriousness of his condition:

> They just had a lot of hope in their faith and their prayers . . . despite two or three weeks of conversations and trying to bring them to an understanding of his prognosis, like our inability to even lighten up his sedation so that he could breathe on a ventilator. And the team had instruction that we weren't going to do any CPR or vasopressors or any extending measures. Just we weren't withdrawing ventilatory support. And I was on the night that he just acutely dropped his blood pressure. His son was at the bedside. And I was basically left in the situation of explaining that there was nothing more that I could do and that his body just wasn't able to keep going. But his daughter came in five minutes later, after he had died, and was really upset that we hadn't done CPR and just there was a lot of hostile anger from the family. And so, despite that we're trying to be there to support them, there was just a lot of anger. He died on a ventilator, with a lot of dyssynchrony. You reflect back and think "what could we have done to make that a better experience"? And I really just don't know. We just couldn't, despite the best attempts to get on the same page as the family, we just couldn't get there. And so the nurses were left caring for this gentleman day in, day out, and it was tough. (P11)

The nurses clearly articulated that end-of-life decision making, particularly related to withdrawing and withholding treatment, can be very complex and difficult. Additionally, many of the nurses reported that a patient's care often remains on a blurred line between resuscitation and end-of-life care, in a state of limbo per se, in which no finite decision has been made. This creates more problems:

> What we were doing for this patient was not enough to save her life but [it was] too much that it was kind of putting her in a little bit of pain, because we were taking [her] on road trips, doing the scan that was an all-day thing, when she's on this horribly hard board, all day. But she's not intubated. We didn't line her. We didn't provide her any support for her blood pressure. So she's super hypotensive, so I couldn't even give her pain medications. And so I just felt like, either let's treat her or let's not, but I felt like we were kind of in the middle. And so I felt very confused and distressed as to how I should proceed (P6)

Several nurses emphasized the importance of ongoing and effective communication to assist families through this decision-making process. As well, participants suggested that these end-of-life decisions are often further complicated and prolonged by situations in which the patient's wishes for care are not respected.

Not Respecting a Person's Wishes

Many of the nurses said they feel uncomfortable when a patient's wishes for care are not respected. They see this as an ethical barrier to quality palliative care":

> We have these personal directives that elderly people sign and they say, "Yeah, I don't want anything done." But the minute they become unconscious, they're worthless…because the nurses are the ones that hear from the little granny that says, "I'm okay, just let me go." You know, and then [the nurses] have to fight with the children, who aren't at the bedside, [but are] saying, "no, do everything." (P5).

Another nurse recalled an experience that left her and her colleagues feeling morally distressed:

> It was a woman who was in respiratory failure, secondary to heart failure. And she was on Bypap. And she did not want the Bypap, was trying to rip the Bypap off. And her sons were adamant that they wanted her to have the Bypap, because that would sustain her life. And they instructed the physician that we were not withdrawing care. “We want everything done, do everything, do everything.” And the nursing staff, it was terrible on the nursing staff, because they were the ones that had to watch this patient suffer in the bed, to try and prevent her from ripping her Bypap mask off. The physician told us to restrain the patient in the bed, so that she couldn’t rip her Bypap mask off. And it was so morally distressing, because the patient didn’t want any of this. She just wanted to be made comfortable. And the family, the sons were adamant that, “No, Mom doesn’t know what she wants. We want everything done, we want everything done.” And it was a difficult case for me. But I also know that that was a very difficult case for several of our other nurses and [they] had a lot of moral distress over it. Because you’re seeing this patient who is so distressed, and doesn’t want this. And yet, you feel that you’re being pressured by the family and the… physician to act in a way that you don’t feel comfortable [with]. (P9)

In addition to concerns related to respecting a person’s wishes for care, the participants felt that there is lifesaving mentality embedded in the ICU culture which can be at odds with quality palliative care.

The Lifesaving Mentality of Critical Care

In an intensive care unit, usually a lot of what we do is save, do everything, keep going, don’t stop. So, I think part of the moral distress on the staff is that we have to realize we have to stop and take a step back, that sometimes we see the numbers and we see what’s happening and we wanna do more, but we

> need to actually hold off and change our course and help the patient in a different way, which may not be starting life-saving means. (P8)

There was a general consensus among the nurses that the culture of critical care is grounded in a "lifesaving mentality," which at times is at odds with providing quality palliative care:

> I think in ICU, we think we're really good at lots of different things, and we are. We certainly have our specific skill sets and our knowledge sets and things like that. But we want to be so alpha and in control. Even though we face death and dying all the time, it's sort of counter-intuitive to what we're actually trying to accomplish most of the time. You either want this great, sexy thing to happen, or, "God, why are they letting him live?" You know? "Why are we doing this, there's no point." But we don't really aid in the experience of death very well, in critical care. (P1)

Several of the nurses suggested that this lifesaving mentality often creates a hierarchy of patient priority. They explained that once a decision is made to shift the focus of care to providing end-of-life care, often times it seems that the patient becomes less of a priority compared to other patients on the unit. One nurse said she thinks that after the palliative process is started in the ICU "it's then left to the nursing staff and the family to kind of go through it alone" (P9). Another nurse said that she

> Feels like we give up on people when they're dying. And – not in a bad way, but we just maybe don't tend to them as much, and we certainly don't tend to the emotional needs, because that's not the ABCs of life. Emotions or feelings are way down there. (P1)

Another nurse said she honestly believes that palliative or end-of-life patients "are on the bottom of the list. You've gotta see your resuscitations and your critically ill first or even your transfers out get seen first, like we just don't see our palliative patients as a priority. (P10)

The nurses in the study associated this hierarchy of priority with another reality in ICU: critically ill patients have priority over palliative patients with regards to bed occupancy, which means that an imminently dying person can be transferred out of ICU to make room for a critically ill patient. The nurses said that they often experienced a substantial conflict between wanting to keep a patient who is imminently dying in the ICU versus the harsh reality of needing to free up the beds for incoming critically ill patients:

> The experience you have of, ”oh my God, we need a bed” so we just have to get this guy out versus it being like, “OK, we know we need to get this guy out, but let’s just let him die in the ICU, where it’s just a little bit more dignified” (P1).

Several of the nurses strongly objected to transferring a patient who is imminently dying to another unit, claiming that this can create additional distress for the patient and family:

> I always hope when they withdraw from people, that they die in our unit, and not when they get shipped to the floor, ’cause they’re in a four-bed ward. I worked on the floor for about a year. And when you have an inner city hospital, the clientele are not stellar. And so you move some… patient who’s on their last legs into a four-bed ward, you know, they is swearing and drinking and drug addicts and you know, crazed people. (P2)

One nurse recalled working with a physician who was eager to move a palliative patient out of the ICU, rushing her saying,

> Get it going, let’s go, why is he is still intubated? He’s taking up a bed for people who need it more.” The attitude was really not very compassionate. We’re just waiting for the guy’s, the kid’s grandpa to come in. He’s gonna be here at two o’clock. [The physician said] “We don’t have ‘til two o’clock. We have people waiting for ICU beds.” And I was not impressed with that. (P3)

Many of the nurses said that the recent introduction of designated palliative care beds to the hospital had been beneficial, but not quite adequate to meet the needs of their palliative patients:

> I know that we do have designated palliative beds within the hospital but they're just not always available. There's just no way to get the patient there on time, right? It's almost more distressing when you move someone. And then, hours later, they pass. Like, it just seems like why put them through that stress, when it was only a few hours later. (P3)

Overall, the nurses said they prefer to care for an imminently dying patient in the ICU rather than transferring such a patient to another unit. However, amidst this desire to provide care to their palliative patients, some nurses said that they are not adequately prepared to provide quality palliative care because there is no formal training available for these skills.

Lack of Formal Palliative Care Education

> But overall, I think the biggest barrier is just that lack of knowledge in terms of, you know, how we can provide care. And that lack of knowledge comes to just the fact that we haven't had any formal training in the provision of palliative care in the critical care setting. (P9)

Some of the nurses said that everything they know about palliative care is what they've learned on the job rather than anything they were taught formally in nursing education programs. As one nurse said, "You know, it's something that you just gain with experience" (P1). Many of the nurses said that a lack of formal palliative care education is a major barrier to quality palliative care in critical care. Because they don't receive formal training, one of the nurses said, palliative care isn't exactly "a foreign concept" but it's also "something that a lot of..."people aren't comfortable with" (P8).

Specifically, several of the participants explained that this lack of formal palliative care training was most evident by the common fear that nurses have of delivering a fatal dose of an opioid or sedative that has been ordered for palliative symptom management. Many nurses suggested that this tangible fear often poses a barrier to adequate palliative symptom management because it can result in withholding medications that are required to alleviate distressing palliative symptoms:

> We've had patients that they've been on narcotics for a very long time. And they require large doses of medication to achieve pain control. And dosages that make you very uncomfortable to give, when you're drawing up multiple vials of Dilaudid at one time, for one dose, it really gives you this horrible feeling in your gut, it's like, "this isn't right. This is too much." And you don't want it to be like, that dose is, you're the cause of things happening. (P3)

Another nurse suggested that the fear of delivering a fatal dose is particularly strong among junior nurses:

> Usually, junior nurses are hesitant to provide enough narcotics or sedation to a dying person because they don't want to step over that line of now, "am I providing assistance in dying to that patient," and those nurses usually need just a small explanation about, although your actions are exactly the same as if you were providing palliation, it's all about the intent. So as long as your intent is to provide comfort versus ending their life, that's where the line is. So it's not really your actions. It's about your state of mind. (P4)

Several nurses suggested that this fear is often exacerbated when a patient remains on a cardiac monitor as he/she approaches death:

> I don't know if it's a barrier. But we tend to keep people on the monitors so we can monitor them to know when they passed. And I think sometimes we get very fixated on those numbers. So if the person's blood pressure is super low, and their heart rate's low, you might not be inclined to give that pain medication, or because you don't wanna be the one to give the last dose where the person still might be in distress. I think sometimes we rely too much on what

> the monitor's showing. And not what our… nursing instincts are showing. Like what our physical assessment's showing. (P7)

This reference to cardiac monitoring was described in terms of misunderstanding, or a lack of clarity as to whether it is necessary to continue monitoring an imminently dying patient. More specifically, several nurses explained that the use of cardiac monitoring of palliative patients can be a barrier to quality palliative care:

> The other thing in ICU is even when we make that shift to comfort care, we still in some ways have them very much as an ICU patient. Like we've still got it in our brains that we need to capture asystole. So they're still on the cardiac monitor. Like how is that gonna change anything? So we've got these very critical care things that we're really hung up on. (P10)

One nurse said that cardiac monitors in palliative care are a problem for the families, who don't like seeing their loved one being disconnected from the monitor. But if the monitors are left on, the families often "fixate on the monitor. And then they're doing the death watch on the monitor rather than… just being with their family". (P11) This lack of clarity regarding the necessity using of cardiac monitors on palliative patients, leads us into an exploration of other specific components of the critical care environment, which were identified as common barriers to quality palliative care.

The Critical Care Environment

So here's the family of Bed Five. And he's going to die. And the guy in Bed Eight is up in a chair, watching TV. But he doesn't have his hearing aids. So he's blasting country music at two o'clock in the morning, at concert volume (P2).

Many of the nurses said that the overall ICU environment can pose a significant barrier to quality palliative care. One nurse described the ICU as a "cold and sterile environment" (P6). Another said that privacy is a significant issue:

> We've [got] clear walls and clear windows and clear sliding doors. There's no privacy. There's not a quiet, comfortable environment. Our waiting room is stuck with a million other people. We have one little, small family room. Sometimes that works. But there's just not an environment that feels like we care . . . whether that's end-of-life or any sort of critical moment. (P1).

Several nurses said that the heavy use and presence of technology in the ICU environment can hinder the quality of palliative care experiences. One nurse pointed out that there is nothing particularly warm or comfortable in the ICU, but the biggest problem isn't comfort, it's lack of familiar surroundings. She said, "ICU is a foreign entity to everybody. Nobody walks into some place and sees 37 pumps and is like, "Well, I've seen this kinda stuff before." Everything makes a sound" (P1). The noise is definitely an issue:

> The ICU's very loud. There's lots of machines beeping. People talking. Lots and lots going on. At least in a palliative unit, the rooms, to my understanding and from what I've seen, the rooms are more set up to have more of a comfort feel, more of an actual room, like at home versus in critical care. Cause in a critical care room, the rooms are large, but there is a lot going on in there. And it's not very homey-feeling. I don't find the ICU rooms very comforting. (P8)

In sum, the nurses shared numerous personal testimonies of their experiences related to the barriers to quality palliative care in critical care. The most significant barriers relate to communication, end-of-life decisions, ethical dilemmas, the lifesaving mentality of ICU, a lack of formal palliative care education, and the critical care environment. Overall the nurses agreed that for the sake of patients and their families, these barriers need to be addressed and corrected, and the facilitators of quality palliative care need to promoted and better utilized. The next section of this report will explore the facilitators of quality palliative from the perspective of the participating nurses.

Barriers and Facilitators in the provision of Quality Palliative Critical Care:

Critical Care Nurse's Perspectives

Chapter 4: The Facilitators of Quality Palliative Care in Critical Care

The Facilitators of Quality Palliative Care in Critical Care

Throughout the interviews, the nurses identified several facilitators of quality palliative care in the ICU. The most significant facilitators identified include effective communication, supportive decision-making, palliative care education and mentoring, contributions of the interdisciplinary team, and an environment that is conducive to positive palliative experiences.

Effective Communication

“Communication is probably the essence of doing this work well” (P11)

The nurses were adamant that effective communication is essential to quality palliative care. Specifically, they said that to be effective, communication must begin early in a patient’s ICU stay. In fact, one nurse said that end-of-life planning for some patients should begin as soon as they arrive at the hospital:

> You don’t wanna plot their trajectory too quickly, because I think people have a tendency to give up on it. But let’s have some conversations about quality of life from the get-go. Let’s have that conversation. And let’s talk about advance care planning and code status before you’re forced to make a decision. Let’s have some conversations with families, to talk about what end-of-life really does look like. (P1)

Another nurse stressed the importance of communication this way:

> I cannot count on two hands the number of families that have said, “I just don’t know what’s going on. I hear one thing from one person, one thing from another.” So I think that once there’s been a shift, even if it hasn’t been written that the patient is palliative, once you’re starting to shift to that sort of thinking, you need to loop into the family, so that it’s not just a shocker when one day [they hear from the medical team] “Oh, sorry, we can’t do anything else. (P5)

Another nurse proposed that every day after rounds the medical team (or nurses, or whomever she meant) need to be talking to the families of patients who are candidates for the withdrawal of care 'because those people don't get it ... and it's understandable. People hear what they wanna hear. They grasp at anything…I mean, it’s only human.” (P2) The nurses agreed that for communication to be effective it must be patient-centered. Accordingly, they emphasized that the goal of communication is to enter into a dialogue with families to identify what is most important to the patient:

> When you’re having those conversations, you get them to tell you about what they’re like, what they were like at home before, so were they a hunter, were they an artist or, you know, we had a man that was a mountaineer. And so, as soon as they really start getting going about who they are and what their values and their beliefs really are, that really helps them cope with seeing how far that person has deviated from the things that they love. And knowing that, as a person, that they’re never gonna go home or they’d be in a nursing home and they’d be in an altered state for the rest of their lives. I think that can be a comfort for the family.” (P10).

