

**NOVICE NURSES' EXPERIENCES PROVIDING PALLIATIVE CARE FOR
CHILDREN AND THEIR FAMILIES**

by

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Executive Summary

The role of registered nurses is complex and involves the holistic provision of nursing care from the beginning to the end-of-life. Although pediatric palliative care is a specialty area, many novice nurses identify pediatric nursing as a field of interest; and therefore require the appropriate education and supports to ensure the best care is provided. Currently, Canadian undergraduate nursing programs seek to provide students with entry-to-practice competencies and rarely focus on providing specialty training (such as palliative care of children) in the undergraduate years. For a novice nurse, the care of a child can be overwhelming, and the care of a child who is dying requires even more expertise and fortitude. There are few research studies that focus upon the experience of the novice nurse in caring for children who are dying. The purpose of this project was to explore the experiences of novice nurses caring for palliative children and families.

As part of the qualitative study, eight novice nurses from two Alberta hospitals were interviewed about their experiences providing pediatric palliative care for children and families. All of the nurse participants had cared for at least one palliative patient since graduation. The participants shared their stories with vivid detail and conveyed the richness and lasting influence of these experiences on them as novice nurses and as people. The caring they provided was influenced by who the nurses were, the knowledge they possessed, the context of their workplaces and societal beliefs about children dying, and the families to whom care was given. The relational practice abilities of the nurses proved to be an overarching theme, as regardless of the scenario the nurse was in, the ability to connect with a child and family was foundational. Five important conclusions emerged from this study: 1) Novice nurse participants appeared to be deeply impacted by their early and more recent experiences with end-of-life care; 2) Participants'

descriptions of personal growth and development of coping strategies were seen as positive outcomes from their initial experiences with pediatric palliative care; 3) The experiences of novice nurses were greatly influenced by their practice settings. The dichotomy between healing and dying was seen as particularly challenging in pediatric nursing and was influenced by society's common belief that children do not die; 4) Novice nurses struggled to communicate with some families about topics that were perceived as difficult such as end-of-life care decision-making; and 5) New nurses did not feel confident and competent in their knowledge of pediatric palliative care.

Although these conclusions are not meant to be a critique of existing undergraduate nursing education, they highlight the importance of purposeful inclusion of palliative theory and practice and lead to several recommendations for the future. Additional education as professional development beyond graduation is also required within workplace settings because experiential learning helps solidify palliative care concepts. Recommendations were derived from this study for nursing education, practice, leadership, policy and research. Nursing education needs to focus on four areas for improvement: 1) Draw connections between foundational skills such as communication, relational practice and end-of-life care throughout the lifespan; 2) Offer interdisciplinary education opportunities for nursing students to learn with students from other health disciplines; 3) Engage students in palliative care concepts through a variety of teaching and learning strategies in classroom and clinical settings; and 4) Introduce end-of-life care concepts such as perinatal loss and terminal pediatric conditions in specialty subjects. Recommendations for nursing practice include: 1) Provide palliative education in hospital orientation programs; 2) Enhance access to palliative resources in the workplace; and,

3) Create a culture of learning concerning pediatric palliative care. Although this study offered important perspectives from the experiences of novice nurses, several implications for further research were identified: 1) Explore pediatric palliative care in a variety of settings such as community and homecare; 2) Examine the experiences of novice nurses providing end-of-life care throughout the lifespan; and 3) Study the self-efficacy of pediatric nurses caring for palliative children and their families throughout their careers (from novice-to-expert practitioners). Recommendations for nursing leadership include: 1) Monitor new graduates' entry-to-practice and transition from novice-to-expert and 2) Encourage nursing innovation and expert practice. Lastly, a nursing policy recommendation is for existing provincial, national and international policies, guidelines and resources to be used to educate and support novice nurses.

In conclusion, novice nurses offer important perspectives about pediatric end-of-life care and provide insight into areas of strength and areas for continual improvement for the ultimate benefit of palliative children and their families.

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Chapter 1: Introduction and Background

The nursing care of children requires a family centered approach and knowledge about growth and development by the registered nurse. For a novice nurse, the care of a child can be overwhelming, and the care of a child who is dying requires even more expertise and fortitude. Currently, Canadian undergraduate nursing programs seek to provide students with entry-to-practice competencies and tend to not focus on providing specialty training (such as palliative care of children) in the undergraduate years. Knowledge about the provision of end-of-life care for children is often acquired in the workplace through experiential learning, mentorship from expert nurses and continued education opportunities. There are few research studies that focus upon the experience of the novice nurse in caring for children who are dying. This qualitative study endeavored to explore these experiences and the existing supports for novice nurses who choose to practice in this field. Ultimately, the better equipped novice nurses feel to provide care for children who are dying, the better the care provision will be for pediatric patients and families.

Background

The first experiences a nurse has with patient death is known to be stressful, with such experiences being variously described as being good learning, rewarding, distressing or causing guilt and helplessness (Kent, Anderson, & Owens, 2012). As a pediatric nurse and nurse educator, I have been exposed to both personal and colleague experiences with providing palliative care for children and families. Considering what contributes to best care practices for children who are dying and their families, I wanted to understand what constitutes adequate support for novice nurses experiencing the death of a child for the first time. As a senior staff nurse, I wanted to mentor the colleagues who I work with as effectively as possible and endeavor

to do so through evidence-based practice. Currently, a gap exists in the literature regarding end-of-life care provision within this specialty in a variety of pediatric settings. After having practiced in tertiary and regional hospitals, I also hoped to explore the differences in organizational, educational and personal supports that these nurses have when providing care.

Definition of Terms

The registered nurse who practices in a pediatric acute care setting is responsible for the care of both children and families. In the majority of cases, this care is focused on health promotion, illness prevention and health maintenance. In the cases where the child expectedly or unexpectedly requires end-of-life care, this change in goals of care can be distressing for the nurse who is providing care. In addition to the demands that this experience creates for a seasoned nurse, the novice nurse may experience increased distress and feelings of helplessness. The following definitions provided guidance to this study:

Pediatric nursing. The area of nursing that applies to the care of the child is referred to as pediatrics. The age range of children receiving care is from birth to 17 years of age. Pediatric nursing can be performed in both community and acute care settings. For the purpose of this study, the acute care settings of a neonatal intensive care unit (NICU), a pediatric intensive care unit (PICU), a hematology, oncology and blood and bone marrow transplant (HOT program), a general medical-surgical and mental health pediatrics unit and a hospice facility are the settings.

Novice nurse. In this research study, the novice nurse is defined as a nurse within three years of graduation. This time period was selected as inclusion criteria for two primary reasons: to ensure that the newness of the experience allowed the participants to share their novice perspectives during the interviews and to ensure that the nurses who were interviewed would be able to provide insight into the critical thinking and clinical judgment of a novice nurse.

According to Benner's model of novice to expert, there are five categories in the trajectory: novice, advanced beginner, competent, proficient and expert (Benner, 1984). It is important to acknowledge that nurses can move back in forth in the trajectory with different situations, and that it is not a linear model. Novice nurses provided important insight into the first experience of a pediatric death.

Emotion work of the novice nurse. Emotion work is defined as the work involved in managing feelings in both self and others (Hochschild, 1983). This emotion work is of extreme importance when novice nurses are providing care in the stressful environment of pediatrics and is heightened when a child is dying. Emotion work refers to activities and behaviors concerned with the enhancement of others' emotional wellbeing and with the provision of emotional support (Erikson, 1993). The nurse must navigate his or her own emotions while additionally supporting families through what is one of the most difficult events of their lives: the death of their child.

Presencing abilities of the novice nurse. There are multiple definitions for the nurse's presencing abilities. Presencing can be described as the ability to understand and be with another (Maunder, 2006). Benner (1984) claims presencing is the giving of self in the nurse-patient interaction. Nelms (1996) states that presencing is receiving another's presence as well as giving one's presence. For the purpose of this study presencing refers to the ability of a novice nurse to be in the moment and supporting a child's family in the presence of a dying child.

Relational inquiry of the novice nurse. Relational inquiry considers the well-being of patients, nurse and systems and how they integrate (Doane & Varcoe, 2015). The patient cannot be viewed in isolation; nor can the novice nurse's experience of caring for a dying child because multiple contextual factors are at play. Taking an intrapersonal lens of relational inquiry allows the nurse to consider what is going on within all people involved and includes the patient, the

nurse who is providing care and what others such as the family and other staff members are experiencing (Doane & Varcoe, 2015).

Palliative and end-of-life care. The terms palliative and end-of-life care apply to patients who are dying. The concept of palliative care evolved from the hospice philosophy of meeting gaps in care for seriously ill and dying patients (Morgan, 2009). The World Health Organization (WHO) describes palliative care for children as the active total care of the child's body, mind, and spirit, as well as a means of providing support to the family (n.d.). In this study, the phenomenon of palliative care is explored with nurses who cared for a dying child, regardless of whether it was emergent or predicted. The provision of end-of-life care is typically marked by a change in the goals of care from being acute and curative to comfort measures. In pediatrics, this trajectory can occur rapidly or over an extended period of time. To provide comprehensive palliative care to a child, the family must also be cared for. For a family, caring for a loved one who is dying can create a greater sense of meaning and connection; however, it can also create significant distress and negative psychological health (Gaudio, Zaider, Brier, & Kissane, 2011). Likewise, the experiences of nurses providing palliative care for the first time to a child and family are rich in both positive and negative emotions.

Project Description

Project purpose and objectives. The purpose of this project was to explore novice nurses' experiences when providing palliative care for children and their families. The intent was to develop knowledge to better inform undergraduate and clinical education for nurses caring for palliative children.

The research questions for the project were as follows:

1. How do novice nurses describe the experience of caring for children who are dying and their families?
2. What types of challenges are experienced in caring for children who are palliative?
3. What coping strategies are used by novice nurses when caring for children who are dying and their families?
4. What personal supports do novice nurses use when providing end-of-life care for children?
5. How do the practice environments influence novice nurses in the care of dying children?
6. How did their undergraduate education prepare nurses to provide end-of-life care for children who are palliative?

Project method. To gain an in depth understanding of the experiences of novice nurses who are providing care for children who are dying, a qualitative research method was used. Specifically, a descriptive methodology was employed to facilitate an exploration of their experiences. The interpretative description method was useful in examining the clinical problems and used the researcher as an instrument in the design (Thorne, 2008). The experiential data was obtained through in person interviews with novice nurses. Data analysis was performed through transcription, coding and full immersion in the data to extract meaningful findings.

Relevance and significance. The role of registered nurses is complex and involves the holistic provision of nursing care from the beginning to the end-of-life. Although pediatric palliative care is an area of specialty, many novice nurses identify pediatric nursing as an area of interest; and therefore require the appropriate education and supports to ensure the best care is

provided. There are few literature examples that focus upon the experience of the novice nurse in caring for children who are dying, and the thesis research began to address this gap.

Outline of Thesis

The thesis is organized into six chapters: Chapter One introduced the purpose, background, key terms and research method. The next chapter, Chapter Two, describes the search and retrieval strategies used for the literature review, followed by an overview of previous research relevant to the study. The research methodology used to explore the phenomenon is described in Chapter Three, and includes information on sample selection, data collection and analysis, scientific quality and ethical considerations. Chapter Four describes the findings generated from the interviews, while Chapter Five discusses the key findings and results in relation to current literature. Chapter Six concludes by providing recommendations for nursing education, practice, leadership, policy, and research.

Chapter 2: Literature Review

This chapter describes the search and retrieval strategies that were used in the literature review, and presents the findings of the review. The literature review was performed to appraise the current literature pertaining to palliative care of children and families and the novice nurse, and to determine the perceived gaps in research evidence.

Search and Retrieval Strategies for Literature Review

The literature review was done in two phases: a preliminary and secondary search. The preliminary search was conducted using CINAHL, Medline and Google Scholar databases. The initial search terms were developed using the CINAHL Headings tool, similar to the MeSH tool in MEDLINE, and expanded on using a personal thesaurus and previous knowledge of applicable synonyms. The key words included: “child or children or childhood or adolescen* or teen* or pediatric or paediatric or youth* or kid*”; “death or dying or end-of-life or palliative”; “nurse or registered nurse or novice nurse or student nurse” and “experiences or coping or fears or anxiety”. The Boolean operators of “OR” and “AND” were utilized in the narrowing down of search results. Additional and differing limiters, expanders, inclusion and exclusion criteria were applied to each database search. A hand search was done of several of the journal articles’ references in order to expand on ideas. Refer to Appendix A for a summary of the preliminary search method.

The inclusion criteria were considered met if the research articles were published within the last ten years. These articles were further scrutinized by their abstracts and included an array of topics related to the key concepts of this study: namely, pediatric nursing, the novice nurse and end-of-life care. Refer to Appendix B for a list of the relevant articles included in the thesis proposal. This list expanded as the thesis project progressed. A more comprehensive secondary

search was conducted throughout the thesis process as new themes emerged from the literature and the interviews with nurses.

To ensure the most current literature was included, I continued to review the results from newer literature searches and modified key word searches as new terms and ideas unfolded during the qualitative research process. Additionally, a forward search of current sources was done and grey literature was reviewed for further exploration of the concepts of pediatric palliative care and the novice nurse.

Through my preliminary literature review of healthcare professionals' experiences with dying patients in a variety of settings, multiple key themes emerged. The main themes included the novice nurse, Family Centered Care and end-of-life care, practice environments, personal and professional support, strategies for improving palliative care and challenges providing pediatric palliative care. The current body of research about nurses caring for children who are dying has not focused on the experiences of the novice nurse; therefore, a gap currently exists in this field of knowledge.

Through my secondary search several months later I paid additional attention to emerging themes and ideas, and revisited previous concepts to identify newly published literature. The literature regarding relational practice and inquiry, emotion work, presencing and Canadian entry-to-practice for registered nurses guidelines and recommendations was explored. Similar to the first search, the secondary search utilized CINAHL, Pub Med and Google scholar and included grey literature, textbook resources, hand searching and articles recommended by others. The additional key words included in the secondary search: "emotion work", "presencing", and "relational inquiry", "relational practice", "entry-to practice competency" and "experiential knowledge". The results of the literature review follow.

Literature Review

Characterizing the novice nurse. Significant transition occurs when an undergraduate nurse becomes a registered nurse and assumes a variety of roles within the healthcare system and practice settings. Patricia Benner's (1982) five levels of proficiency: novice, advanced beginner, competent, proficient and expert are loosely based upon the Dreyfus model and consider two levels of skill performance. The first is a movement from reliance on abstract principles to the use of past, concrete experience as paradigms and the second is a change in the perception and understanding of a demand situation so that the situation is seen less as a compilation of equally relevant bits and more as a complete whole in which only certain parts are relevant (1984, p. 402). Benner's sentinel work has provided a framework for multiple other explorations of the novice nurse's transition and development. Jewell (2013) performed a literature review to determine how to support a novice nurse to thrive, and retrieved 23 articles. Key findings from this knowledge synthesis included: the personal and professional growth that occurred in the first years of practice, the growth in practice from 'doing' to 'being' to 'knowing', the importance of successful transition to nurse retention and the recommendation for novice nurse coaching programs to be developed.

The novice to expert trajectory is integral to consider when nurses are encountering their first experiences with pediatric palliative care. In a qualitative study, Dunn, Otten, and Stevens (2005) interviewed 58 nurses and identified factors such as the past, personal and professional experiences of nurses that influenced both the end-of-life care that they provided and their attitudes towards death and dying. Situating their findings in the existing literature, Dunn et al. (2005) described the nurses' professional experience in palliative care as the months and years of nursing experience and the amount of time in contact with terminally ill patients. A key finding

was that the more experience nurses had with end-of-life care of children and families, the more positive the experience became (Dunn et al.). Hopkinson, Hallet, and Luker (2005) interviewed 28 newly graduated nurses in two palliative care settings in the United Kingdom (UK) and learned that a typical belief amongst participants was that personal learning took place as a result of one's own practice experiences or the observation and inquiry into other people's practice. Although these first experiences were described as stressful in an online survey of early-career nurses, they also describe their first patient deaths as stressful, distressing or causing guilt and helplessness (Kent et al., 2012). It is important to remember that "experience teaches the proficient nurse what typical events to expect in a given situation and how to modify plans in response to these events" (Benner, 1984, p. 405). For the novice nurse, these early death experiences can be very difficult, however, they can help them develop clinical judgment and refine their critical thinking skills, assuming that they have some background knowledge. Maunder (2006) described that through encountering challenges, novice nurses develop coping mechanisms and strategies to effectively surmount challenges in the future. Cook et al.'s 2005 study of 22 nurses providing pediatric palliative care revealed that coping strategies and behaviors changed as nurses progressed from novice to expert. According to Benner's (1984) typology, once they become expert practitioners they will be capable of drawing upon previous experiences to use intuition and focus to solve clinical problems.

Although Benner contributed an important theoretical framework to the professional evolution of the nurse, it can be noted that critiques exist on the quality of the narratives used to form the basis of her work and that the novice-to-expert trajectory is not formulated or based on quantitative research. Altmann (2007) surmises that some of the discourse that exists around the model is related to confusion over whether it is a theory or a philosophy, and maintains that

when viewed as a philosophy her work is more effective and defensible. Intuition and expertise are difficult terms to measure, leading to some of the challenges with applying the novice-to-expert trajectory in a practical way.

Emotion work of the novice nurse. Emotional responses are influenced by societal and cultural norms, and in the case of nurses, they are additionally influenced by professional norms of concealing emotion and internalizing reactions during care provision (Maunder, 2006). The death of a child is not a social or cultural norm which can lead to the nurses' difficulty coping, and can in turn lead to struggles in supporting the needs of children's families.

Emotional responses can be difficult to predict, and have long lasting effects. First experiences are formative to how they will be able to cope with future experiences. As novice nurses encounter further pediatric palliative care experiences, it can be anticipated that they will be able to draw upon previous experiences to reflect and adapt their emotions to the new situations they encounter (Maunder, 2006).

Self-awareness is a necessary component of professional nursing practice; within the realm of palliative care the nurse must reflect on how the approach he or she takes influences the patient and family. The more aware nurses are of the impact of their behaviors, the more sensitive they are to the emotion work that is required from registered nurses for patients and families to feel they are genuinely cared for (Maunder, 2006). Therefore, not only does the nurse need to be aware of the physical manifestations of the dying process, the nurse must be emotionally prepared and committed to self-work.

Within the literature, it is evident that nurses seek to create balance in their emotions in order to cope. In the study conducted by Hopkinson et al. (2005), some participants shared that

they had tried to achieve a balance between emotional involvement versus emotional distance to enable them to cope and function in their nursing role.

Family-centered care and end-of-life care. Family is integral in a child's life and also during his or her death. Bartell and Kissane (2005) stated that while family has been long acknowledged as pivotal within the provision of palliative care, few models successfully integrate them into care. For nurses, meeting the needs of a child and the family can pose a challenge. Care is often focused on the needs of the family as they struggle to cope with the loss of a child and navigate unfamiliar feelings of grief and loss. Gaudio et al. (2011) conducted a quantitative study of 144 families and individuals that revealed that when families care for a loved one who is dying both positive and negative emotions are experienced; examples included a greater sense of connection to the family member who is dying and also higher levels of distress. Nurses play an important role in empowering family to make decisions about end-of-life care for their child and to provide comforting, supportive care.

A focus on family needs by the pediatric nurse providing palliative care can also include maximizing the moments and memories for children and families (Maunder, 2006). This can be done through encouraging family involvement, facilitating fun activities and the creation of mementos for a family to have after the death of a child.

Not surprisingly, it was noted repeatedly throughout the literature that novice nurses care for palliative children and families. It was interesting to note that in a study by Hopkinson et al. (2005), the novice nurses also felt cared for by the families of the dying patients. This caring took a variety of forms from positive reinforcement of the nurses' work to two-way communication that supported everyone involved with the patient.

A necessary skill in children's palliative care is the adaptation of the nursing approach to care, so that it fits with the care needs and expectations of each child and family (Smith, Coleman, & Bradshaw, 2002). The tailoring of nursing approach is not unique to pediatric palliative care, as it is foundational to relational practice in all nursing settings.

The novice nurse and education about end-of-life care. What constitutes required end-of-life knowledge for undergraduate nursing curriculum is not clearly established. Hopkinson et al.'s (2005) study of novice nurses revealed that while few nurses were able to recall the knowledge they had received, they were able to provide care and respond to the researcher's questions in a manner that suggested that they possessed some knowledge of this subject. Linking theory-to-practice and providing students the opportunities to learn through interaction with clients and families in healthcare settings leads to effective learning. Hopkinson et al. (2005) found that the experiential knowledge was easily recalled by their participants and was declared as most useful to their development. The attitude one takes towards undergraduate education experiences also factors into how knowledge is conveyed. Nurses in Hopkinson et al.'s study demonstrated minimal awareness of how education had shaped their practice and perceived little relevance between the classroom and the care of real patients.

Entry-to-practice competencies for registered nurses. A solid foundation of knowledge is a necessary component for novice nurses to provide competent nursing care. The literature search conducted by Hopkinson et al.(2005) evidenced that emphasis on sound educational preparation and an understanding of the psychological processes involved in coping are necessary for competent end-of-life care provision, regardless of age or setting.

The Canadian Association of Schools of Nursing (CASN) created an advisory group which devised a sentinel document outlining the palliative and end-of-life care knowledge and

skills that are required of new graduates. The document outlines national, consensus based competencies and indicators to facilitate greater integration of this area of nursing in undergraduate curricula in Canada (CASN, 2011). Of these nine competencies, it is apparent that some are easier for nurses to demonstrate confidence, knowledge and skill in than others. Foundational concepts include: using relational skills, demonstrating grief and bereavement support for others and utilizing a family centered approach with all age groups and cultures of patients and families (CASN, 2011). Refer to Appendix I for a table of the entry-to-practice competencies for end-of-life care from CASN. CASN's competencies and indicators for palliative and end-of-life care can provide guidance to nurse educators when designing nursing curriculum.