Another nurse shared:

> We’re finding out about the patient, not from the patient themselves, but from their family members, right? So, when we can actually say to their family member, what is this patient like? What are their goals in life? What are their dreams in life? How have they lived their life? How… would they be okay living with pain? Would they be okay living with dialysis? Would they be okay living with dyspnea? Would they be okay living in a long-term care facility? And when families are able to kind of frame what the patient’s future may look like, from the patient’s eyes, I find that often helps them come to a decision in terms of, what decision should we make on their behalf? Or what would the best outcome be, that would be acceptable to their loved one?” (P9)

The nurses explained that effective communication is open and honest and does not provide false hope:

> Whether it be someone who has a chronic disease with a terminal prognosis in the end, and/or whether it be someone who has sustained a devastating and traumatic injury, and their life will forever be changed, I think the biggest thing in terms of being able to talk and communicate with these families is just that we provide them all the information that we have at hand. That we're honest with them, what the outcome in the end is most likely going to look like, based on our experience and what research is showing. But also, not hesitating and saying, "I don't know."…"I know that your loved one will never be the person that they were, you know, before this"…But I also don't know what their end-point will look like either, if we continue to persist." (P9)

Another nurse said that when families ask her if a patient is going to die, she answers honestly and says, "I don't know" and then proceeds to tell them what she does know:

> I know that what we can do is we can really watch their symptoms and we'll make sure that they stay comfortable. And that's for pain and they're not gonna be short of breath, and that we're gonna still turn them and care for them, and still love them as a human being until they pass. And [I tell them] you can be here as much or as little as you want. And I think if we let families believe that you care, then they can be comfortable trusting you to care for their loved one in death. And they don't have to be there, waiting, touching, holding for that last breath. So if they feel they need to just step out to take a minute, just reflect their thoughts, or have a 15-minute sleep, or go grab a bite to eat or whatever, to care for themselves so they can sort of handle this huge emotional impact that's gonna happen to them, we have to build that trust with them. (P1)

As was true with the communication-related barriers, the nurses said that facilitators to quality palliative care that relate to communication are closely associated with the facilitators that relate to end-of-life decision making.

Supportive Decision Making

“I think just making them feel as in control of the situation as they can be. But without burdening them with that decision, that final decision” (P10).

Many nurses emphasised the great importance of supporting patients and their families through a decision-making process, particularly when decisions have to do with withdrawing and withholding life-sustaining treatments. One key to supportive decision-making is to allow a family the time they require to make a decision that they feel is best for their family member. For instance, one nurse noted:

> I think for the most part we’re pretty good at not making families feel like we’re pushing them, as though we need the bed or we need the room or anything. But I do think that just like slowing down that process a little bit and giving them time… even if the family needs a day just to come to the conclusion that we need to withdraw, then give them that day. I mean, in the end, what’s important is the patient and making sure that they’re not in pain and… we’re not prolonging their life for any other reason than just because the family wants to. So, I think finding that balance is appropriate. But often, these things happen very quickly. (P6)

Another nurse observed:

> If they know that their husband would never want to live in a long-term care facility, then there’s not that guilt or that angst in terms of you know, deciding to proceed with comfort measures and palliative care. That they feel that they’re truly making the decision that’s in the best interest of their loved one, from what their loved one would want. And I think those conversations, they can’t be rushed. It takes time to have those conversations. It takes time to

> figure out, you know, the true beliefs of the patient and their family members. And then it takes time, and it takes a lot of honesty, to discuss with the family – and with the patient, if they're able to participate in those conversations, what is that process going to look like? You know, and potentially, what is that process going to feel like? (P9).

Several nurses identified the importance of respecting a patient's or family's decisions, particularly in the context of a disagreement regarding directions of care:

> I think we have to learn how to say, "I don't agree with what you are doing. But I can work past that, because I'm a professional, and I'm a human being, and I respect that you're a human being who has emotions and feelings. And that I support your decision, or maybe not your decision, but I support what's happening." (P1)

Many of the nurses identified the positive impact that advance care planning can have on end-of-life decisions because it removes the burden of decision-making from family, and helps prevent disagreements regarding directions of care. Overall, advance care planning was viewed as a strong facilitator of palliative care and an important component of supportive decision-making because it enables people to speak for themselves in the event that they no longer have the capacity to make personal decisions:

> I think those situations, when pre-existing conversations happened, or even if there is a medical directive in place prior to the patient coming into the hospital, those are the best case scenarios. When the patients have had the conversation in terms of saying, "If something ever bad happened to me, this is what I would live with or not live with… I think the easiest conversations to start between the family and the medical staff [are] when family has already had that conversation with the patient. (P9)

Another nurse agreed that having those conversations in advance of a hospital stay can make a big difference:

> They can say, “No, my mom was very adamant, you know. She wouldn’t want to be on dialysis.” Or, “My dad, you know, told me, never, ever would he want to have CPR.” Or, “You know, my husband said, if I could never walk on my own, or feed myself, then no, don’t put me in a long-term care facility.” I think those are the best conversations that can happen before the situation, because then that gives us a good understanding of what the patient would be comfortable with, which means that’s what the family wants. And we can work together as a team in order to make sure that that outcome happens. (P9).

Having observed many families “talking about palliation and the dying process,” one nurse had this to say:

> ”We’ll have a lot of people come in who are very advanced in age, and the family’s not clear on what they want, necessarily. Because it seems like talking about death and dying is a faux pas when really, it shouldn’t be. And that would be a huge factor, I think, for families, if talking about death and dying was a more open conversation, so that when it does happen to their family member, they can feel more at peace with their decision and also more confident and potentially, who knows, decrease the arguments or the disagreements between the members when they’re making the decision to make someone palliative and say, no, that’s what their loved one would want. (P8)

In addition to identifying that effective communication and supportive decision-making are essential to providing quality palliative care, the nurses suggested that critical care staff require palliative care education in order to enhance their skill of caring for a palliative patient and their family. As such, palliative education was identified as a facilitator of palliative care. However, the nurses suggested that palliative education is a resource that is not readily available to critical care health care professionals.

Palliative Care Education and Mentoring

"We need understanding of what death is. Like the physiology of death. We're good at the physiology of life. But we're not good at the physiology of death and comfort care, and treating symptoms." (P1)

Several of the nurses in this study expressed their concern that so little formal palliative care education is available to critical care nurses. They also frequently expressed a desire for more in-depth palliative care knowledge. One nurse suggested putting a component of palliative care education into the ICU school education, which she described as "fixated on the physiology behind all the illnesses and the treatments and the fixes":

> I think if they did even just a small little tidbit of, "Okay, sometimes you're gonna be withdrawing on your patient, and this is what you should be expecting and it's perfectly acceptable to be giving morphine even if their vital signs are poor, if the person looks like they're in distress." I just think it's such a huge change, when you're new, you're all gung-ho, caring for like the super sick patients that you're trying to provide all the interventions for. And I think that's the focus, initially. But then, you'll get the one patient that you're withdrawing, and I think, when you're new, it's hard to make that transition quickly…we don't really touch on it in our certifications. I think if we did, it would just have to be a short thing, just to remind everyone. I think that would help. I think doing some in-servicing on the unit could help too. And just more information, 'cause we get all the ICU symposiums, the medical symposiums, but we don't usually see any information on palliative symposiums which some people can get interested in, maybe. 'Cause some people are really good at it. (P7)

Another nurse observed that a lot of her colleagues are unsure of proper dosages when they receive orders to switch from life-saving medications to palliative symptom management treatment. They ask questions, such as:

> "How much can I give?" Or, "Okay, well what does dyspnea with passing look like?" Or, "Well, I know I need to turn [my patients] and they're uncomfortable if I turn them, but if I do this, I'm afraid that that that might be it. I don't wanna do something to actually kill somebody." But to actually learn that? You know what: keeping someone comfortable is more important than having someone suffer, or be in pain or uncomfortable in their last minutes, hours, days, whatever it is.(P8)

Several nurses expressed a desire for education on how to engage in serious illness conversations with patients and their families. For instance, when asked what kinds of palliative and end-of-life education would be helpful to critical care staff, one nurse replied:

> The two that I can think about would be what kind of modalities are available to us in terms of helping a patient who is end-of-life.... But I think maybe even more importantly would come to that communication piece, the education or the mentoring, in terms of how we can be there to support the family members of those patients that are dying. How can we be there to support the patient that is dying and that connectedness piece, that support and that caring piece, rather than kind of trying to avoid the situation and staying outside of the room. How can we communicate with the families and let them know that we're there to help provide them [with] comfort and support? By no means do I want families to feel like we're being intrusive on them. But I also want them to feel that we're still working with them through this process. (P9)

Another nurse who has been in the field for 13 years said she feels comfortable communicating with families, but she knows that a lot of her colleagues do not:

> It’s still very much, “Oh no, the doctor has to speak to them about that.” Which, I get that the doctor has to tell us that that’s the prognosis and that’s the way the plan-of-care is going. But once that’s happened, why not train your nurses to have those conversations? We’re the ones that have the rapport. (P5)

Several nurses suggested that there is a need for experienced nurses to support and mentor less-experienced or novice nurses in providing quality end-of-life care to critical are patients and their families. For instance, one nurse explained:

> In the intensive care unit, when it’s our brand-new nurses who may never have taken care of a patient who is dying before, it’s also a very overwhelming experience for them. And they do need to be mentored and led in terms of what the process is going to look like. And what their role is in that process. And how they are going to provide comfort and alleviate suffering for both the patient and their family. (P9)

Another nurse observed:

> I don’t think we mentor great. I tried. But you know, good days, bad days, whatever. But when you see people that are struggling, whether that’s end-of-life care, or a code, any situation, I feel like as nurses we have to be more willing to say, “Okay, I see that you’re struggling. Let’s talk about this.” Or “Do you want me to go talk to your family for you?” and “Just come with me, and I kinda get what’s going on, but I can maybe skin the tail for you a little bit better, so it doesn’t sound so heavy or deep or scary or intimidating or… whatever. (P1)

In addition to identifying that palliative education and mentoring is a facilitator of quality palliative care, the participants highlighted specific contributions that many members of the interdisciplinary team bring to the care of a palliative patient and their family.

Contributions of the Interdisciplinary Team

> "I think… if I could answer it in terms of one thing, it's a multi-disciplinary approach. Very much a multi-disciplinary approach. When we have people involved such as spiritual care and social work, in addition to the bedside nursing team and the physician team, I think that really improves the quality of the palliative care that we are able to provide, because it provides that extra support to the patient and their family member. It helps to bring different perspectives. (P9)

Many nurses indicated that quality palliative care is supported by a multi-disciplinary team approach. For instance, when asked what supports quality palliative care, one nurse explained, "In ICU, we have great physicians. We have the nurse practitioners. We have amazing nurses. We have great support staff, such as social workers, spiritual care…once we are allowed to do palliation, everything just clicks and it works smoothly" (P4). The nurses frequently referred to the strengths of specific members of the multi-disciplinary team.

There seemed to be a general agreement that some members of the health care team are palliative champions who have an innate ability to provide outstanding palliative care to patients and their families. Regarding variations of skill among the physician group, one nurse observed, "Most of the physicians are pretty good. But I guess their philosophy is varied. And some of them have an easier time and seem to have, like, a knack for dealing with it" (P3)**.** Regarding the variation in palliative skill levels among nurses, one nurse acknowledged that "obviously there's just some nurses and physicians that are really great at it. And some of them are less so. And we have physicians who are great critical care physicians. And some are better at end-of-life than others" (P1). Another nurse said that "some nurses are just better with dealing with end-of-life care than other nurses. There's a lot of nurses that are more interested in the high intensity stuff in the ICU…But it's just a different personality. Some people, it's just not for them" (P7).

Interestingly, some of the nurses suggested that it would be helpful for managers, when making assignments, to be mindful of who does what best and schedule people accordingly. As one nurse explained, “I think we just need to learn who’s got the strengths in it and play to those strengths” (P1). Another nurse said:

> We need managers who wanna lead that and assign the right people. Everyone has to have the experience of caring for a dying patient, for sure. But I think you have a tendency to see the same trauma nurses who take care of the trauma patients, or whatever. Why don’t we have the right nurses or the right team of people caring for, let’s play to your skill set, you know? I don’t think there’s anything wrong with that.” (P1)

There was an overall consensus that the more experience that nurses gain in caring for palliative critical care patients, the stronger they become at providing quality palliative care. In essence, experience is what you makes you the expert:

> If I think of the staff who I think provide really good palliative care, novice nurses don’t come to my mind. But even after a couple of years of experience, people seem to really develop that skill set. And then, you know, we have some really fantastic senior nurses. But I do think being a novice nurse doing end-of-life care without a lot of experience is challenging for the nurse at the bedside. (P11)

The nurses agreed that nurse practitioners have unique strengths (in what area?) when it comes to caring for palliative patients in critical care. As one nurse put it, “the nurse practitioners have really steamrolled” palliative care in the ICU:

> A lot of them will be the ones that are speaking to the families on a more regular basis than the physicians. They’re also a lot more willing to talk to nursing staff. Maybe ’cause they’ve been there and provide guidance to someone that maybe hasn’t cared for someone that’s palliative in

> the ICU, because it is different focus: you're focusing more on the comfort. So I think the nurse practitioners are a really good resource on our unit. I think they provided a lot to the staff, a lot of education. And they are pushing for good end-of-life care. (P7)

The nurses also acknowledged the contributions of the Rapid Response Team, giving the team credit for being significant facilitators of quality palliative care, particularly in regards to facilitating goals of care discussions with patients and their families. One nurse said the Rapid Response Team has made a positive difference in patient care because the ICU team and the units work together:

> I think it has made a difference for the nursing staff because they know that they can call us. And there's so many residents in – I mean, an R1 is probably less comfortable than an R3 in discussing it. So we can help them guide that. And we can also talk to the families and usually we have a little bit more experience talking with families about it. So, we can kinda guide them, and tell them if they go to the ICU, this is what you can expect, and then some families will be like, "Well no, that's not what our father or mother would want." They can make that decision. (P1)

The nurses identified several members of the Allied Health Team as having a prominent role in enhancing and improving the palliative experiences of patients and their families. Honorable mention was particularly given to chaplains, and social workers. As one nurse explained, "Our social worker is fantastic.... But she's got a heavy load, too…., I think our unit could almost use two full-time social workers sometimes. It's phenomenal the amount that they do" (P3). Another nurse shared:

> I know in many situations when we have our spiritual care worker that is able to come in and spend time with the family, sitting at the beside, you know, re-living memories of the patient in good times that they've had, or bad times that they've had, you know, and to support the family to, you know, perhaps pray with the family if they're a spiritual family. I feel that it really helps

> to facilitate that palliative process. You know, they're not providing medications, they're not providing sedatives, but they're providing support. They're providing care. They're providing love. And that really does alleviate the stress or anxiety that patients and families may be feeling as they're going through this process and helps them to feel supported through that process. (P9)

One nurse recalled a young aboriginal woman who had lived a hard life and was dying of liver failure:

> She was estranged from all of her family, and one of our aboriginal counsellors stayed at her bedside all night and sang to her, and sang to her while she died, and that just had such a profound impact, that nobody else was really even going in the room. But this woman sat with her. She didn't know her, and sang to her all night. (P10)

The nurses specifically praised the influential role of the Palliative Care Consult Team. As one nurse said, "I do appreciate it when the palliative care team shows up because they're the experts and they can provide the family with some reassurance and a better knowledge base of what is palliative care" (P8). Another nurse said, "I would like to see more palliative care, more of a collaborative approach come into caring for our patients in the critical care setting" (P9). One nurse wondered if it would possible to have a liaison or someone in palliative care that the nurses on staff could page "if there was something they were uncertain about, or if they were looking for this resource, or felt you know, this family could really use something, there's someone you could easily connect with, outside of the critical care world" (P8). Overall, the nurses said they appreciate the unique contributions that each member of the health care team brings to the care of palliative patients in the ICU. They are particularly appreciative of the Palliative Consult Team's expertise. However, they feel it is important to have an established standard of care for all critically ill patients, and recommend that ICU clinicians and palliative experts translate this standard of care into formal palliative medication and care order sets to achieve that goal.

Palliative Order Sets

> To be honest, I'm not actually a super big fan of order sets. But that being said, I think sometimes there are some strategies that are utilized in palliative care sooner. And I think having an order set just to actually tweak people to think of those strategies would be helpful" (P11).

Although many of the nurses objected to the creation of a strict palliative care protocol, they suggested that an overarching palliative order set would be a helpful resource to the medical team to address the unique needs of each palliative patient:

> I know that on the ward units, they have palliative orders…This is a list, step by step, of what you're supposed to do, in order to make life easier for your palliative patients… having a set list of bullet points, so that you can make sure that your doctor has addressed each one of those things, in a unique manner, would potentially be helpful. (P5).

Another nurse explained,

> "I'm not a big fan of order sets, but I think an order set would actually really help. Because it then would delineate whether or not you're continuing your feeds, whether or not you're continuing things like oxygen…something that would then be as a standard of care, like just… say that for every single comfort care patient, we are doing all of these things that you're still turning, that you're still changing dressings. And I think that would at least ensure that there is a standard. (P10)

In addition to the creation of palliative care medication and care order sets, the nurses suggested that specific components of the ICU environment should be maximized when caring for a palliative patient, because those components have great potential to facilitate quality end-of-life care.

Establish an Environment that Promotes Quality End-of-Life Experiences

“I think that the environment, if properly controlled – I think it’s a great environment.” (P2)

Many of the nurses said that to improve palliative care in critical care, it is essential to create an environment that is conducive to a quality end-of-life experiences. Overall, the nurses tended to agree that the critical care environment has the potential to foster positive end-of-life experiences:

> I think in general, I think our staff are really great with patients and families who are dying. I think we have nice private rooms with lots of space for families to be together when that’s happening. We have the one-on-one nursing care where you have a nurse, pretty much dedicated to being there for that patient and that family, and so I think that makes that aspect of the care probably better than what it is outside of the ICU environment. If you can get the technology out of the way as much as you can, then I think that’s an extra bonus. If I had to pick somewhere to be palliated, it would be here…because I think we do it well. (P11)

Several of the nurses suggested that an environment that promotes privacy is essential to quality palliative care:

> I think it just gives the family permission to grieve as openly as they want, but our rooms are very sterile in the ICU and I think that once you’ve shifted to a palliation, at least a comfortable chair, heck, even a chair – half the time, you know, if a family comes in, and there’s more than two of them, they have to stand. There’s no support in terms of making them comfortable while they’re going through probably what is like the worst moment in their lives – directly in the room. And overnight, right? Lots of family members want to be there when their family member passes. Well, I’m sorry, the sterile waiting room, where you have 18 other talking patients – like we have one tiny little family room. And we could have four palliative patients at the same time. Well, how is that helpful, right? I think giving them a place that they can go

> to unwind for even 10 minutes – I mean, the surgical patients, the families have these two beautiful surgical waiting rooms. Well, that's great. But we don't have anything for family members that are losing a loved one. We don't have a kitchen, they have to buy food from down in our food court. Without asking us, they can't microwave anything, they don't have access to their own… anything. So I just think, even if there was a room that would have like a kitchen and maybe access to Wi-Fi, or something so that they could keep other family members in the loop. I mean– that would be helpful. (P5)

The nurses said that it is important to create a calm and peaceful environment. Many nurses praised the White Rose Program, a recent Alberta Health Services initiative introduced to promote a calm and respectful environment when a patient is imminently dying.

> "We do have the White Rose program that was put in place this last year. So we have these… laminated papers, it's a white rose that's on there. So if we know someone is imminently passing, we put the white rose on the doorway. And it's just a visual cue for staff to not be disruptive, so, not rummaging through the C-lockers in the room for supplies when they don't have it in their room. [It's] even for housekeeping, our service aides who empty laundry and stuff like that, just so that they're not being disruptive and… kind of giving the family a little bit of privacy. (P3)

Many nurses said they felt that it would be helpful to humanize the critical care environment:

> I think it can be very impersonal, at times. And that's where, as nurses, physicians, the inter-disciplinary medical team, I think, in order to try and overcome that, we really need to make a strong effort to bring the human side into it. There's a lot of machines that we use; it's very technology-oriented. And if we can try to humanize it a little bit more, and by doing so, I think explaining what the machines are and what they do is very important. But also, making that

> ultimate focus about the patient: it’s not about the monitor, it’s about the patient. And hopefully that can help overcome some of those barriers, ’cause I think at times it can be seen as very technology-oriented rather than patient-oriented, which is what it should be, right?” (P9)

Several of the nurses emphasised the importance of “providing the extra little comforts” (P5) to patients and their families. One nurse talked about another hospital that offers a refreshment cart with bottled water and snacks for families because familes often do not want to leave the area:

> We don’t have that…It’s more relied on the nurse, to like, “okay, maybe these people need some water.” And then, go and get it. But we’re not really set up properly for that. Like, you can only bring them the little Styrofoam cups. We don’t have cups with lids, or anything like that. I think that would be helpful, to the families. We only have that really limited family rooms available. So oftentimes people are either left out in the waiting room with everyone else, when they’re grieving. Or… they’ll go away. But a lot of times, families don’t wanna leave, ’cause they’re scared that they’ll miss it. We don’t have a great system for letting people stay. We can sometimes get a stretcher bed but that’s pretty much just for one person. (P7)

Another nurse explained that it is often therapeutic to personalize the space by decorating a patient’s room with family photos and personal mementos as a means of assisting the patient’s family to “remember their family member as they did in their life and in those best moments” (P6).

Overall, the nurses had a clear understanding of what facilitates quality palliative care in critical care. They identified facilitators that were already a component of critical care, but also had the insight to make suggestions for future improvement. Study findings revealed that participating nurses were highly committed to improving the quality of palliative care provided in critical care.

Barriers and Facilitators in the provision of Quality Palliative Critical Care:

Critical Care Nurse's Perspectives

Chapter 5: Key Messages

Key Messages

In addition to identifying the barriers and facilitators in the provision of quality palliative critical care, pertinent key messages arose in relation to critical care nurses' experiences with death and dying in the ICU. These themes include the reality of death and dying, the difficulty of shifting hats, moral distress, the components of a good death, the nurse's connectedness and relational narrative, and the potential for improvement.

The Reality of Mortality

As the nurses described their experiences, the difficulty of coming to terms with the reality of mortality emerged as a prominent theme. For instance, one nurse said that the first time she had a patient die was also the first time she realized that:

> End of life was a lot harder than I had given it credit for before that. I thought I was so good at dealing with it. And then I was like, 'Oh, I'm not actually as good at dealing with that as I thought.' And then I really started to think about it. (P6)

Another nurse said that the first time she had to deal with a dying patient in critical care, all she could think was, 'wow! Like, tomorrow? You're no longer going to be here". (P1) It was also the first time she'd really thought about how profound and final death is:

> This is a human being. Someone gave birth to this person and they raised them, or someone raised them, and they had family members and people who loved them and cared about them. And now they're going to be gone forever.' You know, it's crazy there. It's a very finite life." (P1).

One nurse described the harsh reality of the physiological process of dying:

> I hate leaving the breathing tube in, because I feel like it prolongs things. You know, a natural part of death unfortunately is obstructing and passing away, because you cannot maintain your airway" (P5).

Another nurse suggested that we must eventually come to terms with the fact that death is inevitable: "But these things come, the issues come up acutely. And people get into accidents. And people get sick before their time." (P4) Along with this difficulty of coming to terms with the reality of mortality was the recognition that switching the focus of care from resuscitation to end of life care is a difficult process for the nurses.

The Difficulty of Shifting Hats

Many nurses spoke about the challenges of "shifting hats" from providing aggressive lifesaving and life-prolonging interventions to providing palliative care. For instance, one nurse shared,

> The nurse experience, I think is not necessarily as good until you get there. So the palliative process in the ICU is not as cut and dry as say, like, working on a palliative unit. You know when you come to that palliative unit, your patient is palliative, and you just put on that hat. Whereas a lot of times, I think nurses feel disturbed, or morally distressed, trying to get to that palliative point" (P5).

The same nurse described this transition in the following way: "when you switch to a palliative patient, it's almost like there's the big backpack of ICU that you are carrying; you just take it off and put it in the corner" (P5). Another nurse said that this shift in focus of care can be challenging because it is contrary to the lifesaving mentality of the ICU, "and then, just having to switch your nursing focus from fixing everything to just providing comfort is kind of a different focus than what you're used to in the ICU" (P7). Another nurse made the point that in ICU:

> Even when we make that shift to comfort care, we still in some ways have them very much as an ICU patient. Like we've still got it in our brains that we need to capture asystole. So they're still on the cardiac monitor. Like how is that gonna change anything? So we've got these very, like, critical care things that we're really hung up on (P10).

Although they often struggle with having to shift the focus of care, the nurses showed pride in their ability to do so:

> I'm always just amazed how quickly the nurses can switch hats because, let's be clear, the ICU nurse is going to ICU because they like the excitement, they like the action, they like doing things to save people's lives. But I'm proud of the nurses for being able to switch hats so quickly, and move into providing comfort and basic care, to provide dignity and a good death. (P4)

Moral Distress

"I think that we all suffer some moral distress in certain aspects" (P9).

Many of the nurses identified moral distress as a substantial struggle for critical care nurses. Overall, this moral distress stemmed from a great concern for the patient's wellbeing. As one nurse said, "The moral distress, for me personally, comes from the fact of 'are we doing the right thing for this patient?" (P9) The nurses recounted situations in which they experienced moral distress specifically in relation to common ethical dilemmas that occur in critical care. Sharing their stories made tangible the sobering reality of the negative impact that these ethical dilemmas can have on the end-of-life experiences of patients, families, and health care providers. The nurses told these stories with strong emotions, including regret. One nurse put it this way: "I've gone home and cried after a shift, because you just feel what you've done is morally wrong" (P7). Another nurse shared:

> “I mean, you lose sleep over it. We have absolutely a warped sense of humour because of it. Because you have to joke about things that are so horrible like that, in order to be able to come back and do it the next day. (P5)

Medical futility was identified as a common ethical dilemma that caused the nurses to experience moral distress:

> We did hear about this one patient who became a quad from an accident. And I think they were in our ICU for three months. And they were in and out of ICU. We’d try and send them out, and they’d get brought right back as a rapid call. And then finally, one day, they just went out and then that day they coded. And passed away. And it’s just, I don’t know where that link is missing or if that would even change anything. But [just] because we have the technology and the resources to save these people, I don’t know [that] that’s always the right decision. (P6)

Overall, the nurses frequently expressed their concerns regarding medical futility, explaining that sometimes they feel a patient’s treatment is overly aggressive. As one nurse asked, “how far do you go when you know what the end point is” (P2)? Another nurse used the following story to express her concern about medical futility:

> A patient who… for example, is 86 years old and has lung cancer with mets to the liver. Mets to the spine. And yet, the family say[s], “we want everything done. We want her to be an R1.” She absolutely needs to go to the ICU. You need to save her. When the reality of the medical decision tree is that she has metastatic Stage 4 cancer in probably more than one area. Yes, we can put a breathing tube into her. Yes, we can pound on her chest if her heart stops. Yeah, we can poke her and put in central lines, and we can make her uncomfortable by tying her to the bed to make sure she doesn’t pull any of these things out, but the end result is that she will die from cancer. I use the age of 86, but it could be a 40-year-old with those symptoms. You still

> know the end result is that they will die of this cancer. And the family, they hear it, but they don't hear it…..So you end up bringing this 86-year-old, or this 46-year-old, to the ICU, ramming a breathing tube down their throat, and the end result is they will die. (P5)

Another nurse shared the following:

> Keeping a person alive mechanically or with medications for a long period of time, I find that more distressing. Because sometimes the person inside, who's laying in that bed, isn't really even there; sometimes it is strictly the machines keeping them alive. And whether it's that we haven't got all the information together yet to deem them palliative for sure, or the person didn't have advance directives, or the family can't make their mind up, I find that, even though letting someone become palliative is sometimes morally distressing, the decision to keep going when morally, to me, it seems like the wrong choice, or we have this one percent chance they may survive, and to know and understand that that's not what that person would want, is harder. (P8)

The nurses frequently expressed their concern that overly aggressive treatment causes undue pain and suffering for the patient. As one nurse said, "I often feel that I am hurting the patient with the aggressive care. We're just prolonging something that is inevitable." (P7). These situations were often described as"torturing" or "flogging" the patient. One nurse observed, "We flog them to death, then we end up withdrawing. It's slow and obscene" (P2). Another nurse shared the following:

> In my perception, if I'm going from my perception, we throw around words in the back room like torturing. We're flogging the patient. So any time I think that you have those kinds of perceptions, you would hope the patient's comfortable. But at the same time, if somebody's dying, why would I be poking them for a blood sugar? Why would I be doing all these painful interventions, even if they are slightly under? I mean, I hope that their GCS is low enough that