The influence of practice environments on pediatric palliative care. In acute care settings, there is an emphasis upon cure and therefore it can be difficult for the interdisciplinary team to shift the focus towards the supportive or palliative care of a child. Certain pediatric practice environments such as oncology units and pediatric intensive care units have greater exposure to end-of-life. As described by Doorenbos et al. (2012), when curative therapies are no longer appropriate, or in cases where the outcome for seriously ill children is highly uncertain and may end in death, staff members face a transition in care to one that addresses the end-of-life issues. This transition can be a particular challenge in the fast-paced, aggressive, cure-focused environment of the PICU, where the initiation and delivery of palliative care requires effective communication between the family and the health care team about possibilities for intervention, the likely and desired outcomes, and the goals of care for the child and family (Doorenbos et al., 2012). Pediatric critical care and oncology units are most often studied in the literature. Cook et al. (2012) described that within these settings the distress, burnout and coping strategies have

been well explored, however, the experiences of nurses who were anticipating curative care as opposed to palliative care and their reactions has minimal literature.

Regardless of the area of practice, pediatric nurses' comfort and competence in providing palliative care is an important phenomenon to explore. In the literature, it has been shown that nurses with greater exposure to dying patients, more years in practice, more experience and more hours of palliative care education tend to have more positive attitudes toward death and caring for dying patients than those with less exposure (Mutto, Errazquin, Rabhansl, & Villar, 2010). Consequently, for a novice nurse, it is essential that he or she is provided with adequate supports to prepare for the first experience of a pediatric patient death.

The practice environment a nurse works in is an important contextual factor. Cook et al. (2012) discussed that institutional resources and colleague support were critical to the coping and grieving process in the cohort of pediatric cardiology nurses that they studied. In summary, the practice of a novice nurse cannot be studied effectively without an exploration of the practice setting in which he or she works.

Personal and professional support. It is important for nurses to be aware of supports that are available to them both personally and professionally. The responsibility of providing pediatric palliative care can have both positive and negative impact on a novice nurse and therefore, nurses must be well-supported. Several factors are identified as key predictors of confidence: age, gender and educational experience during undergraduate training (Dickens, 2009). The past experiences that shape nurses' competence include level of education and palliative training they received prior to providing end-of-life care for the first time (Dunn et al., 2005). In addition to professional experience, the past experiences that will impact a nurse's competence when providing palliative care include the social demographics of the nurse such as

age and religion (Dunn et al., 2005). It has been my observation that workplace settings tend to establish various programs and initiatives to support staff when pediatric patients die. Presently, there is no comprehensive literature review or knowledge synthesis available that details the successes and failures of these programs.

Challenges providing pediatric palliative care. In general, children are healthy and as a result, society has difficulty accepting pediatric death. Health care providers are trained to care for the living and may complete their education and enter the workforce without ever experiencing the death of a patient (Youngblood, Zinkan, Tofil, & White, 2012). Today, pediatric deaths most typically are a result of congenital birth defects, cancers, traumatic injuries, and genetic or neurological disorders (Doorenbos et al., 2012). A literature review conducted by Morgan (2009) identified multiple barriers to good palliative care, including attitudinal, clinical, educational, institutional, regulatory, and financial barriers; all of the stated barriers identify that pediatric palliative care cannot be approached in the same manner as adult end-of-life care. Currently, there are international task forces devoted to developing policy to guide the care of children experiencing life threatening events (Morgan, 2009). In a study of 680 undergraduate nursing students in Argentina (Mutto et al., 2010), it was found that when nurses were exposed to care of the dying without receiving a systematic death education, they suffered a higher incidence of death anxiety and developed negative attitudes toward care of the dying. It was also noted from the research findings that they limited their involvement in death-related situations, and were more likely to withdraw from the care of the dying (Mutto et al.). The aforementioned challenges need to be acknowledged by institutions as they develop palliative care education programs.

Strategies for improving palliative care. Death in children is rare and when it occurs, is often not talked about. However, there is a need for proper education for people caring for pediatric palliative care patients and their families (Papadatou, 1997). Findings from a qualitative study (Rushton et al., 2006) with one hundred participants indicated that although families reported satisfaction with the care provided for their dying child, health care professionals expressed significant levels of distress. Strategies developed within the hospital included palliative rounds and bereavement debriefings (Rushton et al., 2006). Simulation of stressful pediatric medical events, such as a death, can help prepare the multidisciplinary team for their roles when events do occur in the practice setting (Youngblood et al., 2012). A combination of strategies and an acknowledgement of the need to help staff when children die are needed to adequately support novice and experienced nurses.

Chapter Summary

In this chapter, related literature was reviewed. Although there were numerous articles discussing nurse coping during palliative care provision, literature specifically describing the experiences of novice nurse and their knowledge development was limited. The increasing complexity of pediatric cases and extended lifespan for many pediatric conditions means that novice nurses working in pediatric settings will continue to provide end-of-life care. With this consideration, a project to explore the experiences of novice nurses caring for palliative children and families was an identifiable need. The next chapter will describe the research design, methods and procedures used for this thesis project.

Chapter 3: Research Design, Methods and Procedures

The research process was designed to answer the research questions described in this chapter. Chapter sections include design, sample selection, generation of data, and data analysis. In this chapter I also describe how I met ethical considerations, ensured scientific quality and explored limitations.

Design

To gain an in depth understanding of the experiences of novice nurses who are providing care for children who are dying, a qualitative research method was used. Specifically, a descriptive methodology was employed to facilitate an exploration of the meaning of the nurses' experience and acknowledge my personal biases that were explored and reflexively bracketed (Polit & Beck, 2011). Interpretive description aligned with the philosophical underpinnings of the research being conducted and the type of knowledge being sought as the focus of this study was to generate evidence for clinical practice (Thorne, 2008). Following an emergent design that is continually evolving and features the researcher as an instrument (Polit & Beck, 2011), interpretative description was useful in examining clinical problems I encountered in the nursing care of dying children and their families (Thorne, 2008). The experiential data was obtained through a series of interviews with novice nurses.

Methods

Recruitment. Once research ethics approval was obtained (Refer to Appendix F), I recruited participant through advertisements and snowballing at various pediatric practice sites. Recruitment posters were put up on each unit by managers or myself. A recruitment email was provided to the patient care manager for each practice area to be distributed to the staff on the

unit. Nurses were asked to contact me by phone or email if they were interested in participating. A five dollar gift card to either Good Earth or Tim Horton's was provided as an honorarium.

Inclusion. The inclusion criteria included male or female participants between the ages of twenty and 65; registered nurses who cared for children between the ages of one day old and seventeen years of age; novice nurses within three years of graduation who had cared for a minimum of one palliative patient; were currently working in tertiary and/or regional hospitals (i.e., General Pediatrics, Pediatrics ICU, Pediatrics Oncology/Hematology/BMT, NICU); practice in Alberta; spoke English; and were available to complete a face-to-face, 45-minute interview. The exclusion criteria were nurses who did not meet the inclusion criteria.

Sampling. I interviewed eight novice nurses for the thesis project. My recruitment process provided eleven nurse participants who indicated interest in the research project, eight of whom met the inclusion criteria. Four nurse participants were working on a pediatrics unit in a regional hospital in a small city in Alberta, and four nurse participants were working at a tertiary hospital in a large city in Alberta at the time of the interviews. Of the four participants working in the tertiary Children's Hospital, two worked in NICU, two in the HOT Program and one also worked in a hospice facility. The majority of participants had only worked in their current workplace, and all were female and had attended university in Alberta for their nursing education; six participants had completed a 4-year nursing program and two had completed a 2-year after-degree nursing program. Six students were Caucasian, one student was of East Indian descent and another of African descent. While the majority of students had grown up in Alberta, two had been raised in other Canadian provinces. Five participants were under the age of 25, and three participants were between 25 and 35 years of age.

Three of the eight participants had close friends or family members who had died or had a child die, while the other five participants had limited personal experiences with death. Five of the participants had cared for three or more palliative children and families; three of the participants had cared for two children at the time of the interview. Refer to Table 1.

Participant	Demographic Data	Experience	Number of children palliative care was provided to
1.	<25 years Female	1-2 years experience	3 or more
2.	25-35 years Female	6months-1year	2
3.	<25 years old Female	1-2 years experience	3 or more
4.	25-35 years Female	1-2 years experience	3 or more
5.	<25 years Female	6months-1year experience	2
6.	<25 years Female	1-2 years experience	3 or more
7.	25-35 years old Female	>2 years experience	3 or more
8.	<25 years Female	>2years experience	2 patients

Table 1. Participant Demographics.

Data collection. The data collection was performed through conducting face-to-face interviews with eight nurses. Each interview was approximately 45 minutes in length and was conducted with novice nurses within three years of graduation. The interviews took place in Alberta, with registered nurses outside of work hours in delegated conference space at the hospitals or in a mutually agreed upon location. Demographic information was gathered from participants at the start of the interview using a demographic data sheet (refer to Appendix E) for the purpose of obtaining information about the age group, amount of nursing experience and

number of times providing palliative care. An interview guide was used and was re-evaluated after the first two interviews and in consultation with my thesis supervisor. The initial interview guide was modified after the first two interviews (refer to Appendix D).

Most participants cried during parts of the interview and recalled their experiences vividly. I also experienced a wide range of emotions and recollection of personal and professional experiences during and after the interviews. Several of the nurse participants spoke with me for an extended period of time after the recorder had been turned off. The sources of data from each interview were audio-recordings and field notes. The field notes included details such as the setting, the body language of the participant, and any additional comments that were not captured in the recordings. I transcribed each interview verbatim from the audio-recording. In keeping with the emergent design of qualitative research, a second interview with some of the participants was a possibility after the first phase of data analysis to validate and extend the preliminary analytic framework and clarify emerging themes. No secondary interviews were conducted with the participants due to the depth of the primary interviews and participants' open portrayal of their experiences.

Data analysis. The analysis process was reflective, with full immersion in the data through listening to the audio-recordings, transcribing the interviews and rereading the transcripts. NVivo™ software was used to organize the transcripts, develop the code book and perform coding. After the first two interviews, I developed a code book in consultation with my supervisor. The code book identified emerging themes and trends and after it was developed, was used for line-by-line coding of the initial transcripts. The code book required editing at the midway point and after the final interviews were completed. The remaining data was coded and each interview was analyzed using the final version of the code book.

From there, elements and themes began to emerge and a detailed thematic analysis was performed. Participant narratives were written to capture the sample characteristics and perspectives of each participant using memory recall and field notes. A thematic analysis diagram was crafted to help explore the themes as they were discovered. This inductive approach allowed for a thorough exploration of the experiences of novice nurses caring for palliative children and their families.

Through analysis of the data, I identified the overarching theme of relational practice and the themes of caring and self, knowledge, context and family. In the analysis process, the findings were organized and re-organized to explore relationships between participants' experiences. This allowed for a cohesive set of findings; refer to Chapter 4 for additional detail.

Ethics

To enact the proposed research, ethical approval was obtained from Trinity Western University's Research Ethics Board and The Community Research Ethics Board of Alberta (CREBA). Recruitment of participants began after obtaining research ethics approval. At the time of volunteering for the study, participants were informed in depth about the study, and their ability to withdraw at any time. They received a detailed letter of information and informed consent was obtained prior to starting the interviews; refer to Appendix G for the Information Letter and Consent. After the initial six interviews, I had difficulty recruiting additional participants who met the inclusion criteria and my availability. An amendment to the initial ethical approval was sought from both research boards and was granted. This amendment permitted interviewing nurses with up to three years of experience and led to the recruitment of two additional nurses. As there was a risk of emotional distress when interviewing novice nurses about their first experiences with pediatric death, I used empathy and active listening skills

during the interviews and participants were provided with the contact information for the Employee Assistance Program at their hospital. My thesis supervisor and I were the only researchers privy to the raw data. Any information that was obtained in connection with the study that might identify the participants and the children they had cared for remained confidential and anonymous. Demographic information, audiotapes, transcribed interviews and field notes were assigned an identification code and pseudonym and kept in a locked filing cabinet. Any digital information was stored in a password-protected computer and will be kept for seven years for possible secondary analysis or research audit.

Scientific Quality: Validity and Reliability

To ensure scientific quality, several measures were implemented. An essential component of qualitative research is to position the researcher as an instrument and acknowledge any biases. In my role as a pediatric nurse and educator, I might have displayed a bias towards providing additional supports to nurses who care for palliative clients. However, to ensure quality of the findings, reflexivity was performed through an audit trail of field notes and memoing. Within the context of this study, bias did not negatively impact the study, but instead served as a sensitization to the unique experiences of novice nurses working with children who are dying. Another strategy I employed was the use of representative credibility through triangulation of data sources (Thorne, 2008). Although it was a possibility, the themes that become apparent in the analysis did not need to be revisited in a second interview with the participants. The rich data provided the researcher with clarity during the initial sharing of experiences in the interviews. The use of interpretive description as methodology required a carefully thought out frame of reference, attitude and communication style designed to build rapport, encourage depth, and allow correction of the researcher's initial understandings and

interpretations (Thorne, 2008, p.129). I was well-positioned to conduct these interviews through my prior clinical experiences with providing palliative care to children and working with nursing students. Another aspect of ensuring credibility of the research findings is the concept of interpretive authority. This concept acknowledges that the researcher is interpreting the results from the data collected in the interviews, but also states the importance of grounding within the social context of the study and trustworthiness of the researcher's interpretations (Thorne, 2008, p. 225).

Limitations. Overall, the limitations of the study included the small sample size, only female participants and no representation from the PICU. The first limitation was in regards to sample. Although the sample size of eight nurses met the goal of recruitment, this remains a small sample. One unit was not represented in the sample: PICU. Recruitment in PICU proved to be more difficult as it was determined late in the data collection process that few nurses working in this setting who had cared for pediatric palliative patients met the inclusion criteria. All of the other sites were represented by at least two nurses per unit and with four nurses recruited from a regional hospital and four nurses from a tertiary hospital. The nurse participants were all female, which was not surprising as within their work settings the majority of RNs were female.

The second limitation was that novice nurse participants did not have an opportunity to consider the questions prior to engaging in the interview. It may have been beneficial for some of the participants to reflect on their experiences and feelings prior to the in depth nature of the interviews.

Another limitation of a study based on interviews alone is that it privileges self-interpretation and assumes self-awareness. Adding observational data and interviewing other stakeholders could mitigate this limitation.

Participant Narratives

Participant narratives were written based on the demographic data and interview responses of the participants, as well as the field notes I recorded after the interviews. The narratives allow for an introduction to the participants prior to entering into the findings in Chapter 4.

Participant 1. A young Caucasian female under the age of 25, working in a regional hospital with one to two years of nursing experience. At the time of the interview, she was pregnant for the first time. She had experienced three or more pediatric deaths and/or end-of-life experiences and stated that she was surprised by the number of deaths she had experienced. She expressed a personal comfort with death, and had a close friend who has experienced the loss of a child. She stated that she had little academic preparation for her first experiences with palliative care and death and that she had a knowledge deficit regarding physical care, physiologic changes and advanced care planning during end-of-life. With the experiences that she had she described receiving mentorship from experienced colleagues and engaged in reflection as a means of coping. She did not have any opportunity to debrief after her first experiences with palliative care and stated that it would have been very helpful. She had not engaged in continued education about palliative care. When caring for a family of a dying child, she disclosed that she often felt unsure of each family's needs and desire to be involved. She described feeling overwhelmed and underprepared as a novice nurse providing palliative care and described pediatric death as "*one of the scariest things to deal with.*"

Participant 2. A woman between 25-35 years of age, working in a regional hospital with six months to one year of nursing experience. She was working on multiple nursing units at the time of the research interview and had cared for two pediatric palliative patients. She stated that she had an awareness of pediatric death prior to experiencing palliative care as a nurse because it was something that people always point out. She chose to work in pediatrics because of her ability to relate to children and *“act like a kid”*. Two of the biggest challenges she experienced were withdrawal of care and the nursing interventions associated with it and seeing the family after the death of a child. She did not receive any formal education about pediatric or adult palliative care, but had exposure in clinical, primarily in her final preceptorship. She described nursing school as a *“blur”*. Since graduation, she had not engaged in continued education about palliative care. She stated that *“death is something that you’ll see anywhere in your work as a nurse, any nursing job is stressful...you need to learn to cope with life.”* She described the emotion of the unit that can be felt when a child is dying or dies. She sought support from young nurses in her workplace when providing palliative care and described her initial reaction to her first experiences with pediatric death as *“wanting to run away and hide.”*

Participant 3. A young woman under the age of 25, working in a tertiary care setting for six months to one year. She had two experiences with pediatric death and had experienced the death of a family member. She had worked on two different pediatric units. She provided bereavement care directly after a child passed away and spoke in depth about the care of the family during end-of-life and about the importance of mementos. She spoke about the difficulty of decision-making and maintaining quality of life and the role of the nurse and interdisciplinary team. She described some of her areas of strength when working with palliative families as being calm and patient and allowing families the opportunity to *“just talk”*. She described the

areas of strength in her practice environments as the mentorship she received and 1:1 nursing of children and the end-of-life and challenges as to including the family in their child's experience and deciding "*when enough is enough.*" She received no pediatric education in her undergraduate curriculum, and her palliative education experiences occurred during her final preceptorship. She received an introduction to bereavement care as part of her orientation as a new employee on her current unit. Based on her personal experience with the death of a family member and her experience as a nurse she summed it up as "*People don't care how many medical interventions you are doing, they just want to know that you're taking good care of their family member.*"

Participant 4. A woman between the ages of 25-35 years of age, working in multiple pediatric tertiary care settings. She had provided end-of-life care to three or more pediatric patients in her one to two years of experience. Prior to first experiencing pediatric death, she described not really thinking about palliative care of children. She engaged in palliative care of an adult in an undergraduate clinical rotation, and in her final preceptorship encountered infant death. She did not recall discussing pediatric death in the classroom and elaborated that it is because society does not expect children will die. As a new nurse, she did not really think of it until at orientation the palliative care team spoke about it and then with seeing palliative care in practice. She described telling friends and family about her work and that "*they are shocked that I want to be there. They say things like that must be so hard, that must be so sad, why do you want to do that?*" A suggestion she had was to incorporate more education about palliative care prior to the first experience to "*change the perception around death in general, because no one really wants to talk about it.*" She described herself as feeling other people's emotions and having the ability to really empathize with people, to the point where she becomes emotional.

She recognized that it is important for nurses to show their human side, but that it is challenging to find a balance between that and doing the tasks that are required. She described that there are resources available to support her learning such as online modules, in services and a palliative care team and that she planned to access these. In comparison, one practice area she worked in placed a greater emphasis on palliative care than the other. She stated that her takeaway experience is:

I don't really feel afraid of death, it was something that was very foreign to me, and something we don't talk about. But after having these experiences and working in this area as a nurse I've learned that it is a part of life and it's okay to talk about it. And in fact, to talk about it because, I think just talking about it sheds light on the situation and makes it not so scary and um, and.....I've just really learned how important it is, that our society, in general, make that part of life important for families.

Participant 5. A young woman under the age of 25, working in a pediatric tertiary care setting with one to two years of nursing experience. She had cared for 3 or more palliative children at the time of the interview and had personal experiences with a medically fragile family member and friend. She decided to become a pediatric nurse because of an interest in biology and the experiences she had with a sick pediatric family member. She described knowing what to say and supporting colleagues who are caring for palliative children as challenges. In addition, she described her number one challenge as lack of follow-up with families after the death of a child. She identified that each family is unique, as are their needs at the end-of-life. She did not recall formal palliative training in her undergraduate education, and identified that there was probably a case study that touched on pediatric palliative care and that coping and self-care were talked about in depth. She verbalized that she felt that there is sometimes disconnect

between nursing school and what it is really like to be a nurse. She described her practice environment as having resources to support palliative care, however, perceived a deficit in mentorship and education around palliative care. She had attended one workshop on caring for a palliative child and family. She drew support from the novice nurses and experienced nurses that she worked with when providing palliative care. She described the perspective that she has gained from being a part of someone's story and the family will always remember her and she will always remember them. She so eloquently stated "*it's perspective, nothing really feels quite as important, oh, you know when your car gets broken into...well...I can handle this, I can cope with this.*"

Participant 6. A young woman under the age of 25 working in a regional hospital. She had cared for 3 or more pediatric patients at the end-of-life at the time of the interview and had one experience that was very unexpected and led to additional distress. She disclosed that she knew that pediatrics was the area that she wanted to work after her placement in nursing school. She described children as incredibly resilient and that death is something nurses will see everywhere; likely less in pediatrics. She reflected that she has seen way more death than she expected. She described not having thought about kids dying until she had an experience caring for a palliative child during her final preceptorship. She stated that she had more emotional challenges with the families that she got to know better and for the older children that she cared for she experienced some comfort and relief when they passed away due to their multiple comorbidities and her perception of their diminished quality of life. She had engaged in a debriefing experience, however, no formal continued education. She was surprised at the amount of mentorship that she had received, in particular from the younger nurses. In her undergraduate education she cared for a palliative adult who passed away during her shift but did

not receive theory on end-of-life care. A wish for her practice was to have the ability to talk openly with families and children about palliative care and what their needs are. She shared new perspective that she gained from her experience: *“it makes you see that you do make a difference in your job. It’s sad that sometimes it has to be that drastic to feel like that, because on a day to day level you don’t feel that, but when you see a family go through that experience and thank-you.”* She stated that although it is difficult, her work with palliative children and families was rewarding.

Participant 7. A woman between the ages of 25-35 with more than two years of nursing experience. She had practiced in a variety of tertiary settings at the time of the interview and had cared for three or more children at the end-of-life. She described the uniqueness of each family; their culture, spiritual beliefs and involvement. Family centered care, withholding judgment and being present came up frequently in her stories and interview answers. She discussed the difficulty in making end-of-life care decisions in her setting *“that their want for that baby overshadows what they would truly want as a parent for that child, like, their health and wellbeing and their peace.”* In her undergraduate education she remembered there being some discussions about end-of-life but no specific courses. Most of her experience was in clinical: with an adult and then in her pediatric preceptorship there were palliative children on the unit, although she did not directly provide care to them. Prior to her nursing experiences, she believed pediatric death was a rarity because of advancements in technology and treatments. When she reflected on her experiences she stated:

I’m glad that it didn’t happen any sooner or any later because I think at that time, had it been any earlier, that I wouldn’t have been emotionally ready or up to par with those skills. I didn’t want to be in the position to provide care that wasn’t quite there,

competent, complete, understanding FCC, understanding like even just the baby and conditions and stuff like that. I feel like now I'm more ready, even though I question it sometimes, I can offer better, I can offer a little bit more.