> they can’t feel things. But maybe it’s just low enough that they can’t communicate their discomfort for those things, right? And so, I mean, I tell myself that they’re comfortable in order to sleep at night. But I mean, if I’m being honest, using those kinds of words, how could they be? (P5)

Many of the nurses expressed a strong desire to protect their patients from the pain and suffering caused by medically futile and overly aggressive interventions. As one nurse said:

> But instead of dying a peaceful death, where you say to the family, “there’s nothing more we can do at this point in the ICU that will benefit, let’s just keep her comfortable and be with her while she passes,” no. Instead of that, we flog a patient. And it’s almost like torture and I know your recorder can’t see my face right now, but it makes me angry… and you just, you wanna walk up to families and be like, “do you understand, like everything we’re doing, hurts? It hurts.” And so that’s what flogging is. It’s like a torture. And we call it flogging because there’s nothing you can do about it from a nursing perspective. Your hands are tied. Your physician has ordered these treatments. And you still have to be friendly to the family member who becomes almost like an enemy in your mind, right? Because you’re like, “look at what you’re doing to my patient.” And you develop that “it’s my patient.” You’re almost like a momma bear. And you’re like, “you are hurting my patient. And I’m supposed to be doing everything to not hurt them.” So, flogging is just like a whole psychological badness, and it angers you. It doesn’t benefit the patient, not one bit. Not one bit. All it does is hurt them. (P5)

These concerns regarding medical futility often led participating nurses to experience haunting questions related to the person's overall quality of life, specifically, how the person’s quality of life was being affected by aggressive treatment, and what quality of life the person would have if the treatment was successfully lifesaving and/or life- prolonging. As one nurse explained:

> I’ve often wondered about this,. We do so much for these patients and we bring them back from the brink of death every day. But what happens when they leave? What is the survival rate? And sometimes I question, great, we saved them this week, but what about next week? What now is their quality of life? (P6)

Another nurse described a situation that had been bothering her since it occurred:

> The patient had come from the States. He had had a motorbike accident. But a few months prior, he had written out a living will. And in it, he had said that if there was ever a time where he was not gonna be able to live without deficits, that he was gonna have to rely on family to care for him, that he didn’t wanna be kept alive. He’d had this horrible accident in the States. They were able to stabilize him and they shipped him back home. When we got him, his CTs and stuff were terrible. His vital signs were terrible. He was extremely unstable. And the physician had discussions with the family, and the family was like, “he’s already made this known. This is not how he would wanna live if he’s gonna have deficits.” I think he came in on a Tuesday. And the physician talked to them, and they were like, “hey, this weekend, all of the family will be there. We’ll withdraw on him them.” So, he was withdrawn on. (P7)

By the end of the week the patient was doing so poorly that the medical team expected him to die on Saturday, but not only did he pull through, he rallied on Sunday. On Monday a new doctor took over. After looking at the CT scans, he observed that a certain percentage of patients would survive the sort of trauma the patient was undergoing, and he began to order medications to regenerate brain tissue. The doctor said, "I think we can help him. He's breathing on his own without the vent." The nurse went on:

> “We started feeding him again. Started him back on medications to help him. But we weren’t doing inotropes and we weren’t gonna put him back on the vent. The family made that very

clear, that they did not want that. But we were still treating him quite aggressively. And I had taken care of him the day after they made that decision to restart feeds. And the family was questioning me about, “well, have you seen people recover from this?” He’s not really waking up.” And, just really questioning, “is this a good thing?” And then, I had actually had the opportunity to work with them two additional days that week. So they were quite comfortable with me. And I was talking to them one morning, because I could tell that there was something wrong. And they’re like, “We feel really bullied.” And I was like, “Well, bullied in what regard?” They’re like, “This is not what we want. We tried to withdraw on him. And now, we’re treating him and we’re being told that there is this percentage of chance that he’s gonna recover. But if he’s not in that percent of a chance that he will recover, then he’s gonna be in a nursing home and he’s gonna hate us.” And, they were really upset that they felt like they could not say, “No” to this doctor. It ended up I had a discussion with one of the NPs that was taking care of him. And I’m like, “This is wrong. The family does not want this. They’re quite upset: they feel like they were pressured and bullied into it.” So he went and had a meeting with them. And then we kinda guided them in what to say to the doctor. And the NP had had a conversation with the doctor about how the family didn’t feel like this was appropriate. So eventually he was withdrawn on, completely. But it was like a week later. And I had gone in and checked to see where he had been transferred to, and I saw that he had passed away the day after I had taken care of him. So that gave me comfort that he finally got his chance to pass away. And he had tons of secretions so, like, I was in there every five minutes with the suction, because his stats would drop. But we’re kinda treating him, so we can’t let his stats drop. It was really distressing for me. It was really distressing for the family. I’m sure they’re gonna

> remember that there was a week where he was kind of experimented on, to see if the drug would work. And I think that is one of my worst experiences. (P7)

Many of the nurses suggested that there is a great need for resources and processes that support critical care nurses by helping them to cope with moral distress. One nurse said that she thinks that critical care nurses should speak to therapists because of "the stuff that we see. But I think that there's sometimes this stigma about an ICU nurse: that you work in ICU because you're this type of person. But it doesn't mean you're not human and that you don't need those supports" (P6). Another nurse said that it would be helpful to have a formalized debriefing of each case:

> I know that I myself feel better and I think a lot of others feel better when they can talk about a particular situation in terms of what did we do well, what we didn't do well, what could we improve on [and do] better for next time? I think you learn a lot out of those experiences and those conversations, you know, to have different perspectives at the table. (P9).

Another nurse said that when she began to think about what resources were available for debriefing, she realized there weren't many:

> I can only think of one instance in… the ICU that we've ever formally debriefed about a case. And it was one of those exceptional circumstances that really did affect the unit as a whole … So I think that, like a formal debrief or something like that, I think there should be something more in place, for staff. And I don't know that there is. Or if there is, I'm certainly not aware of it. (P6)

One nurse said that recently efforts have been made to provide more support for staff who have experienced moral distress:

> I know that on our unit specifically, we're trying to implement a peer-to-peer support for that. It's not easy to do. . . . I mean, critical incident stress management exists, for say, some sort of

> massive event that affects the whole unit. But there's nothing that exists if I was having a bad time, I mean, I can call our employee assistance, But the onus is on me, and to be honest, they're not particularly helpful, because they don't know. Peer-to-peer I think would be more beneficial. And yet, trying to get funding to get a few peers trained in that, it's impossible. I mean, we can't even budget for an appropriate number of nurses on the unit. How are you gonna budget for fluffy things like that? (P5)

Several nurses suggested that more supports need to be in place for families who have experienced loss in critical care:

> Sometimes I see that the medical team sometimes withdraws from the family and the patient themselves, to try and stay away. And I understand that. I think in their mind they're trying to give the family time to be with the patient, to have that private time and those private moments. But I wonder too, if to the family it looks like they are forgotten about, because the critical care setting is a setting where it's very busy, it's very interactive. There's always things going on…So going forward, I think we could do a better job of still connecting and communicating with the family once the end-of-life decision has been made – once we withdraw care. (9)

Another nurse explained that palliative care in the ICU can feel like an abrupt severing of the relationships between the nurses and the family once the patient dies, which can cause the family to feel abandoned. Additionally, it can create distress for the nurses as they grieve over the sudden loss of this nurse-family relationship that was formed as a result of such an intense and monumental event:

> Passed, and then, we'll give them some time to say good-bye. But then, once they say good-bye and they walk out [of] the unit, it's like, that's it. Right? We prep the body for the morgue. And… you never hear from the family again. Even as a nurse, I don't know a whole lot about what happens. I just know I take the body to the morgue. And then, eventually, the family picks

> out the funeral home and they come and get the body, but that also could be a fairly big loose end because the families have come to rely on the nurses during the dying process. And then it's like, "Okay, they're dead. See you later." (P8).

One nurse said it would be helpful to have a psychologist available for the families who don't know what to do after a patient has passed away:

> They don't know what to do with their feelings. And they're all so different. And I mean, we're the only contact they seem to have with any sort of medical professional for the most part – like as far as them being able to actually talk about their feelings and their situations and things like that…the bedside nurse is the one that actually has the time to be able to spend talking about that stuff. But I've often thought, we don't provide grief counselling…I think not a lot of people know what to ask for. They're just so lost. And they often leave: they're going, "I don't know what happens next." And, I mean, even just dealing with the planning of a funeral. But I've often encountered people that are just – they're very lost and just don't know what to do. So I think grief counselling would be something that would be really good to be able to offer somebody…… How to deal with grief. And anger. Some of them are really angry. So yeah, that would definitely be something helpful. (P3)

The Components of a Good Death

Despite the struggles the nurses have experienced caring for a palliative critical care patient, the nurses very clearly articulated that positive end-of-life experiences are also a reality of critical care. The interviews were rich with personal testimonies of caring for critically ill patients who were imminently dying. All of the nurses shared experiences of what they considered to have been a "good death" in intensive care. Common themes began to arise, leading to a rich description of the components of a "good death" in critical care. Although not an exhaustive list, the commonly mentioned components of a good death include promoting patient and family comfort, maintaining the person’s dignity, honoring the person’s wishes, having a family presence at the bedside, and ensuring that the person does not die alone.

Promoting Patient and Family Comfort

Attending to the comfort needs of end-of-life patients was a seen as significant component of promoting a “good death” in critical care:

> Keeping them comfortable, I think, is the most important thing, ’cause they are a human being, they’ve had a life, whatever it was they chose to lead, it was their choice. But still, they should pass in comfort. To me, the biggest thing is that they’re comfortable. Whether it’s physically comfortable with repositioning them, or comfort with managing their secretions or their pain and dyspnea, to me, that’s really important. (P8)

One nurse recalled one of her first experiences having end-of-life conversations with a patient who was fully mentating. The patient was a lovely woman in her eighties and she had been on a ventilator for months, despite the medical staff’s efforts to get her off the machine:

> She was just such an absolute doll. And she would like touch your face….she would kind of ask about your day in her way, you know, just such a sweetheart. But it became obvious that she was never gonna leave care, the hospital, or a facility. And I don’t remember the particulars about it, but ultimately, we decided, in conversation with her and her family, it was decided that this was no longer acceptable anymore. And this is not how she wanted to live her life, so we withdrew care on her if you will….And we tried really hard to prevent her from suffering, and ultimately, she didn’t suffer….And she went so quickly. But it seemed so peaceful. And she got an opportunity to say her good-byes…We managed to keep her extremely comfortable, and in a very humane way…This was a really great opportunity to see a really great death. (P1)

Another nurse highlighted the importance of responding to the unique comfort needs of each patient: “Some people miss their pets, and I think if we could accommodate bringing in a pet so that the person can say good-bye, I think that would just provide them with a small, small sliver of comfort. (P7)

Several of the nurses identified the importance of addressing the comfort needs of the dying patients’ family. When asked what quality end of life care looked like, one nurse went into detail about making the patient comfortable, ensuring that there is no pain, anxiety, discomfort, or ill feelings. Then, she added:

> Looking after the family is just as important as looking after the patient. The patient is going to be dead. The patient is going to be done in whatever time frame it is. And that’s the end of that… the discomfort, then memories. But the family, the family is going to carry on their memory and all the associated feelings with how their loved one died for the rest of their lives. So the repercussions of providing good care for them, seeing their loved ones treated humanely, with dignity, with no pain and no anxiety, that knowledge, that they had a good end-of-life, if you will, will stay with them for the rest of their lives. They are gonna remember, and that is very important. So, to me, that is what good palliative care means. (P4)

Additionally, another nurse recalled the following experience with the family of a dying patient,

> “You know, I remember saying to them, “Yeah. Talk to me. I’ll be in as much as you need, or out as much as you need. And if I’m outside and you have a problem, or you’re concerned, come yak at me. I’ll be floating around, helping people. But I’m here for you guys primarily.” And a couple of times they came to me, like, “we’re just worried about how they’re breathing.” And you come in, you’re like, “Yeah. I can see that’s scary.” And you go, “I think that they’re okay. But I’m happy to give a little bit of medication, just to kind of take the edge off things.

> And, maybe not really giving them enough that's gonna super affect anything, 'cause you're like – clearly, that's wrong. But to relieve their anxiety. So, that was a great death. That communication. Trust and communication. Can I sum it up? Trust and communication, that's what we need. (P1)

Dignity and Honoring the Person's Wishes

The nurses frequently emphasised the importance of maintaining a person's dignity and honoring their wishes at the end of life. One nurse explained that a good death consists of the following: "That people are dying with dignity, that people are receiving the comfort that they need [and] that we are not prolonging something that is inevitable" (P7). Another nurse defined dignity as:

> Treating the person as a whole. You're not looking at them like just another patient. I'm not wording this properly. But you're following their wishes and when you're doing your care, you're not exposing them to their families. You're trying to keep them presentable. You don't want the family members to come in and the drool running out of their mouth and… just like keeping them as whole as possible, if that makes sense. (P7)

Maintaining a person's dignity was frequently described in conjunction with honoring a person's end-of-life wishes. One nurse recalled caring for a woman:

> So that evening, when I got her, she was saying, "no, this is not what I want." Now her two daughters happened to be there, one was a retired CVICU nurse, and the other was a retired ER nurse. So that's what the family decided, so I called ___ [Doctor] and he comes over and he says, okay so, what do you want, and you know, she didn't want any of this. And so, we turned off all the pressors. We turned off the maintenance IV. And we put her on a morphine infusion, zero to 10. And she passed away peacefully. Just like the daughters and she wanted, right? Now how nice is that? I think the dignity. I think, Number One is the dignity for the patient. And the

> selflessness of her family. And the willingness for the Intensivist to not negate her wishes. That's what she wanted. And you know, he talked to her about it. And that's what she wanted. And he said, "yeah. I will respect your wishes (P2).

Another nurse said that the best "thing [she'd] ever seen in the ICU" started when she was called to the ER to assess a vivacious patient in her early 80s who had come to the hospital for something routine but had very poor blood pressure and didn't look good. The medical team was bringing her up to the ICU in the elevator when she began falling unconscious:

> We got her into the ICU. And she actually had a cardiac arrest. And we resuscitated her and got her back…We realized she had this massive GI bleed… and… where the bleed was, they weren't gonna be able to repair it permanently. And the physician that was on is very like, end-of-life care is important. So he had a conversation with her, while she was still intubated, and told her, "this is how it is," and he's like, "you're probably not gonna live through this." And she had written him a note, "can I have a beer?" So, they made a plan. The next day, they would extubate her. And he brought her out a beer. And she sat in her bed, and she was able to talk to her family a little bit. And take some sips of her beer. And she just passed away. And that was like the best death ever. 'Cause she was perfectly in acceptance and she got what she wanted" (P7).

One nurse recalled a situation where she had a young male patient who was quadriplegic and had been sent from the palliative care unit to the ICU because he was in respiratory distress:

> He was awake enough that when they said we need to put the tube back in, he said, "I want to die. I do not want that tube in. I will die before I get that tube put back in." And so they sent him back up. So that was a good thing. They actually respected his wishes. (P3)

Family Presence and Not Dying Alone

There was an overall consensus that family presence at the bedside of an imminently dying patient is a strong component of a “good death,” One nurse started an anecdote by saying that she might get "a little bit teary" when recalling a 23-year-old man who had been involved in a motor vehicle collision and he had a devastating head injury:

> I couldn’t just help thinking this is a 23-year-old kid that has the rest of his life ahead of him…And I just remember the dad at the bedside, asking his son to wake up, and telling him that this was a terrible joke, and would he wake up.… and then, just the… resiliency and the love that that family had, as we went through the next four days…There was a lot of love in that family. And there was a lot of talking in that family. And we had some amazing conversations with that family, in terms of A, not only what the medical condition and the injuries were, of their son. Um, but also, potentially what that was going to mean for his outcome. And even though he was only 23 years old, it was quite clear, from the family that he was an active and a robust 23-year-old guy who just had a love of life. And if he wasn’t going to have that, they wouldn’t want him to have a life that he didn’t want…And the mom came to me at four o’clock that morning. And said, “you know, if he’s not gonna get better, could we help other people?”…We had more conversations with the family… And even though the conversation had moved towards how his life would end…in terms of providing help and donation of his organs to others, we still very much focused on him as a patient…And then, the following day, when it was decided that the – he was gonna go for a procurement, the family had asked, could they walk him to the OR… and we made those arrangements to happen. And their family walked him to the OR and they made their final good-bye at OR door…And it wasn’t about sadness. It wasn’t about regret. It was about love and it was about doing the right

> thing. The right thing for their loved one and doing the right thing by their loved one would be to donate his organs, because he would want to help others at the end of his life. So for me, that's the one that kind of stands forward. There's many. But, that's the one that stands out in my mind the most…to see that love and that support in that room, that all the family had for each other, and I think that made our job as the health care providers that much more enriching…And it was truly a celebration of life. And I know a lot of the nurses that cared for him during that time, felt very much the same way (P9).

Another nurse recounted caring for young woman was an epileptic who had had a grand mal seizure and her brain was no longer functioning and her family knew she had a catastrophic brain injury and were ready to let her go. And her husband just wanted to be close to her:

> So my colleagues and I made it so that we could scootch her over in bed enough so that he could crawl beside her… I don't know if she could feel that he was there, but I think it made it better for him… And I would hope that she could hear it. I would say that's my most memorable palliation, 'Cause it was done like I wanted it. There was no flogging. You know, a decision was made. You know, they knew it was a catastrophic brain injury at this point. They kind of had been in the loop about… you know, with the physicians the entire time. And so they knew that she was going. And it was just a matter of, "let's make her comfortable." So, extubated, with her husband beside her, holding her. Her mom sitting on the other side of the bed. Right? Like… and there was laughter in the room, right? They were talking about… her life. And I was able to be a part of that. And so that was a good death. Yeah." (P4)

The nurses expressed a universal commitment to never allowing a patient to die alone. If a patient did not have any family or friends present as they were dying, the nurses would go out of their way to ensure that they were present with the patient at the time of death. One nurse recalled being with a patient:

> “I honestly felt like it was the biggest blessing in the world to let this man go, who had just been suffering. And you know, have that look of pain and grimace – no matter what, in his eyes. Like never slept, and never had rest and never felt well, in this entire time after this horrible trauma. And to be there – and I remember just holding his hand and you know, it was time for break. And I’m like, “no, I’m just gonna stay here. Like, I don’t know how fast he’s gonna go, but I remember just… feeling like, he just needs someone here with him. Like, who wants to pass away alone. (P1)

Overall, the nurses expressed a great desire to providing each patient with a “good death”, which really highlights their deep connection and commitment to each of their patients.

Nurses’ Connectedness and Relational Narrative

> I remember one lady, it was in the second pod, and she just came out of the room, and she was just crying. And I’m like, ‘Oh, my God.’ And she’s like, ‘I just need a hug.’ I’m like, ‘Oh yeah. For sure. Let’s do it.’ And then we all started crying, all the nurses in the pod. And it was like a great day. And we felt such a connection. We were all laughing and crying and hugging. And she’s like, ‘I just feel so much better.’ And we’re like, ‘Awesome. That’s the best thing that we could hear from you is that you feel better that we’re here for you.’ You know? And those – those are the deaths that I like, where you just feel like you’ve connected. So to me, it’s connection. It’s communication. Trust. (P1)

The nurses often referred to the strong emotional connections they formed with many of the palliative patients and their families. Their testimonies began to formulate a mosaic of a relational embracing of each patient and their family. Their testimonies included many recollections of crying with families over the loss of a loved one. For instance, one nurse explained the following, “There are many times that I’ve cried with families over the loss of their loved one” (P6).

Another nurse shared the following story of a patient who had a great emotional impact on her:

> There was one man that will stay with me forever. An, he was one of those cases where it just went on and on and on and on. But he was very stubborn, if you wanna call him that, or he just wouldn’t give up. Wouldn’t give up, wouldn’t give up. And it was just one thing after another, one complication after another that continued to happen to him. And we could just see him wasting away and all of us were like, “oh, this guy’s never gonna get out of here…But yet, two things happened. One, we found a connection with him, because we had a really great conversation with his wife, who gave us more background about who he was as a person. And we realized why he was so stubborn. Because it was just him in life, he was just a strong fighter of a man who did like the most crazy, difficult things in his life. And that was him…he had been making some progress and then he just had a really, really tough week. And I remember I was giving a report to my colleague, and, he was having a tough go. So we went in…we could just tell he was uncomfortable, something like that. And he grabbed both of our hands, and his wife was there and we kept saying that, “no, it’s okay. It’s okay. Like we’re gonna help you.” And he just like looked at us and we got that look. And all three of us just knew that he was saying, “I’m done.” And so that was a case where we had a patient that it was just such a clear non-verbal communication of him just saying, “let me go. I’m done.” And, yeah, it was hard. Because you now had this patient on your unit for like three months. And you’re pushing and trying so hard, and….it was funny, ‘cause we were all butting heads for so long, and then once we made that connection, all of us got really invested. And so, when he passed, it was one of those cases where we all texted each other and we were like, “oh, Mr. So-and-So died and…”

> You know, we all really wanted to know and we cared a great deal about was it peaceful? Was it okay? And it was. (P10)

Several of the nurses recalled the strong impact made on them by some patients and families. often describing them as unforgettable. For instance, one nurse explained, "There's just some people that touch you in a way that you think " Oh my God!", You know? I don't know why I remember you, but I will never, ever, forget you and your experience!" (P1). Another nurse shared, "I have this little group of patients that follow me around in my head, both goods and bads that help me adjust how I approach things now. They're like my teachers with palliative care" (P10). Another nurse recalled an experience of caring for a women who had an unexpected event that resulted in a devastating head injury, and her husband was determined have an active role in her care decisions:

> The husband…he was 85, 90 years old. And he couldn't stand anymore. And he wanted to stand and talk with this physician, man-to-man, face to face. So, I stood behind him – and he had kind of a looser pair of pants that I could grip onto, and I kind of gripped him and helped him stand up. And then, kind of stood behind him while he held onto the railing and talked to the physician, 'cause that was his wife. And then, when the family had made the decision to extubate and to withdraw care…he held her hand and… the daughter was on the other side, and they said good-bye…when she passed, I'll never forget this – this gentleman, he grabbed me by my hands, and he said, "thank you. Thank you very much. I know that my wife is in a better place now."…And so, I don't know what it was about that man, or the characteristics of him... But, he's one person I'll never forget him….I think it was the connection with the husband. And I'm not sure what it was about him, but I kind of looked at him, and of course you could immediately see that he was an older guy and he had medical issues but I looked past that into kind of the person he was inside. All he wanted to be with his wife. But he wanted to stand up

> even though he couldn't stand and have a conversation with the doctor, to show that, you know what, just because I am old does not mean that I cannot make a decision and that I don't understand. I'm still a man. I'm still her husband. And I can still speak and I still have a mind. Like, I am alive. Listen to me, I wanna be heard and I wanna be part of the conversation. And I think that's important because sometimes when people get older, the other kids or other people don't necessarily want the spouse – or think that they understand what's going on, or can deal with it. But that man stood up to say, "Hey, like I'm still here. I'm a big part of this. Like I've been a part of her life longer than anyone in this room's been alive. And so, I don't know what it was about that man, or the characteristics of him, of that older gentleman. But he's one person, I'll never forget him. (P8)

This deep connection between nurse and patient, described in nursing literature as "connectedness" (Latimer, 2013) or the "relational narrative" (Gadow, 1999), has deep implications for nurses who provide palliative care in any setting. As such, this theme will be further explored in the discussion section of this report. Overall, most of the nurses said that they feel that palliative care is an integral component of the critical care setting which certainly has great potential for improvement.

Great Potential for Improvement

The nurses said that palliative care is indeed something that they practice frequently in critical care. As one nurse acknowledged,"I would definitely say that we care for people, at end-of-life, very frequently in the intensive care unit, whether that be an expected trajectory, a disease process, or whether it be very sudden onset" (P9). The nurses were keenly aware that the quality of palliative experiences in critical care ranged from positive to negative. A number of factors come into play, including the illness or event that landed the patient in ICU in the first place, and how imminent death is. For instance, one nurse explained,

> "I think it's so dependent, it just depends what they're dying from, and it depends how imminent their death comes. 'Cause I think I can say there's a number of people who have had a really wonderful death or we've been able to plan it or their family's gotten there in time and they've been able to say good-bye. Or I feel like they felt the love from their loved one. And maybe they've had a bit of a blessing from a spiritual advisor that they feel is important or the family feels is important. And you know, maybe the lights were low and the room was warm and we had the right environment, and we had one family that sang hymns as the patient died. And like, what a great way to go. And then there's some when you're bleeding to death and your family's sobbing. That is not a great death. I mean, we try our best. We called it because we couldn't do anything else. And we were trying, but it's just not a great way to go. (P1)

Overall, the nurses' outlook on palliative care in critical care was positive. They viewed it as a key component of critical care that holds great potential for improvement. As one nurse explained, "It's something we do frequently. I want to make it better. I think we could do it better. I'm not saying that we do it poorly, but I think we could do it better" (P9). Another nurse observed, "We do it for a very short period of time, but we do it for a very intense period of time. And there's ways that we can certainly do it better" (P1). One nurse suggested that improving the quality of palliative care in critical care requires a team approach: "in order to make palliative care successful, it takes many people, it can't just be one person or one profession that is doing it." (P9)

The nurses agreed that palliative care is an integral component of critical care. Their attention to promoting a "good death" was apparent, and the positive emotional connections they had experienced with many of their patients was extremely touching. Overall, they were clear that quality palliative care can and often is provided in critical care, but there is room for improvement.

Barriers and Facilitators in the provision of Quality Palliative Critical Care:

Critical Care Nurse's Perspectives

Chapter 6: Discussion

Discussion

The themes in this study mirror similar findings reported in the critical care literature, such as: palliative care is an integral part of critical care; barriers and inconsistencies in palliative care approaches in critical care often result in negative end-of-life experiences for patients and their families; and critical care is a setting that holds great potential to provide exemplary palliative care, but there is room for improvement. As I prepared to synthesize my research findings, I conducted a brief overview of literature published within the past two years. There are numerous studies that explore and examine the experience of death and dying in the intensive care unit (ICU). There have also been efforts to pilot specific initiatives to improve the quality of palliative care in critical care. These initiatives include providing palliative care education for staff, introducing palliative care guidelines and protocols, and fostering greater collaboration with palliative experts. Additionally, there has been an increase in studies that explore the experiences of the family members of deceased critically ill patients. Indeed, it is apparent that palliative critical care is an increasingly prominent topic of interest in critical care literature. In alignment with what is suggested in the most recent literature, the findings of this study support that efforts must be focused on developing and engaging in processes that serve to enhance the quality of palliative care in critical care. Although not an exhaustive list, such efforts should include promoting advance care planning, early integration of the palliative approach, providing palliative education to critical care staff, developing processes that support effective communication, adopting end-of-life medication and care orders sets, promoting an environment that is conducive to a quality end-of-life experience, fostering connectedness and the relational narrative of a nurse-patient relationship, and combatting moral distress. Below, I will discuss each of these implications in context of the literature.

Advance Care Planning

Previous surveys have shown that hospitals are the least-preferred locations to receive end-of-life care (Burge, Lawson, Johnston, Asada, McIntyre, & Flowerdew, 2015). However, according to a National Hospital Discharge Survey (2010), between one-third and two-thirds of people die in hospital, and approximately 20% of people die in an intensive care unit (ICU). Several of the nurses in this study reported that many patients who come into the ICU have never spoken to their family about their health care wishes and decisions in the event that they are no longer able to speak for themselves. Frost et al. (2011) found that active participation in end-of-life decisions is impossible for many critically ill patients because of their impaired capacity resulting from the underlying illness or from pharmacologically induced sedation. As such, the health team often relies heavily on direction from the patient's family or alternate decision maker (Frost et al., 2011). However, Mcgree and Reed (2016) reported that end-of-life care conversations are difficult to have with family, particularly in the critical care setting, where time is limited and quiet and privacy are suboptimal. Moreover, in the absence of previously expressed wishes, there is always a risk that the decision to pursue aggressive treatments and interventions may not be congruent or consistent with a patient's values and preferences for care (Khandelwal, 2015).

Recent evidence suggests that people want to have greater control over decisions that occur during the last phases of their life (Brinkman-Stoppelenberg, Rietejens and Van Der Heide, 2014). However, while most Canadians support advance care planning (ACP), only a small number have actually engaged in it (Canadian Hospice Palliative Care Association (CHPCA), 2014). ACP empowers patients to articulate their wishes and determine the direction of their future health care in the event that they are no longer able to make decisions for themselves (Brinkman-Stoppelenberg et al., 2014). ACP is defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future care" (Sudore et al., 2017, pp. 821).