She had received limited palliative care continued education, but has signed up for an upcoming workshop on pediatric palliative care. She identified palliative care and new nurse orientation as areas of passion and hoped to champion new initiatives in her practice area.

Participant 8. A young woman less than 25 years of age practicing in a regional hospital. She had cared for two palliative patients and worked as a nurse for greater than two years at the time of the interview. Her first experience caring for a pediatric patient who died during her shift was as a preceptorship student. She described her initial response as being shock and then feeling overwhelmed. She described the lasting impact of the family and the close connection a nurse forms with a palliative patient and family. She regularly referred to herself as a young nurse and reflected that *“you don't talk about the dying process. I feel like as an experienced nurse, you kind of know the signs and the changes of the body progressively shutting down and you kind of know but as a young nurse you kind of just walk in the room and expect them to be still alive.”* She described wanting to be a pediatric nurse from a young age, however, felt naïve as a novice nurse and realizing the stress involved and that *“the role is so much bigger than I realized.”* She described her biggest challenge as lack of experience and knowledge, however felt the support of the team and her communication skills were areas of strength. She did not have any undergraduate experiences that taught her about end-of-life care, and had not yet taken any continued education courses. She had engaged in debriefing with the leadership team on the unit and found it beneficial. She reflected that her perspective had changed:

Knowing that this isn't just one family; this is something that happens more often than I initially even realized. And just knowing that this is something that is going to happen, and that this something you're going to come across in your career and you can't just turn a blind eye to it, and that it is a reality of nursing and having that first experience and being able to take that in a different way.

Summary

This chapter described the research process for the project. To learn about the experiences of novice nurses providing palliative care for children and families for the first times, a qualitative study, specifically an interpretative description methodology, was determined to be the most appropriate research method. After ethical approval, the recruitment process provided eleven nurse participants who indicated interest in the research project, eight of who met the inclusion criteria. After they provided consent, the nurse participants were interviewed using an interview guide. An initial code book was compiled and coding was commenced after the initial two interviews. The codebook was revised and applied to all interviews after they were completed which provided categories and themes for analysis. NVivo™ software was used for organizing the transcripts, noting memos and performing coding. The richness of the data revealed both obvious and more complex themes. Scientific quality was maintained by keeping an audit trail which included field notes, and memoing to allow questioning and self-reflection. Regular contact with my supervisor and second reader challenged personal assumptions and potential biases when interpreting the data. Although every effort was made to ensure the scientific quality of the project, limitations included the small sample size, female only participants and lack of representation from the PICU.

Chapter 4: Findings

The purpose of this thesis was to explore the experiences of novice nurses when providing palliative care for children and their families. The intent was to develop knowledge to better inform undergraduate and continuing education for students and nurses. Data analysis of the interview transcripts demonstrated that novice nurses were by and large seeking to meet the care needs of children and families in a relational, family centered fashion. Through an analytic process, codes and sub-codes were developed and, in the careful review of the eight transcripts, one overarching theme and four categorical themes emerged. Relational practice was integral to the experiences of novice nurses when caring for palliative children; this became the overarching theme. The four themes of caring and self, caring and knowledge, caring and context, and caring and family profoundly influenced the way nurses described and enacted their relational practice. Refer to the provided schematic diagram of the themes and overarching theme (see Figure 1).

The first theme of Caring and Self refers to the qualities, emotions and coping strategies of the novice nurse during care provision for a dying child and family. Their accounts of involvement with families and children were characterized by a mix of emotions ranging from caring to avoidance to ongoing distress. The nurse participants shared stories, often with heartfelt responses, about families and children who were dying who they had cared for in their nursing practice. The majority of participants shed tears during the interviews and disclosed the lasting influence of their experiences on them personally and professionally. The second theme of Caring and Knowledge refers to the knowledge that nurses developed in their undergraduate education, continuing education and personal experiences about palliative care of children and their families.

Figure 1

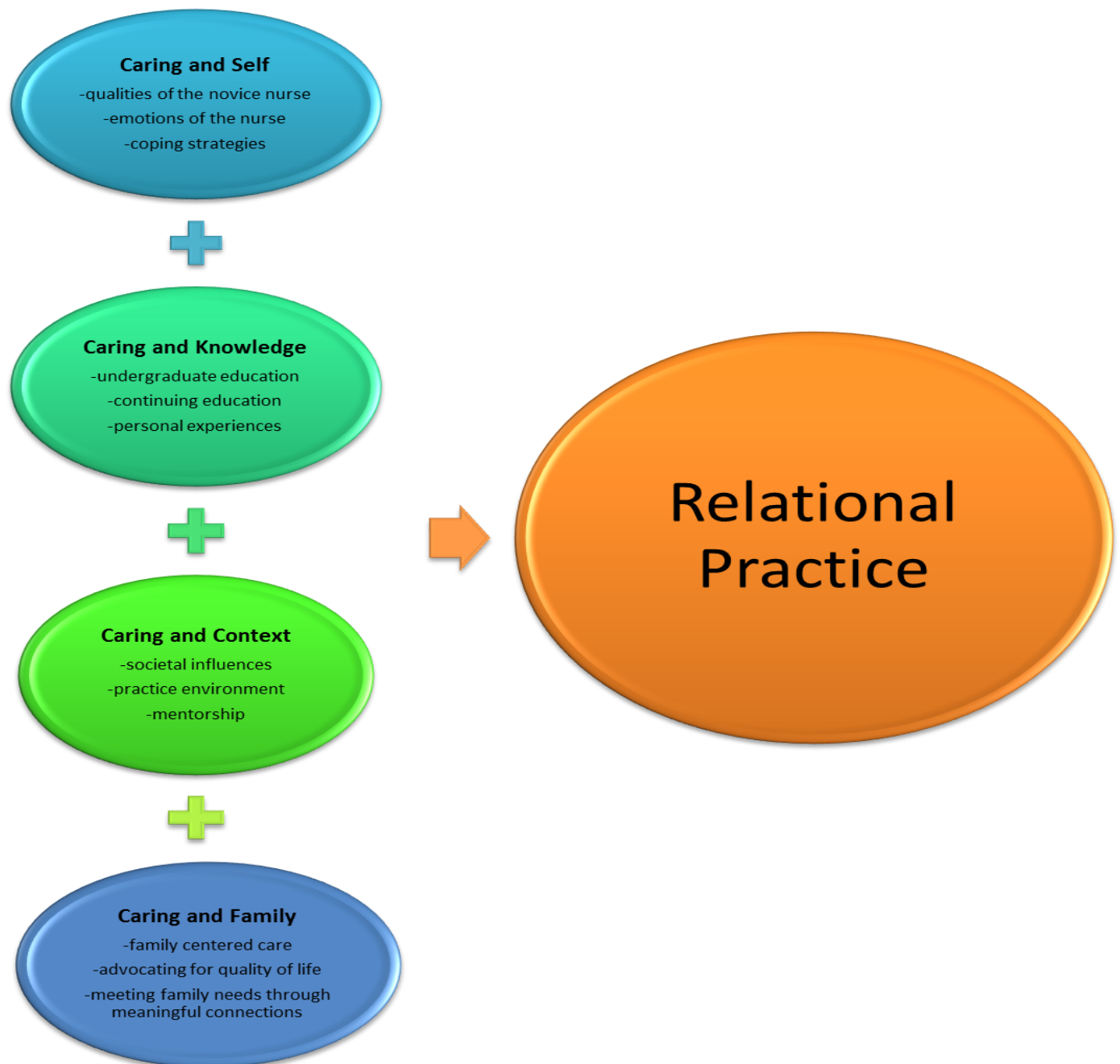


Figure 1. Relational Practice Schematic Diagram.

The third theme of Caring and Context refers to the practice environment in which the nurses engaged in pediatric palliative care and included factors such as societal influences, practice environments, and mentorship. The fourth theme of Caring and Family refers to the nurses' experiences with family centered care, advocating for quality of life and meeting family needs through meaningful connections. The nurses' ability to practice relationally was influenced by variations in each child and family, which were captured in the participants' descriptions of the uniqueness of each scenario. Together, the four themes enabled the nurse to enact Relational Practice. Refer to the provided schematic diagram of the themes and overarching theme (Figure 1).

This chapter will be organized into a discussion of the four influential themes: caring and self, knowledge, context and family. The overarching theme of relational practice will be integrated throughout the chapter, and explored in further detail within Chapter 5. Lastly, a summary of key findings will close the chapter.

Caring and Self

Each nurse participant reflected on who she was as a person and the qualities that she brought to her nursing care. Caring and Self was about the qualities of the novice nurse, the emotions experienced during palliative care provision and the coping strategies instrumental to caring for self. "Self" within the concept of caring is not a new one in nursing literature; the self-awareness and personal attributes of novice nurses are foundational to their relational abilities. Within this study, who the novice nurse was and the influence of self on pediatric palliative care emerged as a new phenomenon from what currently exists in the literature. To interpret the meaning in the experiences of novice nurses' stories, it became apparent that who the nurses were as individuals played a significant role.

Qualities of the novice nurse. The nursing profession is widely viewed as a balance of art and science; the art in pediatric palliative care is demonstrated by the novice nurse's ability to interact with children and families in a relational way, and the science is demonstrated in the provision and understanding of physical care needs. The nurses revealed that "self" influenced their career choice of pediatrics and described their personal qualities that were assets when working with children. Within the interviews, the participants revealed the balancing act that often occurred between personal and professional attributes and the experience of being a novice nurse.

Self as a career influence. One of the interview questions posed to the nurses was how they came to choose pediatrics as their area of practice; their career. In response to why they became pediatric nurses, several nurses disclosed that their career decisions were made early on; one even stated "*I've kind of always known*". They described longstanding personal qualities such as "*loving kids*", "*being fascinated by biology*", and "*wanting to take care of people*" as influences on their career choices. In contrast, other nurses shared that they chose this career option in their adult years. They described becoming interested in nursing, specifically pediatrics, because they were influenced by working with children at a summer camp, as a student teacher and as a care aid. Several nurses found that their undergraduate nursing education shaped their career choices. Participant 6 shared:

It was in my second year, and I started doing the pediatric course, and I had an awesome clinical instructor and a really good experience...caring for the kids and then I really had fun, kind of learned how to care for the kids in a more interactive family centered way. When I had more experience with the families, I realized that that is the type of nursing that I like to do.

Based on these comments from the participants, it was obvious that there were a multitude of factors that led them to pediatric nursing. Later in the interviews, when asked if their experiences with palliative care would negatively influence their decision to continue working in the field of pediatrics, all participants answered “no”, indicating a firm commitment to pediatric nursing. This response demonstrated that despite the difficulty of these experiences, novice nurses did not feel their career decisions were negatively influenced by the challenges associated with palliative care provision.

Attributes of self: balancing the personal and the professional. With the decision to specialize in pediatrics carried out, the nurses shared personal attributes that suited their work as pediatric nurses, as well as the challenges of balancing their personal and professional selves. Certain personal qualities were perceived as being assets to the pediatric environment. Participant 2 stated: *“I grew up working with kids, so I have the ability to get to their level and am able to talk about things that they do and basically have the personality of a child.”* Similarly, other participants shared about their ability to relate to children, and their ability to be calm, patient and empathetic. Participant 4 disclosed: *“I really feel other people’s emotions and I can really empathize with people, um, to the point where I start to feel myself get teary.”*

It was evident from the nurses’ responses that empathy and sensitivity were important qualities to exhibit; however, these attributes were not without challenges. One participant described: *“I think sometimes you have to separate yourself from what’s actually happened -to do your job well. I think that’s not where I’ve gotten into trouble...but have been more emotionally distraught...is when it’s related back to my own personal life.”*

The concept of putting on a professional demeanor is not unique to pediatric nursing. However, as evidenced by the responses of the participants, in practice areas where end-of-life

care is provided, there is not an easy line to draw between compassion and professionalism.

Nurses described the situations where there was a need to put on a “*brave face*”. Participant 8 explained:

In these situations where you're dealing with children passing away and stuff, it would be good to be less of a softie sometimes, and just be able to hold emotions back a little bit more; just to help be a brave face for a family.

Participant 4 elaborated further on this: “*I think it's important for nurses to show their human side, but it's also important to be able to still think straight and stay on track and do the things that you need to do to facilitate that time for the family.*” Both nurses (Participant 8 and 4) captured their attempts to put on a “*brave face*” for families in order to provide the professional care they felt was required as registered nurses.

As new nurses, the participants were still learning about themselves as professionals during the time that they were providing palliative care. Many recalled comments that were made by nursing instructors during their undergraduate education or by nurses that they worked with about maintaining professionalism when a patient is dying such as being “*objective*”, “*stoic*” and “*maintaining composure*”, but struggled to know what this looked like in practice.

Most nurse participants spoke of being “*young*”, “*new*” and/or “*young to nursing*”. The participants ranged in age from 22 to 35 years of age. The self-efficacy (that is, their belief in their ability to perform and successfully carry out a specific task) of the participants when providing palliative care varied depending on their perception of their ability to “*be with*” a dying child and family. From their descriptions, it was clear that one of the most valuable tools nurses have when providing care to families and children was being with them, and not

distancing themselves too much from the palliative experience. This constitutes as important emotion work for a novice nurse.

Emotions of the nurse. The second element of caring and self is the emotions of the nurse. Although the concept of emotions is central to the theme of caring and self, it was also a common thread throughout all aspects of the thematic analysis. To respond with emotion is a human reaction, and novice nurses' responses proved to be strong, raw, and varied depending on the connection and length of relationship that they had with the child and family. Terms used to describe the emotions that their experiences evoked include: "*overwhelmed*", "*sad*", "*helpless*", "*angry*", "*frustrated*" and "*afraid*". The timing of their emotional responses proved to be different amongst the nurse participants. Some revealed emotions during care provision, others felt emotionless at the time of providing palliative care, and several suggested that their emotions surfaced afterwards.

Showing emotion in the moment. Seeking a sense of balance between their own emotional responses and their professional responses while still being 'human' came up throughout the interviews with novice nurses. Participant 1 shared her experience: "*I don't think it's wrong to show emotion to families either. They understand that we're human too; we feel, especially when we've come to know and love these people.*"

The concept of 'how much' emotion is okay came up throughout the interviews. Some nurses queried what was appropriate during palliative care provision; others wondered how well they were coping when they continued to have emotional responses long after the care moment had ended. Several asked the interviewer what was 'normal' in regards to grieving and whether ongoing distress was something nurses regularly experienced.

Lack of emotion at the time of death. Two nurses commented on their lack of emotion at the time of a child's death and the mixed feelings they had about their response. Participant 7 described feeling guilt-ridden when she was not emotional at the time of a child's death: "*I wasn't as emotionally ridden at that moment because it was always there in the back of your mind; you knew it was going to happen, it was just a matter of when.*" Thus, even in the timing of emotions, the nurse participants were trying to determine the 'right way' to grieve and show their emotions.

Emotions that surfaced afterward. Several of the nurses described having more intense emotional reactions after the death, and in some cases, days later. Participant 7 shared: "*But the emotions hit after and that's only one situation where that happened, because it was such a prolonged experience.*" Two of the nurses described the deliberate suppression of emotions until after they were alone and away from the eyes of the families and co-workers. They chose private places on the units to grieve such as the bathroom and laundry room, or held back their emotions until their commute or arrival home. Participant 8 shared: "*I remember I was so devastated, and I went to the laundry room in the back of the unit and just cried.*"

The novice nurses shared the vulnerability that they felt caring for children and families and the sadness that they felt when kids died. Some nurses described the surprise they experienced at the loss they felt when a child died. Participant 2 explained: "*I wasn't expecting to become so emotional. It kind of went to show how, building relationships, you don't realize the relationship you build with the family.*" These excerpts illustrated that the emotional work inherent in the role of the pediatric nurse could be a challenge, as nurses sought to navigate their personal emotions yet provide professional, relational practice. Some nurses had previous experiences with death; for others this was their first experience with death. This factored into

their emotional responses and will be discussed in further detail within the theme of Caring and Knowledge.

Coping strategies. In the interviews, nurses shared strategies that they had developed for coping with pediatric end-of-life care. All participants used reflection, although in various forms. For some, coping involved making healthy choices such as exercise, healthy eating and meditation. Seeking support by talking to others was something that all of the nurses did, whether they were co-workers, nurses practicing in different settings, or family and friends. These conversations occurred in formal and informal ways. Several nurses described gaining perspective and developing strategies with each palliative care experience.

Reflection. Reflective practice is an expectation of developing nurses and experienced nurses. As part of the requirements of maintaining a nursing license, there is a component of professional reflection. Although there were variations in the way nurses chose to reflect, all novice nurses spoke about including this in their nursing practice and finding it helpful when coping with the death of a child.

Several nurses described the process of internal reflection and the benefits of being able to engage in it anywhere and at any time. Participant 2 shared about the value of internal reflection:

I don't necessarily write it down because I find that I can reflect quicker than I can write.

So I just um, in my head, that's probably the only one that I do right now, but ya. Just think about things in that sort of sense.

Timing of the reflection varied, some chose to reflect about the events to come; others reflected after the events occurred. Participant 2 described how she mentally prepared herself:

I would say that I just did a lot of reflection. I remember hearing that a patient was going palliative and they had told me, that they had decided. And I remember kind of reflecting and thinking this is probably going to be your first pediatric patient who passes away. So I did some reflection at home; just kind of preparing myself in that sense in knowing that it was coming.

Most nurses engaged in reflection after a difficult day. Several shared about the way in which they reflected; this varied from on the drive home, before bed or on days off. Several nurses found keeping a journal, both in their personal and professional life, a valuable tool. One participant (Participant 5) shared her reasons for using writing in addition to internal reflection:

I think that journaling actually is really good. Now that I'm saying it out loud I'm thinking that I should do more of it, because when I do it in my personal life, it really slows down my thoughts in different ways. You think, think, think, but journaling allows you the opportunity to slow that down. Because you can't write as fast as you think, so it really forces you to write down what's important and the other stuff, that helps you to see this is the thing, and this is what I'm really holding onto and the other stuff, the other things that are flying through my mind aren't as helpful.

Participants also shared the type of reflective questions that they would ask themselves. Common phrases included: "So what happened?", "How did I handle this?", "What could I have done differently to handle it better?", "What did I do well?", "What could I improve on?" and "How does our nursing have to change?"

For nurses who felt they did not have time to engage in the reflective process after providing palliative care, obtaining closure and mitigating distress was more challenging.

Participant 7 shared: *"You know, you just don't have the time to sit around and think about things. I think maybe, that's why I was upset with myself too."*

In summary, reflection was a common practice amongst novice nurse participants. In sensitive nursing competencies such as end-of-life care, reflection offered obvious benefits such as slowing and organizing thinking, as well as valuable learning about personal coping and practice approaches.

Healthy Choices. Another coping strategy described by the participants was that of making healthy choices about exercise, eating well, sleep and alternative therapies such as massage, reiki and meditation. Participant 4 spoke to the value of maintaining personal health: *"I try to maintain a healthy lifestyle. I try to exercise and that definitely helps. And sleep and eat properly. All those things that they tell you to do; they actually work."* Other participants acknowledged knowing that a healthy lifestyle was important but also challenging to maintain. Participant 5 stated: *"I think I could be better at that. I feel like I do, but sometimes you're like exhausted, so the self-care is like sitting on the couch until you crawl into your bed. Like, it's not...I don't know if that really qualifies as self-care."* Although novice nurses saw the value of integrating healthy practices into their day to day life and coping strategies, they also were realistic in discussing the barriers that shift work and a high stress job created.

Coping through conversation. All of the participants shared that coping through conversation was one of the best strategies they utilized when providing palliative care. Most engaged in a mix of formal and informal conversations about their experience with pediatric palliative care. Amongst the nurses, there was also a realization that being the nurse caring for a dying child can be an isolating experience.

Nurses categorized informal conversations as being with nurses or non-nurses. Many nurses spoke to nursing co-workers who work in the same settings; others spoke to friends who were nurses in different settings. Participant 1 described: *“As a nurse there are days that are great and you come home from work on top of the world, and there are days when you just come home and cry. Nobody can really understand, except for another nurse.”*

The majority of participants engaged in conversation with nurses in the same practice area as them. Participant 4 stated:

At work, generally I find, that when we're on break sometimes, and I know that when we had the child on the unit that was palliative, that was quite a difficult time for everyone and um, a lot of just kind of informal discussions in the break room with a couple of people.

This statement shows the importance of a novice nurse experiencing belonging and support in her practice setting. Without this support, those important clinical conversations would not happen. Similarly, Participant 5 described how she coped:

Nurse to nurse conversation, so we talk about our patients a lot, in the break room, we are talking about what's going on the unit, so that's a really great resource I think. Just because there's no confidentiality breach and we talk about it freely and understand; obviously what happens on the unit stays on the unit.

Being able to talk to nurses on the same unit helped the novice nurses maintain confidentiality. The nurses were very aware of the vulnerability of the children and family they cared for and purposefully took measures to ensure their privacy was maintained.

Some novice nurses experienced a degree of isolation during care provision for palliative children. To provide respect and dignity for the child and family, nurses often tried to minimize

the number of healthcare providers in the room during care provision. As the goals of care for the other patients on the unit are often curative, this left the palliative nurse with a very different focus than the rest of the team during her shift, leading to feelings of isolation. While the isolation was temporary for the nurse participants, it is important to note that nurses moved between feeling supported and alone without adequate practice setting resources.