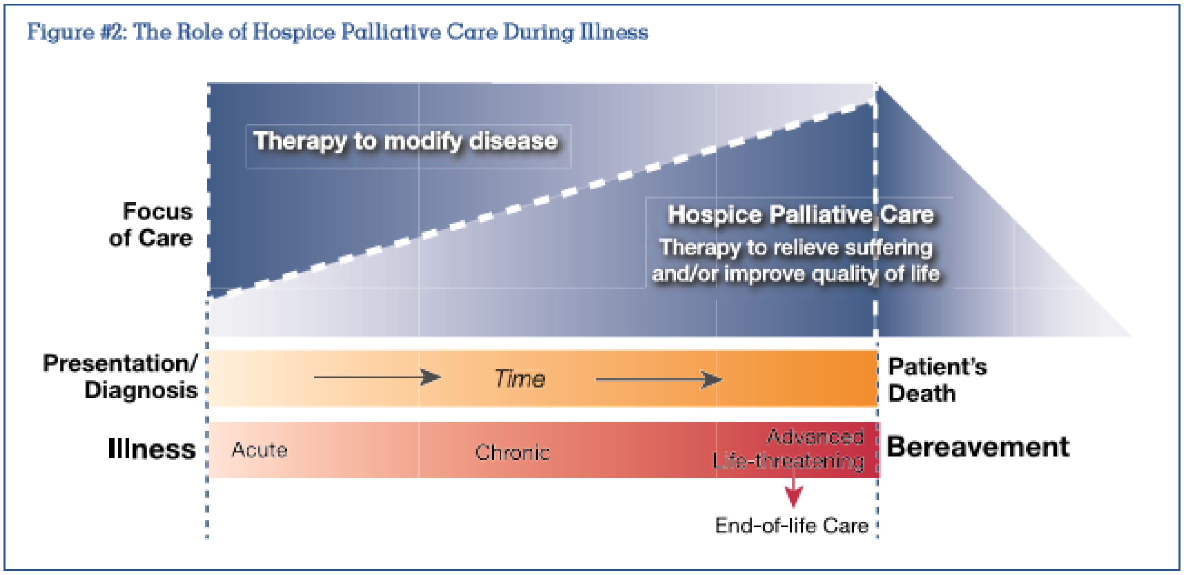
The Alberta Health Services Advance Care Planning and Goals of Care Designations Policy states that "all adults should be given the opportunity to participate in Advance Care Planning as a part of routine care, started early in a longitudinal relationship with a healthcare provider and revisited when the health or wishes of an adult changes" (Alberta Health Services, 2015, pp. 2). The key element to highlight in the aforementioned statement is that ACP should be started early in a person's illness trajectory. Lakin et al. (2017) assert that when early conversations about end-of-life care between clinicians and patients begin before the final days and weeks of life, the result is enhanced care that is more congruently aligned with a patient's preferences, fewer non-beneficial medical interventions, decreased family distress, and lower medical costs" (Lakin et al. 2017). Furthermore, Brinkman-Stoppelenberg, Rietejens, and Van der Heide (2014) explain that the potential outcomes of early end-of-life conversations include preventing ethical dilemmas at end of life, and improved quality in end-of-life care. In essence, ACP prevents the ethical question faced by so many health care professionals: "just because we can, does that mean that we should"? Khandelwal (2015) report that clarifying a person's goals of care and exploring whether critical care interventions are congruent with these goals may reduce the intensity of end-of-life care (Khandelwal, 2015).

Frost, Cook, Heyland, and Fowler (2011) report that "providing compassionate end-of-life care that is appropriate and in accordance with patient wishes is an essential component of critical care" (pp. 1174). Dempsy (2014) reports that ACP is an essential component of quality palliative care and should be provided to all consenting individuals. As patient advocates, health care professionals have a responsibility to help move end-of-life conversations and decisions out of crisis situations by engaging their patients in early ACP conversations. Moreover, as a health care entity, we need to promote initiatives that increase public awareness of the importance of ACP and support these initiatives to engage people in a process of thinking about, talking about and documenting their wishes for health care.

Early Integration of a Palliative Approach

Historically, palliative care was offered only in the last weeks or months of a person's life, when all curative treatments had been exhausted (Bacon, 2012). However, in the late 20th century, experts began to suggest that the increasing duration of life from disease diagnosis in cancer and non-cancer populations requires a revised approach to palliative care that introduces the principles of palliative care at an earlier stage of illness (Glare & Virik, 2001). Accordingly, the Canadian Hospice Palliative Care Association (2002; 2013) now emphasises that palliative care extends the trajectory of a person's illness with greater emphasis on cure at the beginning and on symptom management and quality of life near the end of a person's life (Figure 1).

Figure 1. The Role of Hospice Palliative Care during Illness



From Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice and palliative care: Based on national principles and norms of practice*. pp.7 Retrieved from http://www.chpca.net /media/319547/norms-of-practice-eng-web.pdf

Note: This model is a revised version of the Canadian Hospice Palliative Care's (2002) The Role of Hospice Palliative Care during Illness Model

Cameron-Taylor (2012) advocates for integrating palliative care in generalist settings, rather than relying entirely on specialized palliative care settings. Bacon (2012) explains that a palliative care approach focuses on enhancing a person's quality of life throughout the entirety of his/her illness. Essential aspects of palliative care are accessible to that person at appropriate times.

Reflecting more about my own palliative experience in critical care, I have concluded that simultaneously providing resuscitative care and palliative care is not necessarily a conflicting dynamic or a problematic dichotomy. Baker, Luce, and Bosslet, (2015) found that successfully integrating palliative care into the critical care culture promotes quality of care, enhances quality of life, and improves the experiences of patients, families and health care providers. Athari et al. (2016) explains that a comprehensive palliative approach in critical care entails the following: effective communication with patients and families about appropriate directions of care; decision-making that supports a person's values and wishes for care; ongoing options to discontinue or even avoid burdensome or painful therapies; individual tailoring of interventions that eliminate or minimise a patient's discomfort and symptom burden; thorough and ongoing assessment of the patient's need for opioids and benzodiazepines and appropriate titration; psychosocial support; utilizing strategies that minimise moral distress, burnout and post-traumatic stress disorder among the health care team and family members of critically ill patients; and family bereavement and follow-up care. In their framework to integrate palliative care into critical care, Baker et al. (2015) include the following steps: garnering support from local leaders for the need for palliative care, recruiting and developing a hospital palliative care team, initiating palliative care services into the ICU culture, and fully integrating palliative care services with ICU daily workflow.

Additionally, many authors suggest that specialist palliative services should play a role in the care of a palliative critical care patients who have complex palliative needs. The nurses in this study said that, more frequent consultations with palliative care specialists would improve the quality of palliative care provided to critical care patients. However, Villarreal (2011) found that less than 5% of critical care patients actually receive specialist palliative care services. Perrin and Kazanowski (2015) have identified some of the barriers to palliative care consultation for critical care patients, including misunderstandings about the role of palliative care and not having agreed-upon criteria for referral. Curtis et al. (2011) found that health care professionals often have difficulty determining when a patient may be dying.

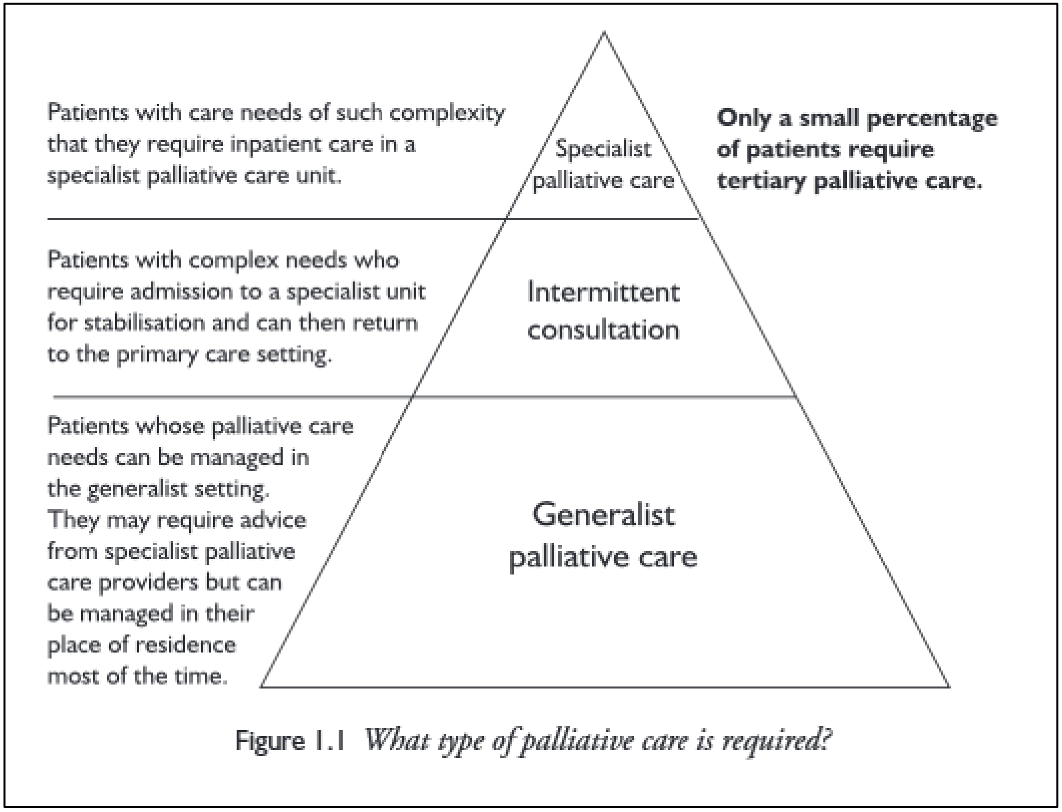
Studies have shown that palliative care has a favorable effect on patient outcomes and patient satisfaction (Mae, Remington, Nannini, & Cifuentes, 2013). Many authors have found that processes need to be in place to assist ICU clinicians in identifying patients and families who would benefit from a palliative approach and consultation. Jones and Bernstein (2017) advocate for the use of electronic medical record triggers that would identify a patient who is a potential palliative candidate. Baker et al. (2015) found that palliative care screening tools and bundles are quality improvement measures that enhance a multidisciplinary approach to palliative care. Several evidence-based palliative screening tools have been developed, among them is The University of Edinburgh's "Supportive and Palliative Care Indicators Tool," (2017) which helps identify people who would benefit from palliative care services. The Royal College of General Practitioners (2011) developed a framework of triggers that assist clinicians in identifying patients who are nearing the end of life. These triggers include the surprise questions (would you be surprised if this patient were to die in the next few months, weeks, days?), general indicators of decline-deterioration, increasing need or choice for not-further-active care, and specific clinical indicators related to certain conditions (Royal College of General Practitioners, 2011). The Improving Palliative Care in the ICU (IPAL-ICU) projects have also developed numerous palliative screening and communication tools. Overall, processes that support integrating the palliative approach in critical care and identifying patients who would benefit from palliative consultation need to be in place in order to improve the quality of palliative care in critical care.

Palliative Education

The benefits of early integration of palliative care in a person's illness trajectory are well documented (Parker, Remington, Nannini, & Cifuentes, 2013). However, Wanniarachige (2015) found that increasing the number of palliative care specialists is not enough to address the palliative needs of the Canadian population. As such, Cameron-Taylor (2012) recommends that the majority of palliative care services be provided in generalist settings, with intermittent consultation from palliative experts when patients develop complex needs (Figure 2). However, most health care professionals working in generalist settings are not adequately trained to provide palliative care (World Health Organization [WHO], 2014).

Palliative care is increasingly becoming a routine component of the critical care culture. Fowler and Hammer (2013) found that hospitals remain the primary provider of end-of-life care for 70% of Canadians, with 10% to 15% of these patients admitted to critical care on their final hospital admission. Accordingly, Standard 5 of the Canadian Association of Critical Care Nurses' (2009) seven standards of critical care nursing practice is palliative-related. It reads, "When life sustaining technologies are no longer beneficial, critical care nurses support patients and families through the transition from active treatment to a peaceful death" (pp. 7). However, many critical care nurses report that they have inadequate palliative care education to meet the required competencies of quality palliative care (Anderson et al., 2017). Price et al. (2017) recommends that critical care nurses be provided with palliative education specifically related to communication skills, inter-professional collaboration, and palliative symptom management.

Figure 2. What Type of Palliative Care is required?



From Cameron-Taylor, E. (2012). *The palliative approach to care: A resource guide for healthcare workers*. pp.4 M&K Publishing; London, UK.

Some organizations have developed programs intended to address the palliative education needs of critical care nurses. For instance, the End-of-Life Nursing Education Consortium (ELNEC) project is an American national, evidence-based education initiative to improve palliative care. It provides training in palliative care to undergraduate and graduate nursing faculty, nurses working in generalist settings, and specialty nurses in pediatrics, oncology, critical care and geriatrics (End-of-Life Nursing Education Consortium, 2017). Another educational initiative is the Palliative Care Professional Development Program which was implemented with positive results in five medical centers that are part of an academic health system in the United States. Although programs such as ELNEC hold great promise for American nurses working in critical care, similar, large scale, and evidence-based educational programs have yet to be developed in Canada. Additionally, many authors suggest that palliative education should be introduced earlier within the nursing undergraduate programs so that palliative care is not a foreign concept as nurses begin their careers (Kaasalainen, Willison, Wickson-Griffiths, & Taniguchi, 2015). The notion that critical care nurses have unmet palliative education needs is greatly supported in literature; as such, greater emphasis must be placed on filling these gaps in education, particularly in the Canadian context.

Processes that Support Effective Communication in Critical Care

The nurses in this study identified ineffective communication as a significant barrier to quality palliative care in critical care. Many of the nurses said that communication between members of the critical care health care team does not occur early or frequently enough in a patient's ICU stay, and is often hindered by miscommunication and inconsistent information. Ideally, end-of-life conversations should occur prior to an unexpected crisis that requires a person to be admitted to the ICU; however, this is not always the case (McRee & Reed, 2016). Many end-of-life conversations are between the ICU medical team and the families of incapacitated patients (Troug et al., 2008). However, admitting a loved one to the ICU is an extremely stressful experience for families and can often lead to feelings of hopelessness, anxiety, and helplessness as well as significant psychological burdens related to decision-making (Briggs, 2017). Effective communication between the health care team and families of critically ill patients has long been identified as a crucial component of quality palliative care in the ICU (Mularski et al., 2006). Yet critical care literature is filled with reports of the numerous challenges associated with initiating end-of-life conversations. Although not an exhaustive list, these challenges include clinicians' discomfort with discussing prognosis, clinicians' inadequate skills and training in conducting difficult conversations, poor interdisciplinary collaboration, and disagreements regarding care goals (Brooks, Manias, & Nicholson, 2017). Additionally, evidence suggests that ethical conflicts often arise within the context of poor communication (Koesel & Link, 2014). Many authors report that efforts focusing on addressing the communication needs of patients and their families are essential to improving palliative care in the critical care setting. Tangible efforts that assist in the realization of this goal include holding frequent family conferences, involving families in ward rounds, and promoting an interdisciplinary approach to care.

Family Conferences and Ward Rounds

According to Briggs (2017), the family conference is the main avenue for engaging in difficult conversations in the ICU. Research has shown that families who participate in frequent family conferences and collaborative decision-making demonstrate greater satisfaction with care, experience less conflict, and are more often able to reach a consensus regarding the direction of patient care (Hwang et al., 2014). Key components of an effective family conference include showing sincere empathy, allowing family members time to talk and ask questions, and enabling families to participate in decisions (Coombs et al., 2017). Briggs (2017) emphasises the importance of supporting family understanding during family conferences by simplifying the medical language that is used, explaining prognosis in terms of quantitative terms rather than vague qualitative descriptions, and clarifying understanding at frequent points during the conversation. Schram, Hougham, Meltzer, and Ruhnke (2017) found that conflict mediation, prognostication, empathy, and a family-centered approach are all essential communication competencies that can support patients and families. Briggs (2017) reported that families need clear, consistent, and accurate jargon-free information about the patient and his/her condition and prognosis.

In addition to holding frequent family conferences, participation in ward rounds provides the opportunity for purposeful interactions between the medical team and the family, and is a component of family-centered care (Briggs, 2017). However, Stelson et al. (2016) found that families have noted some challenges to this method of communication. These challenges include work/family obligations, distance to the hospital, and the unpredictable timing of rounds. Alternatively, they suggest that these barriers can be somewhat overcome by providing the family the option of virtual participation in ward rounds via telehealth (Stelson et al. 2016). Overall, there is a general consensus that family presence and participation in family conferences and rounds are essential components of promoting effective communication in critical care; however, many emphasise the importance of an interdisciplinary approach to communication.

Interdisciplinary Team Approach

Each member of the interdisciplinary team makes a unique contribution in communicating with families of critically ill patients. Coombs et al. (2016) found that holistic care of critically ill patients and their families often requires the input of specialty services such as palliative care, social work, and spiritual care. Nurse Practitioners also have an important contribution to make in communicating with patients and families. McRee and Reed (2016) reported that critical care Nurse Practitioners are specially prepared to initiate and facilitate difficult conversations with patients and their families. Additionally, critical care nurses have been identified as an important source of information and support for family members of critically ill patients, particularly with regards to clarifying and reinforcing information and answering important questions as they arise (Briggs, 20017). However, research has shown that physicians perceive nurses to be more included in end-of-life conversations and decisions than is actually the case (Benbenishty, Ganz, Lippert et al., 2006). Accordingly, many authors suggest that greater efforts should be made to include critical care nurses in end-of-life conversations and decision-making with families (Anderson et al., 2016). Essentially, effective communication requires an interdisciplinary team approach, and many experts support the practice of interdisciplinary collaboration when communicating with critically ill patients and their families.

Palliative Care Order Sets

Many health care professionals report that they struggle with providing competent quality palliative care (Ingleton et al., 2013). Areas of struggle include effective symptom management, communication, identifying that a patient is dying, providing culturally sensitive care, and coping with ethical challenges (Crump, Schaffer, & Schulte, 2010; Ingleton et al., 2013). There is a great need to support health care professionals in providing effective, consistent, timely, and evidence-based end-of-life care (Northern Health, 2014, pp. 1). To address these concerns, many health care organizations have developed palliative care pathways and guidelines that direct the care of patients who are imminently dying. However, a recent systematic review revealed that there is limited evidence of the physical, psychosocial, and clinical effectiveness of palliative care pathways (Chan, Webster, & Bowers, 2016). Conversely, order sets are commonly used in the hospital for admissions, surgery, palliative care, critical care, emergency, diabetes, anesthesia, and obstetrics (McGreevey, 2013), and there is evidence to support their efficacy in terms of their role in anticipatory prescribing.

According to National Clinical Guideline Center (NCGC) (2015), poorly controlled symptoms cause considerable distress to patients because they interfere with the ability to engage in other activities that are important at the end of life. Additionally, the complexity of palliative care is furthered by the fact that most patients suffer from five or more co-morbidities within the last six months of life (Van Nordennen, Lavrijsen, Vissers & Koopmans, 2014). However, many dying patients are not provided with the necessary drugs to alleviate their common symptoms (Lindqvist et al., 2013). In their study, Finucane et al. (2014) found that only 54% of patients who had died had anticipatory medications prescribed to them, and only 15% had medications that addressed all four of the most common end-of-life symptoms (pain, breathlessness, anxiety, respiratory congestion, and nausea). This is a particularly severe problem in non-specialist settings in which patients are dying

(Lindqvist, 2013). According to the NCGC (2015), “Optimal symptom control in the last few days of life requires considerable skill and may be challenging for even an experienced palliative care clinician” (pp. 163). Freeman et al. (2013), report that clinicians are often unaware of which medications they should prescribe or request for symptom management. Due to this complexity of care, health professionals frequently report the need for palliative resources to assist them to competently care for a dying patient (Ingleton et al., 2013).

Anticipatory prescribing is a process by which medications are ordered to manage common end-of-life symptoms in advance of being required (Finucane, McArthur, Stevenson, Gradner & Murray, 2014). Although there is some consensus regarding which medications are essential for imminently dying patients, end-of-life prescribing remains complex; consequently, many experts suggest the need for anticipatory prescribing and standardized order sets (Bailey et al., 2014). According to Wilcock (2011), anticipatory prescribing for a patient at end of life should include the following four types of medications: analgesia for pain, an anti-emetic for nausea, anxiolytics for anxiety and distress, and an anti-secretory for respiratory congestion. End-of-life medication order sets are one form of anticipatory prescribing. Ultimately, the goal of medication order sets is to provide the prescriber with a list of medications, dosages, routes, and frequencies that apply to a specific population (CARNA, 2015). According to Furst et al. (2012), a consensus-based list of medications made available to a dying patient is cost effective, and has the potential to improve the quality of care by increasing the confidence of the physicians and nurses who are caring for these patients. Although medications are an important aspect of order sets, most order sets are not limited to prescribing alone, but include directions with regards to other aspects of care (Chan et al., 2012). For example, Walker, Nachreiner, Patel, Mayo, and Kearney (2011) developed an order set that includes standard palliative medications with starting doses and intervals, and directions on mouth care, repositioning, and other aspects of comfort care. Overall, “order sets are a group of medical orders that work to standardize diagnosis and treatment following pre-established clinical guidelines and protocols” (Chan, Chan, Cafazzo, & Rossos, 2012, pp. 235). The College and Association of Registered Nurses of Alberta (2015) considers medication order sets a standard of best practice.

Many authors suggest that end-of-life order sets are an effective resource for clinicians. The goals of end-of-life order sets are to guide treatment with evidence-based medications, improve assessment and recognition of symptoms, prevent the delay of treating symptoms due to tracking down orders, prevent symptom crisis, treat symptom crisis in a timely manner, and provide nurses with autonomy to administer medications when necessary (Northern Health, 2014). There is an overall consensus that order sets are a clinical decision support tool that promote safe, efficient, and evidence-based care (McGreevey, 2013). Walling et al. (2011) found that end-of-life order sets can be successfully used in the care of patients who are expected to die. In their pilot study, Walker et al. (2011) found that palliative care order sets improve the availability of necessary medications for symptom management and the use of comfort interventions for dying patients. Another study found that end-of-life order sets increase the availability and proper use of opioids, antipsychotics, benzodiazepines, and medications for respiratory congestion (Bailey et al., 2014). Chan et al. (2012) found that order sets are cost effective and efficient and positively influence care by improving treatment adherence and outcomes and processes of care (Chan et al, 2012). Although order sets are considered a valuable end-of-life tool, some caution must be applied in their use. According to McGeevey (2013), for an order set to be effective, essential components must be in place during its development, implementation, and evaluation. Order sets do not take away from nursing responsibility, as nurses must still “question and clarify orders that are inconsistent with therapeutic outcomes, best practices and safety standards prior to administration of the medication” (CARNA, 2015, pp. 9). There are varying opinions on which medications are the most effective for treating specific symptoms; therefore any order sets that direct the use of medications must be based on the most current evidence. Finally, ongoing evaluation of end-of-life standardized order sets is crucial because it provides the opportunity to identify areas for quality improvement and missed opportunities for use (Walling, Ettner, Barry, Yamamoto, & Wegner, 2011).

Promoting an Environment that is Conducive to Quality End-of-Life Experiences

The balance between technology and calm, interventions and presence, isolation and vigilance, efficiency and time for pause, and communication and silence makes critical care a challenging environment for the end of life (Fournier, 2017). The nurses in this study identified that the ICU environment can be both a barrier to and a facilitator of quality palliative care experiences. Zakaria (2016) confirms that the cold and sterile ICU environment can create challenges. Salins, Deodhar, and Mukaden (2016) emphasise the importance of establishing an environment that supports the comfort of imminently dying patients and their families. Fourneir (2017) identifies essential environmental factors that promote quality end of life. These include ensuring that the patient's room is clean and devoid of clutter; removing unnecessary supplies and equipment (monitors, pumps, ventilators); making the patient's bed a space of comfort through the use of extra pillows and blankets, which may be brought in from the patient's home; ensuring that the patient is accessible to the family so that they can visit with and be encouraged to touch and to support the patient; eliminating distressing sounds such as alarms; providing a private room to accommodate larger numbers of visitors and to ensure privacy; encouraging family members to bring in photographs and other special objects to transform the space into a personalized environment; and ensuring that there are adequate locations for the family to sit and rest with the patient. Additionally, many authors have identified the need to remind staff to maintain an environment that is calm and devoid of noise (McCallum & McConigley, 2013).

Several of the nurses in this study stressed that greater effort needs to placed on providing “extra little comforts” to family members of imminently dying patients. These can includea small bed, comfortable chairs, blankets, warm drinks, and snacks. For this purpose, many health care locations have developed comfort carts that are brought to the rooms of imminently dying patients. For instance, in an effort to create a more healing ICU environment, The Banner Good Samaritan Medical Center Critical Care Unit in the southwestern United States implemented a grieving cart for imminently dying patients and their families. The cart contains reading materials, information pamphlets, hygiene products, snacks, condiments, and warm drinks (Whitmer, Hurst, Stadler, & Ide, 2007).

Many of the nurses in this study expressed concerns over having to transfer imminently dying patients out of the ICU to other units. Murphy and Wunch (2012) suggest that critical care can be an appropriate location to provide end-of-life care to imminently dying patients; however, doing so is a delicate matter. One problem is that the resource-intensive services of critical care are extremely costly to the health care system and, as such, are generally reserved for patients in dire need of critical care interventions (Canadian Institute for Health Information, 2016). Additionally, if an imminently dying patient is occupying a critical care bed, this means that another critically ill patient is either being refused ICU admission or their admission is being delayed, which has been shown to increase a patient’s risk of mortality (Murphy &Wunch, 2012). Morrison (2016) confirms that there is a crucial balance between providing life-saving technology when it is useful and appropriate to do so, and providing comfort and peace when it is the right time. Many of the nurses in this study suggested that establishing designated palliative critical care beds promotes an environment of comfort for patients and their families and prevents their being transferred to another unit. This is indeed an issue that requires further exploration.

Fostering Connectedness and the Relational Narrative of a Nurse-Patient Relationship

According to Fry et al. (2013), a core nursing skill is the ability to develop strong and compassionate and caring interpersonal relationships and connections with patients and their families. Certainly, the nurses in this study frequently expressed their feelings of deep empathy and strong emotional connections with their palliative patients and families. Latimer (2013) found that human connectedness evolves when individuals are actively engaged with one another, resulting in a sense of comfort, security, and overall well-being. (Latimer, 2013). Phillips-Salimi, Haase, and Koken (2011) define connectedness as: “the degree to which a person perceives that he/she has a close, intimate, meaningful and significant relationship with another person or group of people. This perception is characterized by positive expressions (i.e., empathy, belonging, caring, respect and trust) that are both received and reciprocated through affective and consistent social interactions” (pp. 6). This deep emotional engagement and connection in the nurse patient relationship has also been described as a “relational narrative” (Gadow, 1999). A relational narrative comprises an interaction between the nurse and patient that stands in existential awe of the uniqueness of each individual (Gadow, 1999). Furthermore, it is a therapeutic nurse-patient relationship that conveys profoundness of feeling, cherishing, and treasuring (Gadow, 1999). In particular, fostering a relational narrative has been described as being at the heart of the nurse-patient relationship (Hess, 2003), which creates an ethical cornerstone for nursing practice (Gadow, 1999).

Overall, the positive implications of this therapeutic nurse-patient relationship are well documented in the literature. Evidence suggests that establishing caring relationships is an indicator of excellent nursing care that promotes a patient’s overall health and well-being. (Labrague et al., 2015). Several authors suggest that therapeutic nurse-patient relationships are pivotal to the delivery of patient-centered care, and accurate identification of a patient’s needs (Doherty & Thompson, 2011).

Unfortunately, several barriers to establishing a therapeutic nurse-patient relationship have been identified. These include moral distress, compassion fatigue, busy and chaotic work environments, and time constraints (Doherty & Thompson, 2011). Given the positive impact that a therapeutic nurse-patient relationship can have on patient outcomes, it is crucial that we address these barriers and promote developing a culture of caring which fosters these relationships within each health care delivery context. (Fry et al., 2013). Additionally, a greater emphasis on the humanistic and affective components of caring interventions in nursing should be introduced in nursing schools to enhance the emotional intelligence competencies of nursing students (Labrague, 2015). When nurses engage in connectedness and caring relationships, the resulting relational narrative can expose them to ethical decision- making that can result in personal and professional struggles (Henderson, 2001). Romyn (2003) argues that greater attention to the ethical principles in nursing practice and nursing education would provide nurses with tools they need to respond with ethical certainty in situations that can lead to morally distressing decisions. This brings us to the next topic of discussion, the importance of combating moral distress.

Combating Moral Distress

The nurses in this study described many situations in which they had experienced moral distress. Jameton (1984) first described moral distress as the painful psychological disequilibrium that health care professionals experience when they feel compelled to act in a manner that contradicts what they feel is ethically and morally correct. In the late 19th century Bevis (1989) identified that "advances in medical science have brought us to impossible choices that disturb our deepest sense of ethics and moral commitments" (pp. 17). Critical care is a setting in which invasive and aggressive medical interventions are routinely administered, as such moral distress is indeed pervasive among critical care health professionals (Lamiani, Setti, Barlascini, Vegni, & Argentero, 2017). Bruce, Miller, and

Zimmerman (2015) found that the most common situations that lead to moral distress are those involving initiation or maintenance of non-beneficial life-sustaining treatments, and those involving a lack of full disclosure about interventions. According to Lusignani, Gianni, Giuseppe, and Buffon (2017), moral distress compromises nurses' ability to provide optimal patient care, decreases empathy, creates job dissatisfaction, and often results in burnout. Additionally, moral distress impacts the organizational level, leading to reduced quality of care, decreased job retention, and poor patient outcomes (Rushton, Schoonover, & Kennedy, 2017). In order to improve quality of care, efforts need to be focused on addressing and preventing moral distress (Bruce, Miller, & Zimmerman). In 2016, the Johns Hopkins Institute of Bioethics partnered with the Johns Hopkins School of Nursing, the American Journal of Nursing, the Journal of Christian Nursing, the American Association of Critical Care Nurses, and the American Nurses Association to form a consensus group to examine practices for addressing moral distress and promoting moral resilience. This project resulted in a comprehensive list of recommendations to address moral distress in four main areas: education, practice, policy, and research (Rushton, Schoonover-Schoffner, & Kennedy, 2017). Additionally, some argue that it is necessary to foster a relational narrative between nurses and patients to achieve moral resiliency and serve as a moral guide in distressing situations (Gadow, 1999).