Several pediatric nurses found it valuable to discuss their experiences with nurses who did not work in the same practice setting. Reasons that were shared by participants included obtaining unbiased advice while also having the support of a fellow nurse. Comments the nurses shared included *“it’s helpful because she understands it from a nursing perspective but it’s tied to the patients themselves”*, and *“because we have a similar foundation it’s easier to confide that way. Obviously particulars are left unsaid, but this is what happened, this is what I did, this is how I felt.”* Nurse-to-nurse conversation was a valuable coping strategy for the nurse participants. They were able to identify nurses that they felt comfortable to debrief with that did not work in the same setting but that could still understand the nursing care and role.

The nurses also confided in non-nurses and chose family, friends and roommates as a source of support through informal conversations. Many found that they were able to open up and share emotions they had been repressing. Each nurse that confided in a non-nurse deliberately considered patient and family confidentiality and minimized details to protect their privacy. Participant 7 shared her experience confiding in family:

I also speak with my family members to tell them I had a rough day, there’s only so far the understanding can go because you can’t describe what it looked like when the extubation happened, because they don’t have that same terminology. I mean, they try to comfort you, the best that they can.

Participant 4 shared: *"I was talking on the phone with my mom, and she asked me how work was going and I found myself getting emotional about it, and then I started questioning, and am I okay, do I need to get counseling? Am I okay? I'm not quite sure...how much emotion is 'normal'?"* This can be interpreted as the novice nurse seeking feedback on the grieving process through informal conversation. Nurses were also aware of some limitations when confiding in non-healthcare providers. Participant 7 shared: *"That same type of reassurance isn't there unless they fully understand this is how it went down."* Conversely, one novice nurse disclosed some of the limitations of nursing-only conversations:

There's the casual conversation in the break room. Sometimes that sort of spins, and it doesn't really go anywhere. I find sometimes with just nurses, we are just spinning out of control. There isn't really a sense of conclusion or understanding or growing from the experience.

The formal conversations novice nurses engaged in happened primarily in their workplace setting with their leadership team, the interdisciplinary team in a meeting, or a facilitated debriefing. Participant 6 shared her experience: *"Afterwards, with that one code situation, we were brought in to have someone to talk to, me and the other two nurses involved, so that was debriefing that happened right there."* Participant 5 shared about an interdisciplinary experience she had:

We actually have a pastor who does these monthly check-in sessions. So, it's just kind of an informal time for all staff to go, and the pastor has tea and cookies and will just kind of be there and we can talk about things that are going on at work or we can talk about other things, it doesn't have to be anything specific.

All of the nurses who attended formal sessions found them beneficial. Several of the nurses who had never attended a session stated that they wished they were available in their practice setting or that they were offered at a time when they were available to go.

Summary of caring and self theme. The theme of Caring and Self suggests that novice nurses' qualities, emotions and coping strategies had significant impact on their palliative experience; coping through conversation and reflection were two of the most valuable strategies that all novice nurses used in their practice. Closely related to caring and self was how knowledgeable the nurses were, and the types of knowledge they drew on.

Caring and Knowledge

Novice nurses assume their new role as healthcare professionals with entry-to-practice competencies. Knowledge development is a continual process and once nurses enter into the workplace their education becomes focused within that setting. Through the interview questions that were posed, the participants shared stories about the knowledge they acquired during undergraduate education, continued education and personal experiences with death.

Undergraduate education. Students gain theory and practice-based knowledge as they develop towards entry-to-practice in the workforce as registered nurses. Some of the participants completed a four-year undergraduate nursing program; others completed a two year after degree nursing program. Within the realm of nursing education, some students felt that they entered the profession with the core knowledge and skills they needed. Others felt that they gained the majority of needed skills after graduation or built on them in a more applicable way in practice settings. Undergraduate Bachelor of Nursing education is provided to the students in the classroom, laboratory and clinical settings, and the presentation of findings here is organized to

reflect the types of knowledge (i.e., theoretical, experiential, and personal) gained in these settings.

Theoretical knowledge. Participants were asked specifically about how they gained theoretical knowledge in content areas specific to pediatric palliative care. The following interview questions about undergraduate education experiences were asked:

- 1) How did your undergraduate education prepare you to provide end-of-life care?
- 2) Did you have any specific courses/seminars on caring for the dying patient?
- 3) Was any of your educational preparation focused on pediatric patient death?
- 4) Were there coping strategies you used from your education?

Participants shared that there were subject areas they did not remember learning about, that there was a lot of content and that it was difficult to link theory-to-practice, as reflected in a comment by one participant: *“it was all a blur”*. Participant 5 disclosed her perspective on learning some of the skills of coping and self-care in undergraduate nursing education:

I find that sometimes there's a bit of disconnect between nursing school and what it's really like to be a nurse. You learn all these 12 stages, or 5 stages or 5 ways to cope but I don't know if it's....I don't know...you learn it in a textbook or in an academic level....but I don't know if that's always transferred into nursing.

This quote reflected the limits of retaining theoretical or “book” knowledge, apart from accompanying experiential or practice learning. Overall, novice nurses perceived gaps in their retained knowledge from nursing school in areas that influenced their palliative care provision, namely, end-of-life care and pediatric palliative care.

End-of-life care. Entry-to-practice preparedness of registered nurses is a discussion that comes up frequently in nurse educator conversations and in healthcare settings. In the

interviews, novice nurses were asked if they learned about end-of-life care in their undergraduate education. Several nurses shared that they did not remember what was taught, if it was taught at all. Some recalled learning about ethics and dying simultaneously. Participant 7 remarked that end-of-life care was often embedded in ethical modules and courses: *“Surprisingly, I don’t think so. We touched on it [end-of-life care] probably. There wasn’t a full course dedicated to end-of-life but it was mentioned, or we might have had a module on it from what I remember.”* This statement exemplified that although subjects may be introduced and theory taught, this knowledge may not be retained without threading of key concepts within curriculum or facilitating further opportunity to explore what this looks like in nursing practice.

The desire for more education was apparent from several of the participants. Several key terms came up to suggest that the education was not always comprehensive: *“touched on”, “covered”, “unstructured”, “didn’t stick”* and *“foggy”*. As a result of insufficient education, nurses struggled to put their learning into practice. Participant 5 shared her experience: *“I’m sure that I knew the 10 stages of whatever...at the time, but when it comes to actually putting it into practice it’s a big transition and you’re reading through the policy and nothing feels familiar.”*

From the interviews, and comments such as this one, it became apparent that theory-to-practice connections are not always apparent or existent for undergraduate nursing students. This gap may be related to the amount of content covered, the complexity of linking end-of-life and self-care concepts into practice or other curriculum gaps.

Pediatrics and palliative care. Each participant acknowledged a gap in their education about the end-of-life care for a child and his or her family. The novice nurses conveyed that there are differences between the palliative care of a child and that of an adult and saw this

population-specific knowledge as a perceived need. For example, Participant 1 shared that in nursing school the discussion was focused primarily on older adults:

I feel like all of the palliative care experiences that I had, or anything that we talked about or learned about was usually focused on, um, later in life. Rather than, pediatrics. Um, and I guess some of those principles still apply, but at the same time, it's so different when you're dealing with palliative care families in pediatrics.

Participant 4 elaborated further:

I found that it wasn't really talked about too much, and sort of framed in a way well....yes, this is part of the job, and yes people die and you just have to um...kind of help the family cope with it, but what you see in death, I wasn't prepared for that.

Participant 3 explained that she received no formal pediatric education in her program, never mind pediatric palliative care or family nursing: *"I didn't even have any pediatric education until my final placement, because I was in the after degree program, so there was no option to do peds."* Participant 4 also shared this experience:

I don't recall spending a lot of time talking about death and if we did, the focus was definitely more on adults than on children, because no one expects children to die. It's kind of an area that's not talked about a lot.

From the participants' comments, it can be interpreted that they felt societal beliefs about death and dying influenced the curriculum they received in their undergraduate education. Although pediatric death may be less common than adult death, the need for end-of-life care education across the age continuum was emphasized as important by the participants.

Experiential knowledge. Of the experiences related to pediatric palliative care that nurses received in their undergraduate program, by far the most memorable ones included exposure and clinical conversations they had in practice settings.

Early educational experiences. The early experiences novice nurses had during their undergraduate education were still very vivid during the time of the interviews. Their experiences ranged from helping a co-student or a nurse whose patient passed away to transitioning their care of a patient to comfort care to providing after care when a patient had died. Participant 6 shared:

The patient I had on the second clinical day, passed away...that was a very good opportunity for me because I watched the patient decline and then started providing palliative care at that point, a lot of comfort care measures and pain control and that really was my only experience with palliative care in all of my schooling. I'm very grateful that I had it, because I can remember, even after having that experience, having a nightmare that really bothered me for a long time after, because I was involved once the patient passed away, in wrapping the body, and all of that. That was very traumatic to go from never having seen a deceased body to being involved in the after care. That was hard for me, but I'm so glad that I had that experience, because I had the support of my instructor and the staff on the floor and my clinical group. We all went out after and had some appetizers and kind of reflected on the experience and I'm so glad that I had that, because in another situation, now as a nurse, you don't always get that chance afterwards. So I'm really thankful that I had that during school.

From this comment, we see that the novice nurse was appreciative of the palliative care experience as a student nurse, despite the ongoing distress she experienced afterwards. She

shared about the positive mentorship that she received from the nursing staff and her instructor, as well as the support and debriefing she experienced with her clinical group. The nurse participants who did have experience with a patient passing away were grateful that it happened while they were still in school with the support of an instructor, unit nurses and peers.

Preceptorship experiences. Several of the nurses had their first encounters with death in their final preceptorship. Participant 4 shared about the preceptorship experience she had with pediatric death:

I also actually had an experience in my final practicum experience with an infant which was quite difficult. These were babies who had medical anomalies and they were, the mothers would come in and be induced to essentially give birth to the baby, at an earlier time and it was kind of expected that the child wouldn't survive past birth.

Similarly, Participant 6 explained:

Probably during my preceptorship, we cared for one...and then after talking to some of the nurses that have worked there for a while that they have cared for palliative patients and stuff so it's a bit more apparent. Still not as much as in the year and a half I've been practicing as a nurse, I've encountered it way more than I anticipated I would.

Both participants shared that they had new exposure to palliative children during their last undergraduate clinical experiences. They spoke to the difficulty of these experiences, and how they raised their awareness of pediatric death, however, both commented on their surprise at the amount of death they have seen since graduation.

The practice setting offers diverse clinical placement experiences, with no predictable pattern of life and death experience for student nurses. Some participants had no experience of end-of-life care or death in the practice setting. Participant 5 commented: *"Well I never had*

anyone pass away as an undergrad, I know some students have an experience of a patient passing away.” Although it cannot be guaranteed that a clinical setting will provide end-of-life experience, it was an experience nurses wanted. They spoke to the value of exposure to these skills. Participant 5 explained:

I think that in some ways, there's not really a good way to prepare you for it, without having experienced it. And um, you can't necessarily provide that for every nursing student, so I understand that. So I didn't personally experience it, so I don't feel I was prepared.

Not only was an experience of caring for a dying patient desired, there was also discussion about the need for practice-based exposure to death and dying needing to be done ‘right’. Participant 5 stated:

I think it would have to be done really well. So if there's a palliative patient on a unit, there would need to be, often times, we would be given a patient assignment and we were caring for them and I would think that you would need to be 1:1 paired with that patient and a nurse, I don't think it's fair otherwise, a lot of times, I felt with the assigned nurse, that I'd be like...where are they? And I think it would have to be really well done for it to be a positive experience. I know a few nursing students whose experience wasn't quite as positive, from hearing stories and things like that.

Some spoke of missed opportunities for learning about palliative care, as illustrated in the following comment by Participant 7: “*Surprisingly, never saw them postmortem. The door's closed, I knew that someone had passed away, and that was my first exposure, but never directly had a patient who had died.*” This nurse intimated that she would have been open to going into the room of the deceased patient to at least gain direct exposure to the death of a patient.

Undergraduate education is a mix of theoretical and experiential knowledge development. Although both are necessary, novice nurses vividly recalled their clinical experiences and were more likely to draw on this knowledge to guide their practice than on theoretical knowledge or classroom learning.

Continuing education. Novice nurses continued their knowledge development in workplace settings. Their experiences with continuing education varied from being offered by the workplace setting (employer) to initiated by self (the nurse).

Workplace-initiated continuing education. In the healthcare setting, nurses often receive workplace education that is specific to their practice area. This includes instruction about unit policies, care of the pediatric patient and their family, and common skills and responsibilities that the nurse performs. One of the interview questions I asked nurses was about the workplace education they received about pediatric palliative care provision.

The nurses' experiences were divided. Some nurses stated they did not receive any education on palliative care that was initiated by their workplace. Statements included “*not really, no*” and “*the closest thing I got to it was just in the past year, was uh, kind of like a brief conversation.*” In some settings, nurses did recall receiving education during orientation.

Participant 3 described:

The educator did kind of go through the bereavement care briefly and showed us all the stuff and explained what you do. So that was nice, because in the other unit that I worked on, they never went through it, never showed us any of this stuff. When it happened was the first time I saw all of this stuff that they use to do bereavement care. So it was nice to see and know where the box is.

Another participant had a similar experience. Participant 4 shared: *“We did talk about it in the orientation when I was hired. About how...and we actually had the palliative care nurses come and give a presentation about pediatric death, so I knew it was going to be part of it.”* This participant went on to share about the required palliative modules her workplace uses with new nurses:

There’s um, a lot of online modules, I think that there’s 30 online modules and they’re through it’s a hospice foundation based out of the UK, actually, apparently the UK has a lot of their palliative care, it’s a model for North America. They’ve been doing it a lot longer and they’ve developed a lot of great programs for palliative care, so the modules are based out of the UK.

Nurses described that when they received workplace education, it was provided by a variety of interdisciplinary team members such as palliative care nurses, physicians, pastors and social workers.

Self-initiated continuing education. As a requirement for maintaining current practice, nurses engage in continuing education. Although some of the education is dictated by the continuing competencies within the novice nurse’s practice setting, a significant amount of professional development is left to the nurse to initiate. Several nurses disclosed that they had not independently pursued continuing education in the palliative care field. Participant 1 shared about her experience: *“No I haven’t. You know there have been opportunities, but I haven’t done any yet. I should.”* Participant 7 explained why she had initiated professional development for herself: *“I think that the resources aren’t there, and possibly the awareness.”* A common message from the nurses was a lack of knowledge about available resources for continuing education.

Novice nurses who did initiate and engage in continuing education had a wide range of experiences. Some had read journal articles; others had attended workshops and conferences. For example, Participant 3 attended a teleconference at her hospital: *“I went to a telehealth conference, it was for palliative care, it was Palliative Care and Ethics I believe, like I said, they’re always tied.”* Participant 5 attended a conference that was put on at her hospital:

There was a day-long course that was offered by the hospital. The hospital put on essentially a day-long lecture, and you get paid as education time essentially to go. So I wasn’t required to go, but we were invited to go.

It was noted that the nurses who did engage in professional development were encouraged to do so in their practice settings which provided information about available resources.

Several of the nurses disclosed additional barriers to their ability to pursue continuing education that was not required in their practice setting. These barriers affected accessibility and included availability, location, scheduling and funding. Participant 1 describes the challenge of working in a rural setting: *“It seems to me like there’s lots of really awesome palliative care, pediatrics palliative care, but they’re always up in Calgary, through Alberta Children’s Hospital, and I wish they were more local, I would go.”* Participant 3 worked in an urban setting and talked about the availability of technology to facilitate province-wide education, but went on to note some of the challenges with accessing professional development that was provided outside of Alberta: *“And it’s fine if there’s a lot of conferences that are held within the province, because you can just use telehealth and the ones that are in the city for cheap, but a lot of the really good conferences are not here.”* Scheduling posed one of the most significant challenges for novice nurses. They described their work schedule as *“flip flop shifts”* and *“lots of night shifts”*. Participant 5 shared some of the challenges of nursing rotations:

I think working shift work sometimes is hard, you either have to get your shift covered or be approved for education, and so, I think, like the reality of staffing a unit. To lose a nurse for the day takes a toll on the whole unit, so I think that's a barrier, it's not as easy as just saying I'm going to go to the course, you have to figure out all these other details. And sometimes it's hard to get approved to do that.

Amongst the nurse participants the reality of shift work and shortages impacted their ability to schedule professional development and pursue education opportunities.

The nurse participants all expressed interest in further palliative education opportunities. They acknowledged the challenges of nursing schedules, however, also felt there were additional learning opportunities that they would like to engage in.

Personal experiences. Several of the nurses shared personal experiences that they had with death and dying. Two had family members who had died and two others reflected on the experiences of close friends who had lost a child. None of the participants were parents and therefore had not personally experienced the death of a child. Participant 3 described the loss of a parent influencing her work as a nurse: *"People don't care how many medical interventions you are doing, they just want to know that you're taking good care of their family member.....That's kind of what it comes down to."* Nurses who personally experienced loss were able to display empathy based on their personal knowledge.

Summary of caring and knowledge theme. Caring and Knowledge revealed insight into the foundational knowledge nurses drew on or saw as gaps in their palliative nursing experiences. It was apparent that knowledge acquisition is a continual process which began in undergraduate clinical practice and continued in practice settings as novice nurses. Several nurses acquired experiential knowledge of death through their personal experiences with death

and dying. Although the nurses addressed a need for continued education on palliative care, some had more opportunities and support to pursue continued education than others. Some workplace settings integrated palliative care and modules into the required competencies, while others did not. The accessibility of resources varied amongst practice settings. For some, there were considerable challenges to accessing continued education such as scheduling and accessibility. The context in which nurses provided care influenced their continual knowledge development and will be explored further within Caring and Context. All nurses disclosed that palliative education, whether in undergraduate education or workplace education, should be a priority for supporting new nurses.

Caring and Context

The third theme that emerged is the context of caring which encompasses societal influences, and the practice environments and mentorship of new nurses providing palliative care. It is impossible to consider experiences without exploring the contexts in which they occur. The novice nurses were perceptive in their comments about the influences on their practice.

Societal influences. Societal beliefs about death and dying may shape nurses without them even realizing. The death of a child is a topic that is often not discussed in North American culture. It is not comfortable or natural to see the death of a child, whereas an older adult's death is more socially acceptable. This societal discomfort with the death of a child was reflected in Participant 8's statement: *"Well, I'm talking more that kids aren't supposed to die. I guess that's, because you're never supposed to pass away when you're little, or you're a child, you don't think that it's supposed to happen for kids."*

Embedded in the discussion of pediatric palliative care experiences was the novice nurses' expectation that they would be caring for the living rather than the dying. Most had limited discussions about dying prior to providing palliative care. This assumption was implicit in the wording choice within their interview responses. Most spoke about children "passing away", the families experiencing a "loss", or used more clinical terms such as "end-of-life care". Only one participant regularly used the words "death" and "dying" in her responses. Participant 8 summarized the underlying sentiments of several of the participants:

I feel like when you're a young nurse you don't talk about the dying process, I feel like an experienced nurse, you kind of know the signs and the changes of the body progressively shutting down and you kind of know.

Participant 4 elaborated that she did not have a personal fear of death, but that she learned how important it is to talk about death:

I don't really feel afraid of death. It was something that was very foreign to me, and something we don't talk about. But after having these experiences and working in this area as a nurse I've learned that it is a part of life and its okay to talk about it. And in fact, to talk about it because, I think just talking about it sheds light on the situation and makes it not so scary and um, and.....I've just really learned how important it is, that our society, in general, make that part of life important for families.

However, this transition to become more comfortable with death was not the experience of all of the novice nurses. Participant 8 went on to elaborate on how her perceptions of the role of a nurse were very different before she entered the profession:

To me, I went into nursing because it was caring for people, making people feel happy, comfortable and doing the little things, but then when I became a nurse, I realized how

much stress is involved and how much bigger the job is than I actually ever thought a nurse did.

Several of the nurses indicated that their families and friends were often the first to point out the challenges in the role of the pediatric nurse. Many commented on the emotional burden that others expected they would experience in caring for such a vulnerable population.

Comments from family and friends included “*that must be so hard*”, “*that must be so sad*” and “*why do you want to do that?*”

In contrast, several participants shared about their personal comfort with death. An example of this is the comment by Participant 1, who commented on her personal thoughts:

“I’m comfortable with death. I understand that it’s a process, so I think that for me that makes it a little bit easier.”

Participant 4 exemplified in her response why she is a pediatric nurse and well-suited to guiding families and children through the end-of-life process: “*And I say, honestly, every day’s not sad, and um, it’s quite rewarding to help a family go through that process...and um, I just see it differently*”. She was not alone in this response. Several other nurses described their workplaces as ‘*beautiful*’ and ‘*rewarding*’ and that hope was still present for children and families, even during palliative care.

Overall, the nurse participants were very perceptive in their comments of societal beliefs about death and dying. Many had conversations with friends and families where non-nurses felt that their work environment would be challenging and that pediatric death would be difficult to handle. Although most of the nurses acknowledged that pediatric death was not something they had initially expected before entering this work area, they also talked about the value of their experiences working with children and families at the end-of-life. Several of the nurses shared

their desire to “*start talking*” about pediatric death and the areas they work as being full of “*a lot of life and a lot of hope*”.

Practice environments. The participants worked in a variety of settings in two cities: NICU, General Pediatrics, Oncology and a hospice facility. They also shared experiences from previous settings in Alberta and internationally where they practiced. It was interesting to observe the differences in acuity within the stories the nurses shared and the diversity in resources, unit culture and collective experience of the unit staff within practice settings. Some units typically see more death than others, and many of the nurses talked about the predictability of caring for a palliative patient within their practice setting. One participant shared about her workplace:

The end-of-life experience is much more peaceful and we do have the time to provide extensive care in all forms, holistic care, and not just the medical care or the physical care, and that we're actually able to use all of our skills and knowledge as a nurse and really be there for the family and provide the psychosocial support.

The context of providing care to children who are dying is a unique subset of pediatrics. Many nurses talked about the perspective they have gained from working with children and palliative families. Several participants shared about the difference in caring for a child that is dying than an older adult. Participant 3 described her experience:

It's different than an adult passing away. I've seen an adult pass away and seen the body care done for them. But even something, as little as taking the baby to the morgue, they bundle them up in blankets, and you can't really tell it's a body.