In addition to the aforementioned implications to improving the quality of palliative care in critical care, I would suggest that two facets of care be added to the quality measures of end of life care in critical care as outlined to by Mularski et al. (2006). Mularski et al. (2006) identified that the documentation of pain and respiratory distress assessment and management should be used as quality measures of end of life care in the ICU. However, I would suggest that these measures be expanded to encompass the comprehensive assessment and management of all commonly experienced end of life symptoms. These symptoms include pain, agitation, delirium, dyspnea, nausea, vomiting, and respiratory secretions (Finucane et al. 2014). Additionally, high quality palliative care in the ICU includes family-centered care (Restau & Green, 2017). As such, the elements reflective of family centered care should be included in any measure of quality end of life care in the ICU. One way of evaluating this is to examine qualitative reports of family members or friends' experiences after having had a significant one in ICU.

Strengths and Limitations

The main limitation of this study relates to the transferability of results to other settings and contexts. The scope of this study is limited to understanding the perceptions of critical care nurses within the local context; therefore, the results may not reflect the perceptions of nurses working in other locations. Additionally, as is the case with qualitative studies, there is always a potential for researcher bias in interpreting the data (Loiselle & Profetto-Mcgrath, 2011). As the interviews progressed, I became increasingly aware of my personal biases regarding palliative care in critical care and I recorded these in a reflexive journal. I reviewed my reflective journal frequently during data analysis so as to prevent myself from interjecting these biases into the interpretations. It is possible that my own critical care experience affected, to some extent, the way in which I interpreted the data. For instance, was there something in the data that appeared unremarkable to me because I worked in ICU, whereas someone with no critical care experience would have flagged the same information as significant? Alternatively, I feel that my critical care experience assisted with my analysis because I understand the terminology, the context, and the technology of ICU.

I would suggest that because I had worked in the ICU where I conducted my study and knew most of the participants, it was easier for the nurses to share their ideas and experiences with me, as some of the experiences and patients were familiar to me. Alternatively, it is possible that my previous association with the nurses may have hindered some of the participants' comfort levels with openly disclosing their side of a story.

I attempted to enhance the overall credibility of the study results by frequently engaging in peer debriefing. In addition to meeting with my supervisor on a regular basis, I did three presentations about my research and sought feedback from the audience members at each of the presentations. The audience members consisted of palliative care professionals and critical care professionals. As such, their feedback was invaluable to informing my interpretations. Furthermore, I engaged in a process of member-checking in which four of the study participants responded and provided positive feedback about the themes that arose from the study.

Overall this study has many strengths. Future research may include conducting a similar study in other critical care locations, as the scope of this study is limited to critical care nurses from one setting within the local context. Additionally, it would be valuable to explore palliative care in critical care from the perspective of other members of the interdisciplinary team and from the perspective of family members.

Personal Reflection

As I prepare to conclude this synthesis, I find that I am continually struck by the strong sense of mystery, avoidance of, and aversion to death that seems to permeate the heart of western medicine, particularly in the critical care setting. Alternatively, when I volunteered as a nurse in a Peruvian hospice and palliative home care setting, I noticed that people did not avoid talking about death, and were are not afraid to be in the presence of someone who had died. Additionally, I observed that families seemed to accept death as a natural part of life, and perhaps another great reason to come together to celebrate living. What is it, then, that makes us recoil so much from the reality of death? What is it that makes us pursue the development of technologies and treatments that increasingly and almost science-fictionally prolong life and prevent death and dying? I don’t have an answer to these questions as of yet; however, through the testimonies of each participating nurse, I have gained great insight into the experience of death and dying within critical care.

Conducting this study affirmed my own experience that palliative care is an essential component of the ICU. Although unanticipated, this study brought me on a journey of self-discovery. There are indeed those joyful and peaceful end-of-life stories that warm your memories. Unfortunately, there are also those distressing situations that leave you shaken and somewhat defeated. The nurses in this study very clearly articulated that discrepancies and inconsistencies in palliative critical care can cast a dark shadow over the experiences of patients, families, and health care providers. As I listened to each story, I began to gain insight into my own bittersweet ICU experience, especially because I was familiar with many of the patients that the nurses spoke of during their interviews. I had previously been unaware of my own concrete reason for leaving critical care. I simply recall feeling tired, overwhelmed, and no longer interested in aggressively resuscitating patients. It was only in listening the nurses’ stories that I came to realize that I left critical care because I was morally distressed and burnt out. As such, this study has been somewhat healing for me. Overall, I feel very honored to be able to represent the nurse’s experiences with this study. Additionally, I am touched by the strong commitment that the nurses have to advocate for and provide the best possible end-of-life experience to patients and their families. Critical care is indeed an environment that holds great potential to provide consistent and high quality palliative care to patients and their families.

Conclusion

The nurses participating in this study were keenly aware of the barriers to and facilitators of quality palliative care in critical care. The study participants articulated these themes through key revealing statements, by recalling specific experiences, and in personal testimonies. Each nurse had vast and powerful recollections of both positive and negative end-of-life experiences in critical care. In addition to describing the barriers to and facilitators of quality palliative care in critical care, the nurses articulated key messages reflecting the reality of palliative care in critical care.

Palliative care is increasingly common in critical care; however, there are concerns about the quality of palliative care that is provided in this setting. The Institute of Medicine (1997) summarized it well in stating, "In some respects, this century's scientific and medical advances have made living easier and dying harder" (pp.1). In the past 10 years, numerous efforts have been made to improve the quality of end-of-life care in critical care. There are many barriers and facilitators that influence end-of-life experiences in the critical care setting. Understanding these barriers and facilitators from the perspective of the critical care nurses will provide insight and direction into what supports are required to improve the quality of palliative critical care in our local context. It is my great hope that this study will provide some direction and insight into this very important aspect of critical care.

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Appendix A

[U of A logo]

You are Invited to Participate in the

Barriers and Facilitators in the Provision of Quality Palliative Critical Care Study:

Critical Care Nurse's Perspectives

If you are a Critical Care Nurse or Nurse Practitioner with at least one year of critical care experience, who has cared for a dying critical care patient and would like to participate in this study please contact Lisa Weisgerber at 780 918 6678 or lisa.weisgerber@covenanthealth.ca

Participation will involve a one-on-one interview with the researcher

Appendix B

[U of A logo here]

Information Letter for Critical Care Nurses

Title of Study	**The Barriers and Facilitators in the Provision of Quality Palliative Critical Care: Critical Care Nurse's Perspectives**	
Research team	Anna Santos Salas, RN, PhD Thesis Supervisor, Assistant Professor Faculty of Nursing University of Alberta Phone: (780) 492-3618	Lisa Weisgerber Graduate Student Masters Program Faculty of Nursing University of Alberta Phone: 780 918 6678

You are invited to participate in a study entitled "The Barriers and Facilitators in the provision of Palliative Critical Care: The Critical Care Nurse Perspective.

Background to the Study

Intensive care units (ICU) provide increasing amounts of palliative care. Studies show that a lack of consistency in palliative critical care methods creates negative end of life experiences for patients and their families. Critical Care health professionals can provide insight into the factors that both inhibit and facilitate the quality of palliative critical care.

Purpose of the Study

This research is being performed to explore the barriers and facilitators to quality palliative care in critical care from the perspective of critical care nurses (RN's and Nurse Practitioners). The experience of these barriers and facilitators has not been closely studied in Canada. It is extremely important to understand these experiences in order to develop supports that will enhance the quality of palliative care provided in critical care. This study is part of master of nursing studies in the Faculty of Nursing at the University of Alberta.

Procedures

You will be invited to voluntarily participate in an audio-taped conversation with the researcher. The conversation will last about 45 minutes or a little longer. With your consent the conversation will be recorded. The audio recorder can be shut off at any time. Should you wish to shut the recorder off, notes may be taken with your consent. In this conversation the researcher will invite you to talk about your experience of caring for a dying patient in the critical care setting. The questions will be directed towards what barriers and facilitators you have experienced in providing this care. You may wish to talk about a particular patient and family whose treatment was more challenging in your view. You may wish to talk about your experience and involvement in withdrawing or withholding of treatment. You may also want to discuss a patient that experienced a positive end of life in critical care. The researcher will invite you to tell your own stories and viewpoints.

The following questions will be part of the interview:

1. Can you tell me about your experience of providing palliative care to patients in the intensive care unit?
2. What barriers inhibit quality palliative care in the intensive care unit?
3. What facilitates quality palliative care in the intensive care unit?
4. What resources would you find helpful in providing quality palliative care to your patients
5. What is your most memorable experience of caring for a dying critical care patient? Can you describe it?

The researcher may invite you to voluntarily participate in a follow up conversation to discuss initial findings. This conversation will last 20 minutes or a little more. The conversation will take place at a time and place that is convenient for you. You may decline participation in this activity. You may also be invited to provide feedback in writing to discuss interpretation of findings.

Voluntary Participation and Freedom to Withdraw

Your participation in this research is completely voluntary. If you decide to participate now, you may withdraw at any time without any consequences or explanation required. If you start your interview and decide you would like the tape stopped temporarily or permanently, your wishes will be followed. If you withdraw from the study, dropping out of the study will not affect your status within your employment and will not be communicated to your superior. Any concerns about your decisions to withdraw can be discussed with the researcher at any time.

Benefits

The potential benefit of participating in this study is that you might better understand your experiences of caring for a dying patient in critical care. Your participation in this research may also assist in helping others who go through this experience in the future. The experiences you describe may also contribute to the general state of knowledge on this topic.

Risks

Being in this study is your choice and there are no known risks.

Confidentiality and Anonymity

All information will be held private, except when professional codes of ethics or the law requires reporting. Your identity will be kept strictly confidential. All documents will be identified only by code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. Data stored on computers will be stored on a password protected secure database at the University of Alberta. Your privacy is protected by legislation that requires the researchers and assistants to ensure that access to the records is secure. Only the research team will have access to these data. A typist will have temporary access to the audio files. We will delete your name from all the records. We will assign a number to each file, transcript, and to any other material that results from your participation in this study. We will keep audio files and consent forms for at least five years after the study is completed. Consent forms will be stored separate from audio files.

Future use of data

We may report findings from this study in conferences or published material. Your name will not appear in any report. We may also use information collected in this study in future studies. Before doing so, we will request permission from the appropriate ethics committee.

Additional contacts

Should you have any questions about this study, you can contact Dr. Anna Santos Salas at 780-492-3618 or Lisa Weisgerber at 780 918 6678. If you have any concerns about the research, you may also contact the University of Alberta Research Ethics Office at 780-492-2615

If you agree to take part in this study, please contact Lisa Weisgerber at (780) 918 6678 or by email at lisa.weisgerber@covenanthealth.ca at your earliest convenience.

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Consent Form for Critical Care Nurses

Title of Study	**The Barriers and Facilitators in the Provision of Quality Palliative Critical Care: Critical Care Nurse's Perspectives**

Research team

Anna Santos Salas, RN, PhD Principal Investigator Faculty of Nursing University of Alberta Phone: (780) 492-3618	Lisa Weisgerber Graduate Student Masters Program Faculty of Nursing University of Alberta Phone: 780 918 6678

Part 2 (to be completed by the research participant):

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without affecting your job?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to the information you provide?	☐	☐

Who explained this study to you? ____

I agree to take part in this study: YES ☐ NO ☐

Signature of Research participant

____

(Printed Name) ____

Date:_____________________________________

Signature of Witness ____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANTS

Appendix C

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The Barriers and Facilitators of Quality Palliative Critical Care:

Critical Care Nurse's Perspectives

Interview Guide

1. Can you tell me about your experience of providing palliative care to patients in the intensive care unit?
2. What barriers inhibit quality palliative care in the intensive care unit?
3. What facilitates quality palliative care in the intensive care unit?
4. What resources would you find helpful in providing quality palliative care to your patients
5. What is your most memorable experience of caring for a dying critical care patient? Can you describe it?

Appendix D. Member Checking Feedback

Table 6. Member Checking Feedback

Participant 1:

- I did read through the document and it does represent so much of palliative care in the critical care setting. I think you are working on a truly awesome project and I wish you the best!

Participant 4:

- I reviewed it.
- I like it. Nothing really to pull out as something to fix (from the poster)

Participant 5:

- That looks fabulous. It showcases the stories well and I think your researcher conclusion is brilliant. I am SO proud of you!!!!!

Participant 10:

- Barriers to EOL care- You have identified several themes within this. Some of your statements could likely be lumped together into a broader category so your readers will pick up on your really important messages. For example: family conflict, Physician/nurse variability, moral distress and medical futility could all be broadly considered as "Conflicting values- within the healthcare team and between HCP and family." Poor communication, crisis decision making, and lack of consistency could be considered as "Lack of/poorly timed discussion of values" and "Lack of transparency of intentions and goals"
- Facilitators- same thing here. What I see is EOL care is improved when roles and responsibilities are clearly defined; when HCP have the right knowledge and tools to know how to respond; and that the right people are involved and working towards a clearly communicated common goal.
- Keep the quotes as they are!
- Overall, I love this study. I think you have captured the essence of what it’s like to have an EOL patient in the ICU. Nurses see we could do it better but they just aren't sure how.

Appendix E. Research Budget

Barriers and Facilitators in the Provision of Quality Palliative Critical Care Research Budget		
Expense	***Anticipated Amount***	***Actual Amount***
Gas for Travel to interviews and meetings	$100	$ 100 (approx.)
Parking	$150	$60
Transcription Fees	$750	$1000
Total	$1000	$1160

Appendix F. Time Line

Barriers and Facilitators in the Provision of Palliative Critical Care: Critical Care Nurse's Perspectives

Project Timeline: August 2015 through to December 2016

Activities\Semester	**Fall Semester 2015**	**Winter Semester 2016**	**Spring/Summer Semester 2016**	**Fall Semester 2016**	**Winter Semester 2017**	**Spring/Summer Semester 2017**	**Fall Semester 2017**	**Winter Semester 2018**
Research proposal defence	X							
Ethics approval	X				X (renewal)			X (renewal)
Site approval	X							
Study presentations	X				X		X	
Participant accrual		X	X					
Data collection		X	X		X (Member Checking)			
Data analysis		X	X	X	X		X	
Synthesis of Findings							X	X
Discussion of research findings		X	X	X	X	X	X	X
Meetings with supervisor/supervisory committee	X	X	X	X	X			
National and International dissemination activities								
Submission of article for publication								