Participant 6 elaborated on the experience of caring for a dying child:

Although you have those very sad situations in caring for palliative patients, you also see many kids come and go all the time. Children as a whole are so resilient and I love that part of it! I love I think, that's why I like it so much, because you see kids come in so sick one night, and then out the next night. That makes up for that, because if I worked anywhere else, I would see a lot more palliative care and death.

The concepts of caring for a child's body before and after death, and the nature of children who are sick often getting better were paramount to the novice nurses. Although they experienced challenges, they also spoke about the perspective they maintain due to the number of children they see get better.

Mentorship. Mentorship is a foundational element within the development of a novice nurse. The availability and type of mentorship nurses received in their practice settings constitute part of the context of their experience providing palliative care. Many nurses commented with surprise on the amount of support they received when providing palliative care for the first time, as well after a child died. Participant 6: *"I was just pleasantly surprised with how much support and mentorship I did get from people, even after, even having staff members pull you aside and see how you were doing."* It is interesting to note that mentorship was not always expected and raised questions about what general mentorship occurred within the practice settings of the novice nurses.

Expert mentorship. Novice nurses often sought guidance from expert nurses. Some shared that the mentorship they sought was from nurses who did not have a tremendous amount of palliative care experience, but had expert nursing experience and a willingness to teach and mentor. Participant 1 stated:

I think it helps that I work with so many people that are experienced. And with their experience comes palliative care experience. Um, not only palliative care experience, but they know some of these families better than I would have. There are some people that I feel that are better at providing support, then others, um, at the start of each shift I always try to think, well who am I working with today and who would I feel the most comfortable looking for if I need to.

Other nurses found that the greatest mentorship they received was from nurses who were the most experienced with end-of-life care and walked through the process with them.

Participant 3 stated: *“One of the ladies, whose fantastic with bereavement care, she took me after the baby had passed, and her and I did all of the bereavement care for the baby.”* Participant 8 shared her experience as a preceptee when she walked into the room and found out that her patient had died: *“My preceptor nurse came down within a few minutes, and then she just kind of helped me get him cleaned up and have everything turned off so that they could hold him.”*

Participant 5 shared a recent observation of mentorship occurring on her unit: *“One thing that I noticed the other day was that we had a palliative patient on the unit, and they assigned a new nurse and a more senior nurse to care for the patient. And that was brilliant.”* Although within mentorship they had a variety of mentorship experiences, the novice nurses could recognize when effective expert mentorship occurred and how valuable it was in their practice settings.

Novice supporting novice. An interesting phenomenon emerged where several nurses shared their comfort seeking support and mentorship from other novice nurses and younger nurses. Participant 2 stated:

And other nurses who were younger were easier to talk to. So kind of, talking to them, and discussing how I was feeling or how they were feeling, that sort of thing I found was,

just so peer support in just talking, because I was pretty much one of the only new grads who at that point, had a patient who I'd had who was palliative but at first not palliative and then eventually passed away. So I think that, going through that whole, process, and then having others on the unit who were also going through similar experiences that had more experience, or even a bit more, and other younger nurses kind of helped me deal with it.

A second participant, Participant 6, shared similar thoughts: *"In particular, I noticed it tended to be the younger staff actually who were the ones to pull you aside. I don't know if it's because you kind of build a friendship amongst the younger staff."* One participant shared why she would seek out experienced or less experienced nurses, depending on the scenario. Participant 5:

I think both. It depends on...I find that the more senior nurses if I'm asking about like, um the history of the family or what they suggest in that situation, but I think nurses at my same seniority, when I'm just like looking not for an answer but an opinion...does that make sense?

It can be interpreted that mentorship can take many forms within the practice setting. Novice nurses sought out different people depending on their needs. Although they were cognizant of providing privacy for families, novice nurses also drew strength from the nursing team's presence.

Experiential learning through mentorship. Several of the nurses shared how the mentorship they received in the practice setting was in many ways more valuable than the previous education that they obtained. Participant 2 disclosed:

I think that the education is what your seniors or your elders in nursing teach you, I'm still so new, I feel, and still trying to not sink when I go to work, and it's how they tell you

how things have changed, or how you're supposed to change when nursing a patient who is palliative, that's how I've learned so far. Just watching other nurses and um, learning from them and that sort of thing. Just kind of from my coworkers and asking questions as well, but they also, I think that when there's a patient who is palliative or becomes palliative or has always been palliative um, there, people are more aware and they're more aware that as a new grad that you won't have necessarily seen this in your schooling, or the few months or whatever that you've worked so they're more willing to say oh hey, so this is what you're going to do for this patient and they're more willing to talk to you about how your nursing should change, so I think that's more of an informal education, than formal.

Similarly, Participant 3 shared that: *"I learned more about it on the units and from the nurses that I worked with. Um, then I did in school."* Participant 7 shared that although mentorship was rare in her experience, that it was particularly valuable in developing new techniques and strategies to meet family needs.

I find, that I learn more when they tell me their stories, and what they've gone through and how they were there for, whether it was neonatal babies or any type of passing that they were there to witness or support the family, that kind of thing also helps me into saying okay well maybe I can do that, or maybe I can change my frame of mind to think that way or to offer these things.

Story-telling was an important aspect of learning and sense-making for novice nurses. Hearing the stories of experienced nurses provided them with ideas that broadened their thinking towards palliative care and supporting families.

A couple of the novice nurses also disclosed about the role of the charge nurses and more experienced nurses and the leadership they displayed when supporting novice nurses providing palliative care for the first time. Participant 6 explained:

The floor and the staff were awesome after and same thing, that in other situations that the staff were always very supportive. I know that when they first assigned me, the charge nurse would always come up to me and ask how I was doing and in the situation.

Several nurses shared about the context of the death and how it impacted the mentorship they received. Participant 6 reflected that:

All-in-all everyone was supportive, and more so in that code situation than some of the ones in the floors. It's also interesting that it seems like most palliative patients pass away during a night shift and then in the middle of the shift change you have people come on and talk about it, because when it's just the 3 of you, you don't really have the chance to. You just kind of keep going. And when other staff comes on, you have a little bit of opportunity to talk a bit more.

Based on the novice nurses' stories, the experiential learning that has occurred through mentorship in their practice settings has been foundational to their development.

Continuing the mentorship model. Lastly, there were nurses who believed there would be value in further mentorship for new nurses. As novice nurses, they felt that having support from a colleague would help them to provide better care. Ultimately, the nurse participants stated they wanted to do the best that they could when providing palliative care and felt that mentorship was required. Participant 7 disclosed that her experience was one where many nurses were not comfortable discussing death in the neonatal setting; however that she believes it is necessary:

It was really rare, unfortunately. I just think it's one of those things that people don't want to share, I don't know if it's because they're like really sensitive, I myself have trouble sharing it, but you gain more knowledge when you share, and you're helping other people and it's also helping you put things in perspective too."

Participant 5 added:

I do think that there is a bit of a missing link, of coming alongside new nurses. There's a lot to caring for pediatric palliative patients. I think that I would have really benefitted from....um...just even more...ya more mentorship, and I don't know quite how to facilitate that or what necessarily.

Although the novice nurses revealed that it was difficult to be mentored in palliative care, they also acknowledged the value of receiving guidance from experienced nurses and the support of less expert nurses. Several mentioned that death is not a topic nurses openly share their experience with, however, that this discussion is valuable to their development.

Summary of caring and context theme. In summary, societal influences, practice environments and mentorship impacted the novice nurses' first experiences providing end-of-life care. Positive workplace relationships often led to better experiences within the practice environment and with receiving mentorship. Nurses often were reminded of societal beliefs about the death of a child through conversations with friends and family, however, spoke perceptively about how their opinions and outlooks have changed because of their experiences.

Caring and Family

The work of a nurse is never in isolation. Novice nurses engaging in pediatric care work closely with children's families. When children are dying, often the focus in relationship shifts to further emphasize the family's needs at a difficult time. Within different settings and patient

demographics, the length of relationship between the nurse and her patient and family can vary from hours to days to years. Participants shared their experiences providing family centered care, advocating for quality of life and meeting family needs through meaningful connections. The ways in which they have provided caring impacted their development as nurses.

Family Centered Care (FCC). The Family Centered Care model has become foundational to the provision of pediatric nursing care. In each practice setting, nurses shared stories about the variations in families that they cared for and demonstrated their desire to care in this fashion. Participant 6 described the value of family centered care, especially when a child dies:

It just shows you how important family centered care is, and not just in pediatrics, because I think it's so important in every dimension of nursing but I think that it was really amazing to hear that whole point about family centered care, and how it's so important all the time, and that palliative care it kind of takes it to that whole new level.

The nurses spoke about family centered strategies they use: tailoring the nursing approach, promoting respect and dignity, encouraging family participation and creating memories.

Tailoring the nursing approach. In effort to provide family centered care, many nurses described taking the lead from the family around how palliative measures were enacted. This philosophy often meant being more flexible in their nursing approach, promoting privacy for the family unit and encouraging decision-making that was individual to the child and family.

Participant 3 described the nursing staff and that they followed the directions from the family:

Just going by what they want to do for care, how much they want to do, what they want us to do, how much they want us to come into the room, how many other measures they want us to take.

Tailoring the nursing approach involved the presencing that occurred when a nurse was able to understand and be with a family. Benner (1984) defines this as the nurse-patient relationship and the giving of oneself. Participant 4 shared her experience:

And end-of-life is such a complex event, and it's.....it's....different in every case, in as little experience as I've had, I've seen so many different types of situations and every family is unique. And so, I've learnt a lot and it's really challenged me.....um.....to refocus my nursing and how I provide care. And what's important, and really focusing on finding out about what's important to that family and not just doing what I think needs to be done. But really, asking the family what are their needs, and really tailoring my nursing care towards what their needs are, but as a young nurse you kind of just walk in the room and expect them to still be alive.

This rich quote can be interpreted as the novice nurse approaching the family through a lens of inquiry, with a desire to get to know the family members and what is important to them in the palliative process. The learning that occurred for this novice nurse was then described as translating to every family she cares for and how she seeks to find out what their unique needs are. Additionally, when it came to relational practice, nurses acknowledged that each family was different in how they chose to be involved. Participant 1 spoke about the variety in her experiences: “*Case by case. Totally. I'm not totally sure how comfortable the families are with doing care.*” It was difficult at times for novice nurses to gauge the level of involvement the family wanted through observation of non-verbal cues, culture, patient scenario and family type. One nurse described her uncertainty around her role and involvement:

You know, talking about involvement, sometimes some families are more comfortable with nurses, then others. That's another things, I'm never really sure how much I'm

supposed to be involved. Some, I get the impression from families that they would rather just be by themselves, me leaving them alone, and then they'll call. But other families are quite needy I guess, and that's okay too. But I, you know, wonder what their coping strategies are and if that makes a difference.

In this statement, it was clear that the novice nurse was more comfortable with the care she provided when families asked for specific things and verbalized their emotions, coping strategies and needs.

Promoting respect and dignity. An important core concept of FCC is promoting respect and dignity. According to the Institute for Patient and Family Centered Care (2013) "Health care practitioners listen to and honor patient and family perspectives and choices (para 2). Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care." Participant 3 provided an example of the way in which decision-making was left to the family out of respect for their beliefs:

We left it for them to deal with the best way they could rather than otherwise, only because that's a comfort for the family, we also don't want to make them feel like we're forcing them to do something that they don't want to.

Nurses described that promoting respect and dignity proved to be most difficult when there were cultural and/or language barriers. None of the nurses recalled receiving education about providing culturally-sensitive end-of-life care. Neither did the nurses identify their own cultural or religious beliefs and values when discussing their patient experiences or identify spirituality as a source of coping when asked about strategies used in their nursing practice.

For example, some of the families shared that they believed God would save their child. This could create a dilemma on the part of the nurse as she sought to understand and meet

their spiritual needs. The ways in which each family grieved varied and could cause distress for the nurses as they described that some families were very vocal and others very stoic, that some had up to fifty family members present, while for others it was only the parents. One nurse describes her experience and initial confusion:

They didn't speak much English and that was what I found the most difficult. Even though they knew it was coming, they were quite vocal and um...kind of in how they responded to the death. And it caught me off guard, because I interpreted it initially, as them wanting us to do something...

Nurses were able to identify that some of the choices families made about death and dying were related to their religion and culture. In some cases this included the length of time they stayed after a child died; some to left very quickly and others stayed for hours. A foundational aspect of relational practice is forming a connection with families through engaging in the process of inquiry. This proved to be most difficult for nurses when there were cultural and/or language barriers.

In summary, most nurses developed experiential knowledge of the cultural practices of death and dying when providing care. During the provision of care, preservation of dignity and respect was a priority for the nurses. However, there were challenges in interpreting the wishes of the families when they were unfamiliar with the culture or unable to communicate effectively.

Encouraging family participation. Within the Family Centered Care model, participation is defined as “Patients and families are encouraged and supported in participating in care and decision-making at the level they choose” (IPFCC, 2013, para 2). Participant 4 shared a story of how she empowered a parent to become more involved in a child’s care: *“I was trying to position him, I had asked the dad to come over, because the parents were kind of standing on the*

other side of the room, and almost didn't know how to help or be involved." This novice nurse described that afterwards the father of the child receiving palliative care became more comfortable providing care to his son.

It was evident in the interviews that the nurses rejoiced in the positive experiences of parents. These experiences ranged from the parents holding their children to providing care when they had been previously hesitant. Participant 4 elaborated further on the experience she had after working with a parent:

I did notice that the dad was doing that a lot after...just sort of trying to make him more comfortable using the pillows, using the pillows to relieve some of the pressure off of the joints. So I felt like that was a really good experience.

Family participation was supported and encouraged by the novice nurses. They acknowledged that by empowering families they also felt more rewarded in their work.

Creating memories. Several of the nurses described creating lasting memories for the families, further illustrative of the philosophy of FCC. Novice nurses acknowledged that part of their role is facilitating positive experiences for family, regardless of the outcome. This ranged from providing mementos to facilitating time for the family to be together. One participant described the importance of taking the time to slow down and how the nurses took the lead from the family and celebrated the living, not the dying, of a palliative child:

The way that the family is dealing with the situation and that they're not treating her as though she's dying...they're treating her like she's still living and they're really making an effort to get her out doing things that a child her age does.

Participant 3 shared:

We let her know, you know that we were thinking of her and I handed her the poem. And the mom read the poem, and grandma started crying and I think that it just meant a lot to them. And that was just the most memorable end-of-life care 'thing' that I've done. Because you just try to pick out something that is important to the family and make it a positive experience, even though it's not necessarily a positive experience.

In some cases death was predictable, in others it was not. Some of the mementos nurses helped create were handprints, locks of hair and photographs. Memory making after the death of a child included helping parents to provide the final bath, dressing their child in favourite clothing and allowing as much time as the family needed to say good-bye.

In summary, the participants' experiences with Family Centered Care in pediatric palliative care included tailoring the approach, promoting respect and dignity, encouraging family participation and creating memories. All of the novice nurses acknowledged that practicing in a relational fashion included caring for the entire family.

Advocating for quality of life. One of roles of registered nurses is that of an advocate for patients and families. When providing palliative care, several of the nurses described re-focusing their care on the family and their well-being, rather than the more traditional, medical approach. As new nurses they were very aware of quality of life and viewing the patient as a person, rather than through a medical lens only. Participant 3 shared: *"It's really, the biggest challenge, is getting people away from standard medical care. And more what this specific family or baby needs to be comfortable."*

In this statement the participant conveys the challenge nurses can have with advocacy and shifting goals of care to comfort care, especially in critical care areas like the Neonatal and Pediatric Intensive Care Units.

Several of the nurses disclosed feeling that they lacked the skills and knowledge to provide comprehensive palliative care, and were unsure about the goals of care and when certain lifesaving measures should be halted. Participant 1 shared an example of providing care and being unsure of the level of invasive measures that should be performed:

I didn't really understand everything that was going on with these little bodies. You know, I don't think that we always have to understand everything. 'Palliative care' I was taught is comfort care only. But when you're pushing feeds and IV fluids and all that kind of stuff, oxygen and suction, I don't know, it's just something I don't really understand and find really confusing.

Participant 4 disclosed about her changing perspective and how it has forever altered the way that she cares for living and dying children. She spoke of the importance of quality of life above all else. *"From those experiences I've learned a lot about kind of, quality of care, quality of life, really providing care not only for the patient, but for the whole family."* The nurse participants played important advocacy roles in their practice settings and became increasingly aware of the need to promote quality of life for their patients and families. One of the participants described the need to information share openly: *"I always feel bad when parents want to know everything and people withhold information."*

Novice nurses reflected on the positive and negative experiences they encountered where their nursing voices were needed to advocate for families.

Meeting family needs through meaningful connections. In pediatric nursing there is emphasis placed on meeting the needs of both the patients and families. When a child is dying, this adds a new dimension to meeting family needs that requires strong interpersonal skills, and the ability to make meaningful connections.

The nurses all reflected on their experiences interacting with patients and families and their perceived abilities. It became apparent during the data analysis process that the nurses' interpersonal skills played a role in their experience. In undergraduate nursing education, one of the foundational elements of the core curriculum is therapeutic communication and the subsequent development of interpersonal skills. Although pediatric nursing in specialty settings requires specific skills, the ability to be able to communicate and build a relationship with patients and their families is not fundamentally different.

In some scenarios, nurses felt more comfortable with providing words of comfort or silence as was appropriate. Participant 1 stated her interpretation of knowing when it was or wasn't a good time for words: *"Maybe sometimes I don't have to say anything to comfort them, you know just a look and them knowing that it is in my best interest to make their child comfortable."* At times, one nurse described the importance of including communication that wasn't only healthcare focused, but met the psychosocial needs of her patients' parents.

Participant 7 stated: *"I was able to just sit there with the mom and every day we would kind of have talks, not necessarily about the situation, but just 'kicking it' I guess you could say."*

In contrast, several of the nurses described feeling they didn't know what to say, to the detriment of their nursing care. Many of the participants discussed working with family as a challenge; in navigating their personal emotions and the emotions of the family, determining the level of involvement the family wished for and communicating about sensitive subjects. An example of this is Participant 6's statement:

Unless the families are obviously upset, I don't really go into it with the family, I don't initiate conversation. I think that you ask really generally, how are you doing today, but I could do more...I think eventually with further experience, being able to sit down with

the family and talk about their worries, where they are at with everything, that kind of thing.

In this quote, Participant 6 clearly reveals her present discomfort with initiating conversations about end-of-life with children and families. At the same time, she also addresses this as a need in the patient and family. Acknowledging the needs of a family, but feeling ill-equipped to begin these deeper conversations about sensitive topics was a common thread amongst participants. A response that occurred as a result was avoidance for several of the nurses. An example of this is Participant 2's statement:

I think there could be more taught about dealing with families afterwards, because as terrible as it is to admit, I just wanted to avoid them. I didn't know what to say, I wouldn't have known what to say in that sort of situation. I found that was the hardest, just seeing her whole family.

From this quote, it is evident that Participant 2 experienced ongoing distress at her inability to interact with the family and her innate response to avoid. In her statement, she acknowledges the value that advanced preparation in how to talk to families after the death of a child would have for her.

Overall, the nurses drew great meaning from the work they did with palliative children and families. It was obvious that they felt deep respect for each family they interacted with and acknowledged the uniqueness of each palliative child and family. Participant 5 disclosed about the honor of being part of a family's story and the strength of the families that she works with in the oncology setting:

What a gift it is to be a part of people's story, when they're in their most vulnerable state. So, people really let you in, so some people are a little more closed off, but for the most

part they are just so exposed, and um, they trust you, for the most part, and again we have such amazing families and having the opportunity to work with families who are so resilient and so strong and passionate about their kids' care and willing to participate in it. We have a lot of really amazing families that are up at like two in the morning, three in the morning with us, doing chemo, settling their kids, and I think that experience is quite incredible.

Participant 6 shared that despite the child passing away in a code scenario, how grateful the family was. She also described that in the day-to-day work as a pediatric nurse that nurses may not always feel valued or receive positive feedback about their work. Although it was challenging providing palliative care to a child, she felt extremely rewarded.

And I can remember after that code situation, that that mom was just so thankful for everything that we did do, even though we were unable to save her child, she was soooo thankful and hugging, and to you that makes you see that you do make a difference in your job. It's sad that sometimes it has to be that drastic to feel like that.

Another aspect of practicing relationally was revealed in conversations with nurses; they had vivid memories of the children and families they cared for and what made them different and special. One nurse stated: *"I'll always remember it, even though it was only thirty minutes."*

Summary of caring and family theme. The idea of caring and family was explored through family centered care, advocating for quality of life and meeting family needs. Within each of these concepts, it is apparent that relational practice is foundational to the practice of nurses; regardless of setting or population. Within the pediatric population, the nurse often encounters the patient within the context of their family and seeks to provide care to the entire family unit. Some nurses stated experiencing different types of challenges with families such as

initiating frank discussions about the death and dying process. Depending on family dynamics and the length and depth of the relationship that was formed between nurse and family, some found it easier to develop rapport and connection more than others.

Chapter Summary

The nurses shared many examples of their experiences caring for palliative children and their families. Throughout all of these examples, it was clear that they were impacted by their ability to 'be with' the children and families and that their experiences were influenced by their perceived ability to provide caring related to self, knowledge, context and family. At the core of relational practice it is essential that the nurse provide holistic care through the acknowledgement of the patient and family's context and walk alongside them in their journey. Many of the concepts of relational practice are integral to family centered care practice. Several key findings emerged through the thematic analysis process. Novice nurses demonstrated that they were aware of the importance of strong interpersonal skills, however, struggled at times to support families and children when the conversations were about end-of-life care and grief. The pediatric nurses showed high degrees of motivation towards becoming nurses and the work they do with children. The nurse participants' experienced many emotional responses to the scenarios they encountered and at times struggled to determine their role as professionals. Although they expressed some distress and challenges with the provision of palliative care, they also demonstrated that they found their work deeply rewarding. They were beginning to engage in strategies for coping in their practice through conversation and reflective practice. The nurses expressed that the most meaningful education they engaged in during their undergraduate education was clinical experiences with death and dying. Most expressed that they felt that they did not obtain the theoretical or practical knowledge that they felt they needed

when they were in school. Since graduation, nurses engaged in a variety of professional development activities, most had learned about them in their workplace settings. The novice nurses' ideas about palliative care were influenced by societal beliefs, their practice settings and mentorship experiences. All of the novice nurses received mentorship from co-workers and felt that the resources in their practice settings helped facilitate better care. Societal beliefs about children dying and availability of educational resources were two areas that posed as challenges to novice nurses.

Chapter 5 will revisit the findings and locate them within the existing field of literature and discuss the strengths and limitations of the research. In Chapter 6 recommendations will be made for the development of initiatives to improve education and support for undergraduate nursing students and novice nurses in pediatric practice settings.

Chapter 5: Discussion

This chapter provides a discussion of the findings in relation to the current literature and the study's research questions. The research questions were:

1. How do novice nurses describe the experience of caring for children who are dying and their families?
2. What types of challenges are experienced in caring for children who are palliative?
3. What coping strategies are used by novice nurses when caring for children who are dying and their families?
4. What personal supports do novice nurses use when providing end-of-life care for children?
5. How do the practice environments influence novice nurses in the care of dying children?
6. How did their undergraduate education prepare nurses to provide end-of-life care for children who are palliative?

The original research questions served as a framework for the foundational literature search, research proposal and development of the interview guide. After the initial interviews, the interview guide was modified slightly to reflect some of the themes that began to emerge early on. The themes of caring and self, knowledge, context and family were identified with the overarching theme of relational practice being integral to the novice nurses' experiences. In answering the research questions it was noted that the depth and breadth of the nurse participants' responses to providing pediatric palliative care were more involved than the initial questions. Although the findings from the data analysis answered the research questions, the themes suggested that societal influence and who the novice nurse is as a person influenced the experience of pediatric palliative care provision in ways that were unanticipated early in the

study. Within the discussion chapter, the Canadian Association of Schools of Nursing (CASN)'s Palliative and End-of-Life Care Competencies (ETPC) will serve as an important conceptual framework. The relationship between the themes and influence of the ETPCs is illustrated in Appendix J. The themes (portrayed in Figure 1 on p.43) provide the structure for discussion of key findings in this chapter; (a) practicing relationally with families: using family centered care (b) building blocks of nursing practice: applying foundational and specialized knowledge (c) navigating context: understanding societal and workplace influences on novice nurses (d) managing self: being present, aware and open as a novice nurse. Before discussing each theme in detail, the first section focuses on how these four themes taken together contribute to our understanding of relational practice by novice nurse in the context of pediatric palliative care.

The Novice Nurses' Relational Practice Foundation

Relational practice was integral to the experiences of novice nurses when providing palliative care for dying children and their families; this became the overarching theme in the findings. The relational inquiry approach to nursing practice includes a relational consciousness and inquiry as a form of action (Doane & Varcoe, 2015). Relational consciousness includes an understanding of people as relational beings and with an interplay occurring between intrapersonal, interpersonal and contextual levels (Doane & Varcoe). Within the study's findings, the novice nurses' intrapersonal practice manifested as caring and self and caring and knowledge. Examples of the intrapersonal level included qualities of the nurse and knowledge base. The interpersonal level was represented by the theme of caring and family and considered the relationships between the nurses and the children and families. The contextual level was explored in the theme of caring and context and included societal and practice environments' impact on the nurse when providing end-of-life care. When it came to relational practice, nurses

acknowledged that each family was different in how they chose to be involved. The nurses' ability to practice relationally was influenced by these variations in each patient and family, which were captured in the participants' descriptions of the uniqueness of each scenario.

A key element the novice nurses were beginning to include in their palliative practice was approaching the family through a lens of inquiry. This meant getting to know the children and families and what was important to them in the palliative process. The novice nurses described that they felt more equipped to provide care in a family centered fashion when families felt comfortable to verbalize their needs and desires; openness between family and nurse was more common the longer the nurse knew a family and patient. Nurses' relational practice was often strengthened in scenarios where relationships existed over a longer period of time; however there were greater challenges with emotions for novice nurses as these relationships deepened. The emotional responses of novice nurses are discussed in greater depth throughout the discussion chapter.

Supporting relational practice with relational ethics is a key component of palliative care provision. Wright, Brajtman, and Bitzas (2009) speak to the necessity of a relational ontology for palliative care ethics; and describe that the theme of connection between nurse, patient and family is central to nursing practice. The findings from the interviews suggested the importance of this connection, and highlighted the discomfort novice nurses felt at times with developing a connection during such a vulnerable time. In summary, effective palliative care requires relational practice; an aspect of preparation that new nurses receive exposure and training with during their undergraduate education. Purposeful connections need to be drawn between relational practice and end-of-life care across the lifespan for it to be seen as a valuable strategy for novice nurses to draw upon during the unfamiliar new experiences they encounter when

children are dying. Relational practice can serve as a valuable framework to understand the experiences of novice nurses and necessary guidance for improved palliative education and preparation.

Practicing Relationally with Families: Using Family Centered Care

The value of working with families as pediatric nurses emerged throughout the findings in the theme of Caring and Family. Important aspects that will be explored in relation to the literature are the concepts of Family Centered Care, CASN's entry-to-practice competencies for palliative and end-of-life care, a cross-cultural approach and facilitating hope at the end-of-life.

Enacting Family Centered Care. As explained in Chapter Two, FCC involves the entire family, although few literature examples and practice models describe how this can be done effectively at the end-of-life. It appeared that philosophy and core concepts of family centered care were embedded within the novice nurses' practice; however, in both the literature and the interviews it was identified that pediatric palliative care required additional emphasis on family centered care. The novice nurses described that due to the complex emotional reactions, stress and decision-making when a child is dying that FCC was of pivotal importance. In each practice setting, nurses shared stories about the variations in families that they cared for and demonstrated their desire to care in a family centered fashion. They described the necessity of finding out what is important to the family and not focusing only on what nursing staff believed needed to be done. Similarly in the literature, this was described as not focusing on tasks alone, but including families in team meetings and attending to their worries, fears and hopes (Gaudio et al., 2011). Doane and Varcoe (2015) describe this deeper knowing of a family through curiosity as a necessary aspect of relational inquiry. In the findings, when nurses did not have open discussions with family they were left trying to interpret how much privacy the family wanted

and what strategies for coping were being used by families. All novice nurses in this study used strategies to encourage family participation such as showing them how to do hands-on care and facilitating touch between child and parent. In the literature, when parents were asked about what meant the most, they described when nurses helped them to be involved and create memories that they had a greater sense of satisfaction (Dokken & Ahmann, 2006). In the findings, novice nurses learned and practiced strategies to create mementos such as handprints, poems, locks of hair, photographs and special events. It became evident that family centered care is at the crux of novice nurses' relational practice.

CASN: demonstrating holistic, Family Centered Care. CASN's third competency states that the nurse: Demonstrates knowledge and skill in holistic, family centered nursing care of persons at the end of life who are experiencing pain and other symptoms (CASN, 2012). It can be interpreted that the novice nurse can be expected to have foundational knowledge of symptom management at the end-of-life as well as the relational skills that are required to facilitate family centered care. However, it was difficult at times for novice nurses to gauge the level of involvement the family wanted through observation of non-verbal cues, culture, patient scenario and family type and to provide the knowledgeable care that was required due to the supportive rather than curative focus of end-of-life care. In Branchett and Stretton's (2012) study of 57 parents who had experienced a neonatal death, they identified what families most appreciated from healthcare professionals at the end-of-life: creating memories, empathy, time and space, practical help and understanding, sensitivity, communication, accurate record-keeping and communication, and support afterwards. The novice nurse participants engaged in many of these strategies; some of the strategies they felt most comfortable engaging in were creating memories and facilitating time and space; whereas displaying empathy and communication were

more challenging strategies for the novice nurse participants. Many times they described being fearful of saying the wrong thing or showing how they cared during such a difficult time for a child and family. This finding suggests that novice nurses cared deeply about supporting families, however struggled to find the appropriate words or silence that families needed. Despite having learned strategies for eliciting difficult conversations during undergraduate curriculum, the confidence to apply relational, interpersonal skills during a time of crisis for families was a perceived challenge.

A cross-cultural approach. Tailoring the nursing approach is seen as an important aspect of relational practice and essential to the provision of family centered care. At times participants perceived challenges in their abilities to relate to families, these challenges included: communication, facilitating cultural practices and spiritual support. This was particularly so when families and nurses did not practice the same culture and beliefs. In addition to some of the barriers to pediatric palliative care discussed earlier, communication during care provision proved to be a significant barrier (Lyckholm & Kreutzer, 2010). This was attributed in the novice nurse interviews as being related to language barriers and discomfort starting conversations about end-of-life care. A core concept of family centered care is promoting respect and dignity; this proved to be most difficult when these barriers existed. The nurse participants identified a perceived gap in their undergraduate education of culturally-sensitive end-of-life care. Nurses identified moral distress when they were unfamiliar with cultural practices at the end-of-life or when language-barriers existed that prevented clear and open communication. Acknowledging the spirituality of a family was not something that novice nurses described feeling comfortable with in their interviews; and several described resulting challenges in their ability to holistically care. This was also noted in the literature, where

psychosocial and spiritual issues associated with dying were recognized as important but often were overlooked when people confronted the physical realities of dying (Vachon, 1998).

According to CASN (2012), one of the ETPCs for nurses is Competency 2: Demonstrates knowledge of grief and bereavement to support others from a cross-cultural perspective.

Notably, this was not an area that the novice nurses described feeling competent, comfortable or confident with. However, all of the nurse participants were able to recognize that family choices about death and dying related to spirituality and culture.

Facilitating hope at the end-of-life through advocacy. Palliative care is a basic human right; this is not different for children and families. The novice nurses identified that sharing information with families and advocating for quality care were important aspects of their role at the end of life that fostered hope. Nurse advocacy and facilitation of hope are important concepts that were supported in the nursing literature; as pediatric palliative care nurses, acting as advocates for children and families and in a manner which is honest, realistic and fosters hope were necessary aspects of holistic care. A 2008 study of nearly 200 nurses and physicians perceived barriers to pediatric palliative care such as uncertainties in prognosis and discrepancies in treatment goals between staff members and family members (Lyckholm & Kreutzer, 2010). Novice nurses in this study described scenarios where they advocated for children and families and facilitated parental decision-making, suggesting that they were actively promoting optimal pediatric end-of-life care in this regard. Moro, Kavanaugh, Okuno-Jones, and Vankleef (2009) found in their neonatal end-of-life care literature review that how parents participated in decision-making varied greatly, and was often done in close consultation with physicians. Within this study, it was apparent that end-of-life care discussions also did not occur as early in the illness as nurses would have expected the neonates' critical medical conditions required.

Interestingly, there was a difference in the way that those decisions were made, often physicians prolonged the life-saving measures; whereas families were quicker to choose quality of life measures (Moro et al., 2009). The novice nurse participants working in NICU described the settings in which they practice and the need to adjust the care routines. Catlin and Carter (2002) developed an end-of-life care protocol which was a shift in the way that NICU units often operate to include: flexible visiting hours, an environment that enhances privacy for the family and palliative resources materials. In this study, family participation was one way nurses were able to help facilitate empowerment and hope for families. This was described as one of the most rewarding aspects of the nurses' work during palliative care and alleviated some of the isolation they felt from the healthcare team. Branchett and Stretton (2012) described that families felt most empowered when information was delivered in an accurate and timely fashion which lead to families increased preparation of what was to come and feeling at the center of their children's palliative care. Novice nurses described the strong relationships that they formed with families as a source of mutual support. Relationship building is an effective facilitator of hope. Therefore, it was discovered that by acting as nurse advocates, novice nurses were able to empower families and facilitate hope.

Summary. An understanding of novice pediatric nurses' experiences when providing palliative care provides important information about family centered nursing practice. A new contribution to existing knowledge in the area of family centered care is the concept that breaking down existing communication and cultural barriers is needed for nurses to facilitate hope and family coping during one of life's most challenging experiences: the death of their child.

Building Blocks of Nursing Practice: Applying Foundational and Specialized Knowledge

The necessity of foundational and specialized knowledge emerged throughout the findings in the theme of Caring and Knowledge. The settings in which this knowledge was acquired varied with each novice nurse's experience; however, it was apparent that education needed to be comprised of both theoretical and experiential knowledge for it to be meaningful and relevant. The building blocks for the novice nurse, end-of-life theory to practice connections, experiential learning, novice-to-expert development and mentorship will be explored in relation to entry-to-practice competencies and the discussion of caring and knowledge.

Foundational knowledge. Novice nurses experience an important transition as they enter practice; one which is a challenging, career altering journey. As was explored in Chapter 4, the nurse participants' experiences with palliative care were shaped by their knowledge of foundational nursing concepts such as relational practice, family centered care and communication. Expanding upon this, Jewell (2013) recommends that new nurses require the essential skills of assertiveness and conflict management. It can be interpreted that although novice nurses may have gaps in their end-of-life care knowledge in specialty areas such as pediatrics, that they should be able to draw upon the essential interpersonal skills and nursing attributes to guide them during their initial experiences with palliative care.

Knowledge development is a continual process and once nurses enter into the workplace their education becomes focused within that setting. Nursing knowledge is comprised of many facets; within the findings the nurses' revealed the theoretical and experiential learning that they developed in undergraduate education and since graduation, and also acknowledged perceived gaps.

End-of-life theory to practice connections. While students are in the undergraduate nursing programs, it is essential that they have opportunity to discuss end-of-life care. Within the findings, it became apparent that the nurse participants did not feel confident in the knowledge base they had prior to providing end-of-life care. This was a similar finding in the literature; a qualitative study examining interviews of an interdisciplinary group of seventeen pediatric health care professionals identified lack of formal and informal preparation in pediatric palliative care as a major problem (Lyckholm & Kreutzer, 2010).

The integration of substantive content about palliative and end-of-life care across the lifespan is necessary to provide novice nurses with a solid knowledge foundation upon graduation. Toward this end, CASN (2011) developed national, consensus based competencies and indicators to facilitate greater integration of this area of nursing in undergraduate curricula in Canada. Of these nine competencies, competencies one to five related well to the purpose of this research project and the findings: Refer to Figure 2. The relevance of the entry-to-practice competencies will be discussed in relation to this project's findings. The College and Association of Registered Nurses of Alberta (CARNA) (2011) published a position statement on hospice palliative care recommending that all entry-level nursing education programs should have a core hospice palliative care component.

Palliative care is not an easy concept to teach. CARNA (2011) identifies core knowledge for novice nurses: pain and symptom management, psychosocial support and grief and bereavement (2012). Nurse participants identified that the most valuable education was experiential, and had little recollection of the in class learning that occurred. Along similar lines, in the research done by Hopkinson et al. (2005), they described that very few participants acknowledged that their nursing education had made a contribution to the way in which they

cared for dying people, most either were uncertain of its impact or believed it had failed to address relevant issues. Interestingly, despite such self-perceived gaps, in both this study and in the literature nurses used language, coping strategies and nursing interventions that were indicative of basic knowledge that was likely taught in some form. Hopkinson et al. (2005) also identified that nurses discussed stages of grieving in a manner that suggested knowledge of death and dying beyond practice-only encounters.

In the literature, effective end-of-life care education was identified as a priority however, few studies detail what this should look like in undergraduate education with a lifespan focus. In one study where education was deemed effective, faculty used a variety of teaching strategies to integrate this information, including having students discuss death experiences with patients or significant others and ask for information on what symptoms they experienced and how well they were managed (Wallace et al., 2009). Storytelling and group discussion were perceived as effective strategies because they helped students to identify the connection of ethical issues as faculty and peers used examples from their practice experiences (Wallace et al., 2009). In the United States, an End-of-Life Care Consortium has been developed offering education for students, nurses and nurse educators. According to Caton and Klemm (2006) the training is now taken by approximately 1/3 of professionals working with palliative care patients. Caton and Klemm also describe the Toolkit for Nursing Education at End-of-Life Transition (TNEEL) as being a valuable free resource with six modules covering the topics of comfort, connections, ethics, grief, wellbeing and impact. End-of-life care requires theory and practice introduction in undergraduate nursing curriculum to provide adequate preparation for entry-to-practice.

Experiential learning. Practice is a way of knowing in itself: there is a need for novices to be able to learn and develop from experience. In the findings novice nurses identified that they learned the most about palliative care during clinical rotations and were able to vividly recall their experiences. Amongst the novice nurse participants there was significant variety in their experiences; some had experienced end-of-life care of patients during undergraduate education, others had their first experiences as a new nurse. In the findings, those who did experience a patient death as a student described feeling grateful for the opportunity and the support that was offered to them by staff, instructors and peers. However, exposure to experiential learning of death and dying cannot be facilitated for all nursing students but the need to learn skills that will prepare students for these experiences when they occur was identified by the participants and also in the literature. New nurses in a study by Rosser and King (2003) expressed a need to develop pain and symptom management skills and to extend their existing communication skills. The need to develop core skills of palliative care was identified in this study as well, and was perceived by novice nurses as effective when taught in practice settings. Awareness of the importance of these nursing skills reflects much of the philosophy of palliative care (World Health Organization, n.d) and previously identified palliative nursing skills (Rosser & King, 2003). The value of experiential learning has been acknowledged throughout the literature; however, more effective integration needs to occur in practice settings. The concept of learning on the job implies development of knowledge and skills through experience, the value of which is acknowledged (Rosser & King, 2003), and now forms the basis for reflective practice in nursing. The nurse participants who engaged in end-of-life care as a student were able to reflect on their experiences and use their learning to apply to future experiences. Those that did not have experiential learning of palliative care described feeling unprepared as a new nurse the

first time they cared for a dying child. It is important for new nurses and their colleagues not to denigrate novices for not knowing everything, and instead commit to fostering their learning through practice experiences.

All participants in this study believed that the benefits of clinical supervision and facilitation of reflective practice through supervision would enhance new nurses' experiential learning (Rosser & King, 2003). In the findings, some novice nurses acknowledged that there were opportunities to care for dying patients that were not introduced to undergraduate students and others described that peers did not always have positive experiences in clinical with end-of-life care, particularly when support was not offered or a debriefing was not done. Wallace et al. (2009) had students identify their areas of perceived gaps, many of which were interpretations of experiential learning: junior students identified basic knowledge regarding palliative care was needed including "*signs and symptoms of death and dying*," and "*holistic approach*" and wanted specific clinical education related to the "*psychological impact of grief*" as well as spiritual interventions and other strategies for helping families at the end-of-life. In this study, novice nurses identified that hearing experienced nurses share stories about their experiences with end-of-life care was very impactful as it provided them with opportunities to learn about signs and symptoms of death and dying and how to approach the patient and family. The novice nurses in this study did not describe how their perspectives of end-of-life care changed between their early and later years in undergraduate education. However in the literature, in contrast to junior students, senior undergraduate nursing students desired specific education and experience in palliative care including dedicated clinical days and use of patient examples that were close to death in clinical (Wallace et al., 2009). It can be interpreted that as students and novice nurses

receive more exposure to end-of-life care that they desire more specialized nursing knowledge and to be more involved with palliative experiences.

Designing methods that enable all healthcare students to learn from a variety of scenarios in the practice environment helps maximize learning not only for the students, but also for clinical teaching faculty (Lyckholm & Kreutzer, 2010). Because opportunities for personal experience with pediatric palliative care are often limited, it is recommended that nurse educators provide alternative opportunities for students to consider the many aspects of care for dying children and practice the skills they need to provide expert care to the patients and their families. The experiential education that occurs when a student takes part in the care of a child with a life-limiting illness is transformative. This is cited in the literature as the opportunity to gain new appreciation and understanding that is invaluable to the clinical and professional development for students as they journey with the patient and family, navigating treatment and healthcare experiences (Lyckholm & Kreutzer, 2010).

Novice to expert development. The expert children's palliative care nurse is aware of the way the child and family is responding and how the approach and practice influences the relationship and bond that forms (Mauder, 2006). In general, novice nurses enter practice desiring to progress in their knowledge and skill and need opportunity to engage in end-of-life care with appropriate supports in place. Novice nurses are described as engaging in three characteristic phases: doing, being and knowing during their first few years of practice (Caton & Klemm, 2006). In the interviews, novice nurses described feeling overwhelmed, and underprepared with their initial end-of-life care experiences. In terms of doing and being, they often described the nursing tasks that they did as being familiar, however experienced discomfort with their presence during end-of-life care. All of the novice nurses described feeling that they

did not know enough, it can be interpreted that they were still developing their knowing as novice nurses.

Mentorship. Mentorship is one of the most valuable supports for novice nurses engaging in palliative experiences. The novice nurse participants discussed seeking mentorship from a variety of sources: other novice nurses, experienced nurses and expert palliative care nurses. However, the novice nurses had little knowledge of how mentors were prepared to assume the mentorship role, outside of the experiential knowledge they possessed. It can be acknowledge that it is of equal importance for novice nurses to have mentors as to how those mentors are prepared the provide mentorship. According to Rosser and King (2003), this includes advanced preparation and support in their role in order to maximize their positive influence on novice nurse transitions. This is also supported by Caton and Klemm (2006) who describe that mentors can facilitate improved coping for mentees and benefit from palliative care credentialing and training such as the ELNEC, prior to obtaining the role as mentor.

In the literature it was identified that mentors and mentees had similar perspectives about the value of mentorship and the expectations of the relationship. Mentors and team leaders did not expect new nurses to have specialist skills, only basic pain and symptom management skills (Rosser & King, 2003). New nurses in this current study were acutely aware of a variety of learning needs and considered that skills could be learnt by working alongside experienced nurses. This view was shared by mentors and team leaders: Watching other people is really helpful, listening to what they say, how they phrase things, how they put things to people (Rosser & King, 2003). In the interviews, novice nurses described how they would observe the language and approaches of experienced nurses providing palliative care and later try to emulate these strategies in their own practice.

Summary. In summary, it is necessary for undergraduate students to receive a strong educational foundation on relational practice, communication skills and end-of-life care.

Although introducing in depth specialty knowledge is not realistic, lifespan concepts need to be purposefully introduced. In essence, a well-balanced undergraduate experience that includes theory and practice exposure to palliative care will create the needed knowledge for entry-to-practice. Knowledge development needs to continue into practice settings where more in depth exposure to pediatric palliative care will occur through orientation, mentorship, experience and professional development.

Navigating Context: Understanding Societal and Workplace Influences on Novice Nurses

To understand the experiences of novice nurses during care provision, it is essential to explore the contextual factors such as societal and workplace influences that impact care; in the findings these were described as Caring and Context. Within relational consciousness, it is important to think contextually about the structures and forces that are influencing the situation and shaping the intrapersonal and interpersonal responses of the patient, family, novice nurse and co-workers (Doane & Varcoe, 2015). Important aspects that will be explored here in relation to the literature are the uniqueness of pediatric palliative care, CASN's entry-to-practice competencies for palliative and end-of-life care, exploring the practice settings of new nurses and nurses and families supporting one another.

The uniqueness of pediatric palliative care. The nurses' perception was that there were unique contextual aspects to pediatric palliative care. New nurses reflected society's beliefs about death and dying when they spoke in their interviews about expecting to be caring for living, not dying children. The concept of pediatric death as being unique or unexpected was also found in the literature. Nurses, patients and families on acute care units are not typically expecting to deal with end-of-life care (Cook et al., 2012). Kenny (2003) as cited in Vecchio (2011), stated that "children are not supposed to die, they are supposed to grow big and tall and have time for their dreams and hopes to mature and become reality" (p.33). The dichotomy between healing and dying was evident in the novice nurses' stories, with some perceiving death as a failure and others perceiving it as right, particularly when patients were suffering.

Several of the nurse participants practiced in NICU settings where neonatal death occurred, and described that the care leading up to the death of a neonate did not always include a palliative approach. This is mirrored in a literature review by Moro et al. (2009) who describe that use of palliative services is uncommon for neonates, even after the decision has been made to stop life-prolonging measures.

The influence of contextual factors is also referenced in the CASN competencies. According to CASN (2012), an aspect of competence is that the novice nurse recognizes and responds to the unique end-of-life needs of various populations, such as elders, children, multicultural populations, those with cognitive impairment, language barriers, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and marginalized populations. Children are one aspect of the unique end-of-life needs identified by CASN which serves as an important reminder that they cannot be treated merely as 'little adults', however, it is questionable based on the findings of this study whether undergraduate education alone prepares

new nurses to care for the unique needs of each population that CASN has identified. Perhaps, the important lesson that should be included for novice nurses is that relational practice requires nurses to recognize the uniqueness of each patient and family and adjust care accordingly.

Exploring the practice settings of new nurses. Within the participants' practice settings, there was by and large a culture of mentorship and support and the novice nurses recognized the need for this to continue and advance, particularly in the area of pediatric palliative care provision. Similar findings were reported by Cook et al. (2012) who described an institution's resources and colleague support as important contextual factors; scenarios in which there was a team dedicated to pediatric palliative care was also seen as being extremely beneficial.

The nurse participants worked on four different units where they received varying degrees of continued education, palliative resources and mentorship. Dyson (1996) argues that because clinical settings have different and distinct cultures, the expressions of care will differ not only between the care settings, but also between the individuals involved in that care. The nurses described the community of support they felt from expert and novice nurses, as well as interdisciplinary team members. In the literature it is said that a group creates its own community, and that shared experience becomes significant in how those working within that community manage the emotion work of their role (Mauder, 2006). The sense of community builds a system of social support that Brykczynska (2002) found to be effective in reducing burnout and distress in areas of nursing that carry a high emotional component in their role. For example, studies of stress in nursing have focused on social support and coping strategies as potential mediators (Mauder, 2006). Feelings of isolation were not uncommon for novice nurses in the literature with reasons cited such as highly acute practice areas, fear of asking

questions and desire to fit in (Jewell, 2013). However, in my study the novice nurses also recognized some of the isolation they experienced was due to their attempts to honour the privacy of the family and child.

The nurse participants shared descriptions of how their practice settings played a role in pediatric palliative care provision. Despite the death that occurred within the settings, nurses described their workplaces as 'beautiful' and 'full of hope'; descriptions of nurses' workplaces were not recognized in the literature. However, several articles spoke of the importance of hope in pediatric palliative care and the dichotomy this can create for healthcare providers. Vecchio (2011) queries whether some healthcare providers may be afraid to discuss a palliative prognosis out of fear that families will interpret this as a loss of hope. The novice nurse participants in the study described feeling more comfortable discussing lighter topics, rather than prognosis with the families of dying children. It can be speculated that some of their fears may have been related to attempts to preserve hope for families. In contrast, some families describe the hope that they received from healthcare professionals during the end-of-life as being listened to and not being abandoned (Vecchio, 2011). It can be interpreted that to facilitate the hope of the family, nurses need to overcome urges to avoid and instead engage in meaningful conversation with families about what hope means for them during the end-of-life for a child.

An important aspect of fostering development for novice nurses is workplace education opportunities. Within the interviews, it was apparent that each unit had different approaches to orientation and professional development, and some placed greater emphasis on palliative education than others. Determining strategies that effectively support novice nurses is not a new concept in the literature; however, few studies have focused on new graduate transition when providing end-of-life care; especially within pediatrics. Information on the number of pediatric

hospice and palliative care programs is not readily available, but there are some indications that these programs are increasing in number. In a 2005 survey of 232 Children's Oncology Group member institutions, 58 percent of the responding international institutions had a palliative care team, and 65 percent had hospice services available (Lyckholm & Kreutzer, 2010). Similarly, Gallagher, Cass, Black, and Norridge (2012) describe that in England alone there are approximately 3900 pediatric deaths per year resulting in a need for pediatric healthcare professionals to have knowledge and expertise of symptom management, ethics and communication skills. Thus, to prepare nurses to provide palliative care in these settings requires purposeful orientation and ongoing support of novice nurses. It is identified that there is an existing gap in curricula designed for healthcare professionals in this area (Gallagher et al., 2012). Several of the nurse participants stated that their orientation included conversations about palliative care on the unit, handling of a shroud and family mementos kit and introduction to members of the palliative care and/or chaplain at their hospital. In contrast, Gallagher et al. (2012) observes the increasing emphasis on clinical pathway development but the continual gap in personnel education and development.

Other nurses spoke about the support they received while they were providing end-of-life care and after a death occurred. This support came from multiple sources such as other novice nurses, experienced nurses, nursing leadership and the interdisciplinary team. For some nurses, this occurred in a formal meeting session such as a debriefing and for others this occurred at the nursing desk and in the nursing break room. Gallagher et al. (2012) performed a training needs analysis (TNA) with 111 healthcare professionals from a variety of disciplines; a key finding emerged where the participants reported moderately high levels of support, with the highest levels being seen to be available when a patient dies, breaking bad news to families and when

recognizing deterioration in a patient. In the participant interviews, some nurses identified feeling temporarily isolated from the healthcare team or watching other nurses experience this during palliative care provision. It is important to recognize that new nurses can be fearful of being alone at such a vulnerable time, this was also identified as a stressor for novice nurses in Caton and Klemm's (2006) study, where they suggest that these nurses need help to engage in caring behaviors when patients are dying.

In summary, the practice settings of novice nurses have significant influence upon novice nurses' first experiences and interpretations of pediatric palliative care. Through effective mentorship, program education and promotion of continual professional development novice nurses are fostered into skilled pediatric end-of-life care providers.

Supporting each other: nurse and family. Lastly, novice nurses described the support they drew from the families they were caring for at the end-of-life; although the nurses experienced some feelings of isolation from the healthcare team during the end-of-life process. Instead, the novice nurses described that support was mutual between nurse and family. This was a new phenomenon that was not described in the literature; several articles alluded to the close bond that forms between the nurse and the child and family at the end of life; but none addressed mutual support or mitigation of isolation. However, Hopkinson et al.'s (2005) work did describe that nurses also receive caring; in addition to providing caring at the end of life; this manifests in forms such as the support from colleagues, information about the dying patient and feedback from families about the care that was provided. One of the novice nurse participants described receiving positive feedback from a child's family after the death and how rare it can be in day-to-day practice to receive accolades or acknowledgment. Interestingly, Branchett and Stretton (2012) identified that parents perceived palliative experiences as more positive in units

where many staff participated in bereavement care, not only a specific nurse. It can be interpreted that novice nurses draw supports from multiple sources; and that developing supportive relationships with families can be powerful for the nurses' coping with pediatric deaths.

Summary. The necessity of viewing novice nurses' experiences in conjunction with the social and practice influences is obvious. The ways in which nurses interpret the meaning of their work and make sense of the experiences they engage in cannot be done without considering how society views pediatric death or how their workplaces approach end-of-life care of children and families. Novice nurses require support from their practice environments such as mentorship and continued education in order to increase their confidence and competence in pediatric palliative care.

Managing Self: Being Present, Aware and Open as a Novice Nurse

The self-awareness, personal attributes and coping of novice nurses are foundational to their relational abilities and impact their experiences of palliative care provision. The in depth, personal nature of the interviews allowed nurses the opportunity to share their rich experiences and their emotional responses; the findings from these experiences were explored in Chapter 4's Caring and Self. Important aspects that will be explored in relation to the literature are taking an intrapersonal approach, CASN's entry-to-practice competencies for palliative and end-of-life care, emotional responses of the novice nurse, coping of the novice and personal and professional selves.

Taking an intrapersonal approach. The participants' interview answers revealed personal responses characterized by a mix of emotions ranging from caring to avoidance to ongoing distress. The concept of 'self' within the concept of caring is not a new one in nursing literature; taking an intrapersonal lens of relational inquiry allows the nurse to consider what is going on within all people involved and includes the patient, the nurse who is providing care and what others such as the family and other staff members are experiencing (Doane & Varcoe, 2015). The newness of the experience was very apparent when talking to novice nurses during the interviews. Interestingly, a study by Román, Sorribes, and Ezquerro (2001) found that older nurses having 17–21 years of experience reported more favorable attitudes toward caring for dying patients than younger nurses, nurses on afternoon and night shifts, and nurses with less experience. It is important, then, to recognize the needs of the new nurse entering practice and providing palliative care to children and families.

The findings of this current study revealed that novice nurses were present in a variety of ways during palliative care provision. However a gap was identified in the literature where none of the published studies spoke to what the experience of being present for a pediatric palliative care event is like for novice nurses. It is acknowledged in the literature that the presence of a novice nurse at the end-of-life, regardless of the age, can facilitate learning from the family and a greater understanding about the circle of life (Caton & Klemm, 2006). A key part of the helping role is being there for the child/young person and his/her family. Being there is often referred to in the literature as presencing. In a study conducted with parents of children who had died, Branchett and Stretton (2012) described that parents seemed to welcome the honest, open and human side of healthcare providers and acknowledged that this demonstrated to them that the healthcare providers cared. In contrast in the current study, the opposite phenomenon occurred

for several of the participants. It was evident in the findings that novice nurses experienced some discomfort communicating with the family; for some this manifested as avoidance, for others this led to feelings of helplessness and fear. An interesting contrasting approach nurses used to cope was distancing. Several nurses in Cook et al.'s (2012) study of nurses at all stages of their nursing career revealed that they 'changed gears' and avoided openness, while others maintained contact with families after the child died, which raised concerns amongst some participants about professional boundaries.

One important consideration that emerged in the findings was the novice nurses' attitudes towards end-of-life care. None of the novice nurses demonstrated negative attitudes regarding their experiences; however some had more previous experience with death and dying than others which impacted their confidence and resulting attitudes. Dunn et al.'s (2005) literature search suggests an important recommendation for palliative care education: death education programs that include an assessment of death attitudes with interventions that increase positive attitudes toward the care of dying patients as well as increasing experiences with dying patients may have an influence on the care that nurses provide to dying patients and their families.

Emotional responses of the novice nurse. The emotional responses, emotional intelligence and emotion work of the novice nurse emerged as significant findings and related strongly to the overarching theme of relational practice and caring. Novice nurses' emotional responses pediatric palliative care proved to be strong, raw, and varied depending on the connection and length of relationship that they had with the child and family. The findings of this study revealed that their emotional responses included feeling: "*overwhelmed*", "*sad*", "*helpless*", "*angry*", "*frustrated*" and "*afraid*". These types of responses were also evident in the literature, as several studies explored the emotions of the novice nurse. Caton and Klemm

(2006) described that novice nurses may experience uncomfortable feelings such as anxiety, loss and grief; and just as importantly, may find it difficult to articulate their emotional responses. Notably, emotional responses of nurses are often learned from others and influenced by society and may or may not be genuine (Huyhn, Alderson, & Thompson, 2008). The emotional reactions that were evident in the literature highlight the importance of educating novice nurses about typical responses to death and the presence of experienced nurses for mentoring them through their emotional responses. In Cook et al.'s (2012) study of 22 nurses, they found that nurse participants changed their body language, voice, facial expressions and approach many times during shifts in which they were caring for a mix of acutely ill and palliative children. While this provided the nurse the opportunity to connect in a relational fashion when in the room with the patient, this strategy involves considerable emotional work. For novice nurses, this emotional work may be a struggle to perform and leave nurses physically and emotionally exhausted at the end of a shift.

The timing of the novice nurse participants' emotional responses proved to be very different amongst the nurse participants. Some revealed emotions during care provision, others felt emotionless at the time of providing palliative care, and several suggested that their emotions surfaced afterwards. Regardless of the timing, Caton and Klemm (2006) identified the necessity of dealing with emotions to prevent cumulative loss and burnout from occurring.

The emotional intelligence of novice nurses emerged in the findings; emotional intelligence (EI) is defined as one's thinking about the relation between emotion and reason, which is considered a form of intelligence (Grewal & Salovey, 2005). The new nurses used reflection and conversation to help make sense of their experiences with end-of-life care and demonstrated they were able to draw meaningful connections between their personal responses

and the care of patients and families. EI to some extent maps on to professionalism, and self-awareness, self-management, social awareness and relationship management (Goleman, Boyatzis, & McKee, 2002; Snow, 2001). In the findings novice nurses described how societal influences and personal experiences with death and dying had shaped their expectations of what end-of-life care would be and how many of their ideas changed once they experienced it in a nursing role.

According to CASN (2011), the fifth competency of novice nurses is: Applies ethical knowledge skillfully when caring for persons at end-of-life and their families while attending to one's own responses such as moral distress and dilemmas, and successes with end-of life decision making. In order for novice nurses to successfully care for patients and families, they must be self-aware and commit to considerable emotion work. The findings of this study demonstrated that novice nurses were trying to understand their emotional responses, and at times were surprised by the depth of their feelings. Similarly, Maunder (2006) identified that novice nurses can have unique challenges depending on the length and depth of the relationship with the child and family and be influenced by the age of the nurse and whether the nurse has children.

Novice nurses often seek validation and approval from experienced nurses. During the course of the interviews, several participants asked the interviewer what was 'normal' in regards to grieving and whether ongoing distress was something nurses regularly experience. Similar findings were reported by Cook et al. (2012) who described that the level of nursing experience of the nurse had a direct effect on the nurses' ability to disconnect and set boundaries. In their research, they found that younger nurses talked more about tragic events, finding it therapeutic to retell stories about a patient's death and some inexperienced nurses sought

emotional ties with the family after a patient death, at times creating a reversal of roles (Cook et al., 2012). Maunder (2006) reported similar findings, noting that nurses learn from their experiences and from these experiences are able to develop strategies that help them cope in a difficult field. It can be interpreted that novice nurses' experiential learning is an important aspect of emotion work. Emotional intelligence is also described as developing through experience (Akerjordet & Severinsson, 2010). Knowing this, creating opportunity for experiential learning facilitates emotional growth in new nurses, but conversely, the relationship between experience and emotional intelligence cannot be forgotten: until new nurses engage in end-of-life care they will not develop their emotional responses.

Coping of the novice nurse. All of the novice nurse participants shared that reflection and conversation were two of the coping strategies that they relied on. Nurse to nurse conversation proved to be valuable for the novice nurse participants. Some chose to talk to nurses on the same unit, in order to gain perspective unique to the area of work and family situation; and to maintain patient confidentiality. Telling stories can help novice nurses and experience nurses derive meaning and understanding from the death of a patient (Caton & Klemm, 2006). Others talked to friends who were nurses in other settings. Cook et al. (2012) revealed that nurses often did not feel comfortable discussing their experiences with death at home, but rather typically turned to colleagues for support. One of their participants described *"it can be frustrating when you're trying to explain your day to somebody, like a friend or family member and they just don't get it."* Similarly, two of the participants in my study shared similar sentiments; one acknowledged *"no one understands completely, except for another nurse."*

Reflection activities begin in nursing school and continue into practice competency requirements for nurses. Interestingly, when engaging in end-of-life care all the nurses in this

study acknowledged the power of reflection in their practice. Likewise, Caton and Klemm (2006) discussed the benefits of journaling and novice nurses engaging in initiatives such as writing condolence cards as a source of coping.

Practice setting resources for coping varied; the nurse participants described attending debriefings and memorial services; this was similar in the literature where organized strategies for coping included attendance at funerals and hospital memorials, caregiver support groups and monthly nursing unit sessions (Caton & Klemm, 2006). Coping strategies that facilitated reflection and closure were evident to be helpful to not only nurses, but also families after the death of a child (Dokken & Ahmann, 2010). Notably, novice nurses and families require some of the same things to heal after the death of a child.

A balancing act: personal and professional self. The novice nurses in this study were learning to balance their professional and personal selves as they also developed a sense of emotional well-being. Seeking a sense of balance between their own emotional responses and their professional responses while still being 'human' came up throughout the interviews with novice nurses. Cook et al.'s (2012) work on coping in pediatric nurses during palliative care provision used the term 'boundaries' when referring to the walk between the personal and profession line. In their study, they interviewed 22 nurses who were at varying stages of Benner's novice-to-expert model. Several nurses commented on the nomenclature of the word 'boundary' and that it should not indicate a lack of caring or emotion, one participant in their study stated "The day we stop feeling is the day that we need to quit...if we don't get affected by a child's death, that's when you need to rethink your profession" (Cook et al., 2012, p.15). The novice nurses in the current study were unsure of how much emotion to show in front of families, and the findings highlighted that several of the nurses suppressed their emotions until

they were alone or had left the workplace. Hopkinson et al.'s (2005) work also described nurses grappling with 'balance' in their practice between emotional distance and involvement. One aspect of balancing between personal and professional self includes the self-concept of the novice nurse. Kelly and Court (2007) surveyed 132 new nurses within 6 months of graduation working in general and specialty settings to determine their self-concept and found that the professional self-concept of graduate nurses is influenced by the academic system, educational preparation and professional development. Novice nurses are still developing as professionals and are influenced by their self-concept. They are continuing to question how to achieve balance between who they are as individuals and registered nurses.

Summary. As novice nurses, the study participants were still developing as professional nurses at the time of the interviews. They ranged in age from 22 to 35 and were learning about themselves and developing coping strategies with experience. Although novice nurses can be prepared for pediatric palliative care through theoretical knowledge and mentorship, their own self-work plays an equally important role in their experiences.

Chapter Summary

The purpose of this project was to explore the experiences of novice nurses caring for palliative children and their families. In summary, the depth of the findings allowed for a thorough discussion in relation to existing literature and explored an important topic of growing interest in both practice settings and nursing education. Unfortunately to the detriment of novice nurse development, the realities of healthcare impact the realities of nursing. Nurse participants identified challenges to receiving professional development such as busy schedules, limited professional funds and accessibility. Jewell (2013) spoke about three key influences on the novice nurse in the current Canadian context: nurse shortages impacting scheduling and

education, and patient acuity. In the context of escalating patient acuity and a critical nursing shortage, researchers have reported that most nurses perform emotional labor, as they realize that their actual feelings are not consistent with the caring emotions they should experience professionally (Huynh et al., 2008). At times new and experienced nurses struggle to combine preparatory knowledge and daily practice. This perceived 'gap' has been studied in the literature; Slaikou (2011) describes this gap as multidimensional and includes several factors that pertain to this study: economy, orientation quality and duration and preparation of mentors.

However, the outlook is not bleak. Novice nurse participants demonstrated strong commitments to pediatric nursing and professional development; many spoke to the researcher after the interviews were completed to find out about additional end-of-life care education strategies and discussed a desire to pursue additional credentialing to expand their nurse practice. They displayed emotional responses to the palliative care they engaged in and showed passion to provide the best care possible to children and families. Jewell (2013) states the importance of nurse mentorship and coaching and the value of guiding novice nurses from knowledge application to knowledge construction. In order to guide the next generation of nurses to provide the excellence in caring that is required for patients and families they need guidance and support at an individual, education, practice, policy and research level. While many novice nurses express an interest in pediatric nursing, they may not be fully prepared with knowledge and awareness of the end-of-life care that occurs in specialty areas such as this. Nursing education provides students and new graduates with an important tool to help ease this transition: relational practice. Although it may be challenging to elicit difficult conversations and support children and families in a time of vulnerability and crisis; the novice nurses also disclosed the value their experiences have had on their personal and professional development. Novice nurses who

demonstrate their human side and are present during interactions facilitate deeply meaningful family centered care of children. In addition, it is necessary to recognize that nursing practice is contextual and is shaped by societal beliefs about death; one predominant one is that children don't die. Encountering the reality of end-of-life care requires nurses to develop effective coping strategies; two of which proved most valuable were coping through conversation and reflection. Nurses who felt supported and mentored in their workplace had more positive attitudes towards their work and had increased confidence in their practice. Nursing education typically introduces foundational concepts such as communication, interpersonal skills and general end-of-life care concepts and needs to do so to prepare nurses for entry-to-practice. CASN's ETPCs describe in depth competences and indicators that relate to the findings' themes of caring and family, caring and knowledge, caring and context and caring and self. Some are easier to learn than others prior to obtaining experiential knowledge through clinical exposure and practice encounters. Although CASN's document outlines important aspects of the nursing role at the end-of-life, this study suggests that not all aspects are realistic for novice nurses to demonstrate early in their practice. Chapter 6 will summarize the important messages obtained from the project and discuss implications for nursing education, practice, research, leadership and policy.

Chapter 6: Conclusions and Recommendations

The purpose of this project was to explore the experiences of novice nurses caring for palliative children and families. Chapter 6 will summarize the study, present conclusions drawn from the findings, and discuss implications and recommendations for nursing education, nursing practice, nursing leadership, nursing policy and nursing research.

Summary of Study

As part of this qualitative study, eight novice nurses from two Alberta hospitals were interviewed about their experiences providing pediatric palliative care for children and families. All of the nurse participants had cared for at least one palliative patient since graduation. The caring they provided was influenced by who the nurses were, the knowledge they possessed, the context of their workplaces and societal beliefs about children dying, and the families to whom care was given. The relational practice abilities of the nurses proved to be an overarching theme, as regardless of the scenario the nurse was in, the ability to connect with a child and family was foundational. Although this project does not seek to critique existing undergraduate nursing education, it highlights the importance of purposeful inclusion of palliative theory and practice and poses several recommendations for the future. It also suggests that additional education is required within workplace settings and as professional development beyond graduation as experiential learning helps solidify the palliative care concepts.

Conclusions

The following five conclusions were drawn from this study:

1. Novice nurse participants appeared to be deeply impacted by their early and more recent experiences with end-of-life care. They were emotional as they described feeling overwhelmed,

underprepared and fearful during their first experiences caring for palliative children and their families.

2. Participants' descriptions of personal growth and development of coping strategies were seen as positive outcomes from their initial experiences with pediatric palliative care. None of the novice nurses perceived that their experiences had negative impact on their career decision-making.

3. The experiences of novice nurses were greatly influenced by their practice settings. They described the value of relationship and mentorship with nurse colleagues and interdisciplinary team members. The dichotomy between healing and dying was seen as particularly challenging in pediatric nursing and was influenced by society's beliefs that children do not die.

4. Novice nurses struggled to communicate with some families they cared with about topics that were perceived as difficult such as end-of-life care decision-making. Conversations were more challenging when cultural barriers existed, many nurses saw their lack of familiarity with different cultures beliefs about death and dying as a barrier.

5. New nurses did not feel confident and competent in their knowledge of pediatric palliative care. Each of the five conclusions led to recommendations that are discussed in the following section.

Recommendations

The recommendations based on this study focus on areas of the nursing domain most relevant to this project: education, practice, leadership, policy and research. The recommendations are reflective of findings and discussion from my own project and are supported by previous and relevant healthcare research.

Recommendations for nursing education. The findings of this study add new understanding into the perspectives of novice nurses about their undergraduate education. Several of the participants described disconnect between theory and practice and missing key theoretical concepts during their education. In the literature there was little exploration of pediatric palliative care education of novice nurses, however, existing literature about undergraduate preparation for practice and general end-of-life care provided helpful analysis of the findings that emerged in this study. Slaikeu (2011) explored the gap between preparatory education and practice and cited influences such as economy, faculty shortage, critical thinking skills of faculty, and obsolete curriculum design and instruction. More specifically, Wallace et al. (2009) recommend that EOL nursing education should focus on individuals with life-threatening illness beginning at time of diagnosis and continuing throughout the illness trajectory until death.

The first recommendation is for nurse educators to purposefully introduce communication and relational practice principles through a lens that they are necessary skills when engaging in end-of-life care with a patient and family, regardless of the age of the patient. In this study, novice nurses identified aspects of nursing knowledge that they wished they had learned during undergraduate education. Many spoke about the heavy content and self-directed learning that was expected of them as students in nursing programs. The areas that novice nurses described as most challenging included communication and overcoming cultural and language barriers. It can be argued that these are fundamental skills that are introduced early in nursing curriculum. In the findings, an overarching theme of relational practice emerged as important to the novice nurses' ability to be with a family and provide support through the death of a child. Relational practice, in conjunction with family centered care and emotion work of the novice nurse can all be taught as foundational concepts in the nursing curriculum; however, purposeful

connections need to be drawn between the theory of these concepts and their application into real practice. Some novice nurses recalled very little of the theory they learned about end-of-life care during their undergraduate education. CASN's (2011) document clearly outlines entry-to-practice competencies and indicators for palliative and end-of-life care. It is recommended that nurse educators utilize these competencies and the resource modules available from CASN and other professional associations, such as CARNA's Position Statement on Palliative Care, to guide nursing curriculum. Additional curriculum supports include resources that are currently being used in practice setting such as advanced decision-making policies and the End of Life Network Education Consortium (ELNEC) training and certifications. Another educational program that is helpful for baccalaureate programs to use in integrating EOL content into curriculum is the Toolkit for Nursing Education at End-of-Life Transition which provides educational modules including comfort, connections, ethics, grief, and well-being as well virtual EOL educational tools and interactive methods of teaching EOL care for use in nursing curricula (Wallace et al., 2009). Although nurse educators are not preparing students to work in specific workplaces, the use of existing policies, protocols and programs can be helpful for later integration into the workplace.

The second recommendation is for end-of-life interdisciplinary education to be offered. Novice nurses in this study also described feeling overwhelmed, sad and fearful. Interestingly, some of the same fears of providing adequate support for the dying are reported in the literature as also occurring amongst other health disciplines. Nursing students in baccalaureate programs can learn alongside and from other healthcare program students in disciplines such as practical nursing, healthcare aid, social work, pharmacy, physiotherapy and medicine. In several large pediatric hospitals institutions they have piloted comprehensive, interdisciplinary curriculum that

addresses knowledge, attitudes, and skills that healthcare professionals need to better serve palliative children and their families (Browning & Soloman, 2005). Interdisciplinary education may more effectively set the stage for collaborative, team approaches during end-of-life care provision in pediatric settings. In addition, interdisciplinary end-of-life care education needs to continue in practice settings with healthcare professionals.

The third recommendation is to use a variety of teaching and learning strategies to educate nursing students. Undergraduate education for end-of-life care requires a multi-pronged approach. Key concepts include: theoretical introduction of concepts such as physical changes, symptom management, grief and bereavement theories and approaches and population-specific strategies throughout the lifespan and with a variety of cultures. CASN's Palliative and End-of-Life Care competencies and indicators may serve as an important framework for theoretical education. In order to support nursing faculty in the application of the competencies within a classroom setting CASN (2012) created a teaching resource using story-based pedagogy to engage students in palliative care in a meaningful way. Strategies include use of stories, guiding questions, student and instructor participation in facilitation and several supplementary activities to engage students in reflection on their beliefs surrounding death and dying (CASN, 2012). Strategies for effective teaching and learning include a mix of theory and practice experiences. To provide exposure to the experiential elements of working with a patient who is dying, strategies such as role playing, lab skill practice and simulation can be offered to undergraduate students. Clinical instructors and preceptors need to be offered effective professional development to prepare them for facilitation of positive exposure to end-of-life care for students. Effective clinical educators can guide students to think critically and make sense of what they are seeing and experiencing. The presence of other students appears to serve as meaningful peer

support; students may serve as mentors to each other, and thereby have their learning experiences validated by the presence of a colleague. Effective exposure to palliative care in the clinical setting includes opportunities to discuss and learn about end-of-life care with experienced clinicians, patient assignments, assisting with care and debriefing. Familiarizing students with palliative care teams, clinical resources for end-of-life care provision and patients are all effective strategies to enhance their exposure. In some programs, clinical experiences are offered on palliative units and hospice facilities. Although the capacity is likely not there for all students to engage in these opportunities, the inclusion of them as practice sites sends an important message that this is a valuable role for registered nurses.

The fourth recommendation for nursing education is to include introduction of end-of-life care concepts in specialty nursing. Specifically, as a finding from this study, this would include discussion of palliative care in Maternal-Child courses in undergraduate curriculum. Wallace et al. (2009) describe the use of ELNEC modules in specialty undergraduate courses to guide discussion about pregnancy loss, perinatal death, sudden infant death syndrome, and terminal illness in children with topics specific to loss, grief, and bereavement being addressed. Similarly, CASN's ETPCs could be applied throughout the undergraduate curriculum in the fundamental and specialty courses to ensure that there are threads of palliative care throughout. This would be in line with the World Health Organization (WHO, n.d), who define 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.

In summary, nursing education can respond to the findings in this study by introducing foundational concepts as relevant to palliative care, purposefully including palliative care across the lifespan and providing experiential learning opportunities.

Recommendations for nursing practice. There are several elements to consider for new nurses and their continued education in practice settings and through professional development. In the findings of this study, it was apparent that novice nurses did not feel confident in their abilities to provide end-of-life care to children; this finding was also evident in the literature. Multiple studies indicated that nurses do not feel competent or confident in implementing EOL care throughout the lifespan (Wallace et al., 2009). Therefore, the practice recommendations are focused on improving the knowledge, skill and confidence of novice nurses providing pediatric palliative care.

The first recommendation to improve the experience of novice nurses is deliberate inclusion of palliative care into pediatric nursing orientations. Orientation for new nurses is done in a variety of ways: general hospital orientation, unit-specific orientation and preceptorship with an experienced nurse. Within general hospital orientations, new nurses need to be informed of palliative teams that are accessible in the facility, region and province; policies that the institution follows in regards to pronouncing death and advanced-care planning directives; and resources such as employee assistance programs that are available. In this study, novice nurses were mainly unaware of workplace programs to access for assistance with coping and stress management. It needs to be acknowledged that caring for dying people is often considered to be one of the more stressful aspects of nursing work (Hopkinson et al., 2005). During unit-specific orientation, nurse unit managers and educators need to describe the common demographics that are cared for on the unit and both physical and human resources that are utilized during end-of-

life care provision such as palliative rooms, chaplains and end-of-life care experts. Several of the nurse participants in this study identified that they did not know what resources were available in their workplaces for end-of-life care provision and were afraid to ask. Familiarizing new nurses with where to find bereavement kits, grief resources and contact information for available services can help set them up for when they do engage in care. Inclusion of scenarios where nursing skills will be used and adapted for pediatric end-of-life care can be a helpful introduction such as pain management, enteral feeding, airway support, personal care and critical conversations. An aspect of practice orientation includes matching experienced nurses with new nurses in a preceptorship experience. Lengths of preceptorships for new nurses vary amongst settings, some lasting days and others months. A recommendation is to adequately prepare nurses to mentor novice nurses. In the literature it was made evident that novice nurses who receive positive mentorship in palliative care have better first experiences (Rosser & King, 2003).

The second recommendation is to provide resources in the practice setting to facilitate continued professional development in the area of pediatric palliative care. Effective strategies that were described by novice nurse participants included inclusion of palliative care information into staff meetings and education days, pediatric palliative care workshops that are offered on site or via teleconference, access to existing palliative modules and debriefing/story-telling opportunities on a regular basis for nurses and the interdisciplinary team. In order to facilitate improved patient and family experiences with end-of-life care, preparing the interdisciplinary team to function effectively can be done through use of scenarios and skills training (Browning & Soloman, 2005). Gallagher et al. (2012) recommended that workplaces have a training needs analysis performed, as each practice setting may have differing needs. In this study, due to the

small sample size it was difficult to determine in depth recommendations for each unit.

However, a training needs analysis of the institutions may be of benefit (Gallagher et al., 2012), and in addition, all of the settings may benefit from use of existing programs such as United States' ELNEC and TNEEL. The Institute for Pediatric Palliative Care (IPPC) has five interdisciplinary modules that can be used with healthcare teams to prepare for end-of-life care (Browning & Soloman, 2005).

The third recommendation is to create a culture of learning concerning pediatric palliative care. This recommendation overlaps with several of the other domains of recommendations in Chapter 6. It is essential for policies and leadership to support professional development for nurses. This professional development can be done through encouraging nurses to pursue palliative care certification with the Canadian Nurses' Association and become involved in specialty groups such as the Association for Pediatric Hematology and Oncology Nurses (APHON) that are unique to different areas of pediatric nursing practice. Alternate ways to promote best practice and excellence is through appointment of clinical experts in palliative care and creation of special interest groups that pediatric nurses can volunteer to join. Novice nurses can be encouraged to pursue higher education such as diplomas and Masters-programs focused in palliative care to develop their practice.

Recommendations for nursing leadership. An important outcome of improving novice nurses' experiences providing pediatric palliative care is improving patient and family experiences with end-of-life care. In order to utilize the findings from this study and in the literature effectively, effective leadership initiatives need to continue to occur and expand. Within practice settings, effective nursing leadership includes acknowledgement of novice nurse transitions from novice-to-expert. Nursing unit managers, educators and charge nurses need to

provide novice nurses the opportunity to learn from experienced palliative care nurses and interdisciplinary team members. Nurse unions and hospital administration need to continue to incorporate paid nursing education days into nursing work schedules. Nurse leaders need to model the way with family centered care initiatives at the end-of-life and advocate for safe staffing levels to ensure that as although acuity of hospitalized patients increase that quality of care maintains high. Lastly, nursing leaders need to be prepared to innovate and be exemplary in end-of-life care, as nurses' roles in end-of-life care are seen as intensive and impact other professions' practice. Innovation in end-of-life care involves advocating for family wishes, this may include facilitating opportunities for cultural practices to occur in institutions and arranging for children to die in the setting of their choice such as their home, a familiar hospital unit or a hospice facility.

Recommendations for nursing policy. There are multiple organizations that exist internationally and nationally that have important policies and guidelines for healthcare throughout the lifespan, as well as specific to pediatrics. My recommendation in the area of nursing policy is for the knowledge and expertise of these organizations to be disseminated more effectively into practice and education settings and for healthcare organizations to willingly seek out and embrace these resources.

Globally, the World Health Organization (WHO) and International Children's Palliative Care Network (ICPCN) and EHospice are important organizations that guide international policies, education and programs. The ICPCN has developed free e-modules on end-of-life care for healthcare professionals. Another recommendation in the area of policy development stemming from this is for practice settings implement policy for novice nurses to perform these modules within the first year of practice to help ease the gap between theory and practice.

Currently, there are several Canadian organizations that have developed guiding policies for palliative care of people throughout the lifespan. The Canadian Hospice Palliative Care Association (CHPCA) is a national organization that advocates for public policy, education and awareness about end-of-life care. The CHPCA created a taskforce for Pediatric Palliative Care with interdisciplinary experts across Canada which follows the mandate of the CHPCA while also informing pediatric initiatives. Health Canada had recognized end-of-life care as a national priority and in consultation with the Canadian Institute of Health Research (CIHR) has supported research and exploration of policies to guide best practice in end-of-life care. The Initiative for a Palliative Approach in Nursing: Education and Leadership (iPANEL) is a British Columbia-based group funded by a research grant to engage in clinically-relevant research to improve end-of-life care for Canadians. South of the border, the Center to Advance Palliative Care is a US-based organization provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious, complex illnesses. CAPC offers comprehensive training for palliative care programs at every stage from strategic planning and funding to operations and sustainability and provides materials such as provides seminars, handouts and a website for patient and family education: www.getpalliativecare.org. In summary, through effective use of existing policies benefits include better utilization of care which can potentially reduce healthcare costs and effectively support patients and families to achieve holistic well-being.

Recommendations for further research. Several significant areas for further exploration emerged. The first recommendation for further research is to explore pediatric

palliative care experiences of novice nurses in additional settings such as homecare and community programs. The second recommendation is to explore the experiences of novice nurses providing palliative care throughout the lifespan in all settings, to determine whether their experiences were similar or different to pediatric nurses when it comes to their relational practice. The third recommendation for further research is to explore the evolution of self-efficacy in providing pediatric palliative care through interviewing nurses at all stages of their careers working in different types of pediatric settings, such as was done in this study. Exploration of a larger sample size with the different variables of types of nursing and nursing perspectives from novice-to-expert would expand upon the findings in my study. Additional areas to explore within the aforementioned areas include effectiveness of different teaching and learning strategies for end-of-life care on the competence and confidence of novice nurses.

Chapter Summary

My project explored the experiences of novice nurses caring for palliative children and their families. The results demonstrated that new nurses' experiences were influenced by caring and self, knowledge, context and family. The depth of their caring was apparent through the tears that were shed in several interviews, the emotional responses they described and the vividness to which they recalled their stories. Relational practice was an important cornerstone to meaningful, effective nursing practice. The data analysis and discussion revealed that while novice nurses recognized the importance of relational practice they struggled to feel competent and confident in their initial experiences with pediatric palliative care. They identified gaps in their undergraduate education, and I interpreted that some of these perceptions were related to lack of theory-to-practice connections and experiential learning opportunities. Novice nurse participants appeared to be deeply impacted by their early and more recent experiences with end-

of-life care. Participants' descriptions of personal growth and development of coping strategies were seen as positive outcomes from their initial experiences with pediatric palliative care. The experiences of novice nurses were greatly influenced by their practice settings. The dichotomy between healing and dying was seen as particularly challenging in pediatric nursing and was influenced by society's common belief that children do not die. Novice nurses struggled to communicate with some families that they cared with about topics that were perceived as difficult such as end-of-life care decision-making. New nurses did not feel confident and competent in their knowledge of pediatric palliative care. The recommendations for the future span the domains of nursing education, practice, leadership, policy and research. In summary, novice nurses enter practice with intentions to provide excellence in caring and offer important contributions to the future of the profession and care for Canadian children. It is the responsibility of education and practice to foster new nurses as they progress through the novice-to-expert trajectory. Ultimately, through guiding the evolution of novice nurses' pediatric palliative care practice, the quality of care will improve for children and their families.

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Multidisciplinary simulation in pediatric critical care: The death of a child. *Critical Care Nurse*, 32(3), 55-61.

Appendix A

Preliminary Literature Review Table: Database Results

Dates	Databases	Search Terms	Results
October 2012	CINAHL	“experiences or coping or fears or anxiety” “nurse or registered nurse or novice nurse or student nurse” “death or dying or end-of-life or palliative”, And “child or children or childhood or adolescen* or teen* or pediatric or paediatric or youth* or kid*”	416 524 158 634 185 38 4 articles selected
November 2012	Medline	“experiences or coping or fears or anxiety” and “nurse or registered nurse or novice nurse or student nurse” and “death or dying or end-of-life or palliative”, and “child or children or childhood or adolescen* or teen* or pediatric or paediatric or youth* or kid*”	1271 137 95 27 3 3 articles selected
December 2012	Google Scholar	“pediatric” and “palliative care” and “nurses” and “education” and “novice nurses”	26 800 22 200 1780 1 article selected
January 2013	Course Articles	Articles and textbooks used in other MSN courses and readings	6 resources selected

Secondary Literature Review Table: Database, Grey Literature and Textbook Results

Dates	Databases	Search Terms	Results
August 2013	CINAHL	“experiences or coping or fears or anxiety” “nurse or registered nurse or novice nurse or student nurse” “death or dying or end-of-life or palliative”, And “child or children or childhood or adolescen* or teen* or pediatric or paediatric or youth* or kid*”	345 201 118 601 198 41 2 articles selected
November 2013	Pub Med	“experiences or coping or fears or anxiety” and “nurse or registered nurse or novice nurse or student nurse” and “death or dying or end-of-life or palliative”, and “child or children or childhood or adolescen* or teen* or pediatric or paediatric or youth* or kid*”	501 210 25 5 1 article selected
December 2013	Google Scholar	“pediatric” and “palliative care” and “nurses” and “education” and “novice nurses”	2 articles selected
November 2013- May 2014	Grey Literature	Articles, websites, guidelines and textbooks	25 resources selected

Appendix B

Table of Most Relevant Articles for Thesis

<p>Author/APA Reference: Bartell, A. S., & Kissane, D. W. (2005). Issues in pediatric palliative care: Understanding families. <i>Journal of Palliative Care</i>, 21(3), 165-172.</p> <p>Research Methodology: Literature review</p> <p>Research Question: What are the issues in providing palliative care that encompasses the family?</p> <p>Key Findings While family centered care has always been part of the rhetoric of hospice and palliative care, few models have been developed that successfully integrate care of the caregivers into the overall schema.</p>
<p>Author/APA Reference: Benner, P. (1982). From novice to expert... the Dreyfus Model of Skill Acquisition. <i>American Journal of Nursing</i>, 82, 402-407.</p> <p>Research Methodology: Discussion article</p> <p>Key Findings In Benner's model of novice to expert, there are five categories in the trajectory: novice, advanced beginner, competent, proficient and expert (Benner, 1984). It is important to acknowledge that nurses can move back in forth in the trajectory with different situations, and that it is not a linear model.</p>
<p>Author/APA Reference: Dickens, D.S. (2009). Building competence in pediatric end-of-life care. <i>Journal of Palliative Medicine</i>, 12(17), 617-622.</p> <p>Research Methodology: Quantitative study</p> <p>Sample: 157 nurses</p> <p>Research Question: What factors influence provider confidence in managing eleven different end-of-life care issues?</p> <p>Key Findings Several factors were key predictors of confidence: age, gender and educational experience during undergraduate training.</p>
<p>Author/APA Reference: Doorenbos, A., Lindhorst, T., Starks, H., Aisenberg, E., Curtis, J., & Hays, R. (2012). Palliative Care in the Pediatric ICU: Challenges and Opportunities for Family-Centered Practice. <i>Journal Of Social Work In End-Of-Life & Palliative Care</i>, 8(4), 297-315. doi:10.1080/15524256.2012.732461</p> <p>Research Methodology: Literature review</p> <p>Key Findings The PICU is often cure-focused, using aggressive therapies to focus on healing. Can be difficult for patients, families and the interdisciplinary team to transition to palliative care.</p>
<p>Author/APA Reference: Dunn, K., Otten, C., & Stephens, E. (2005). Nursing experience and the care of dying patients. <i>Oncology Nursing Forum</i>, 32(1), 97-104. doi:http://ezproxy.student.twu.ca:2189/10.1188/05.ONF.97-104</p> <p>Research Methodology: Descriptive qualitative study</p> <p>Sample: 58 Registered Nurses</p> <p>Research Question: What are the relationships among demographic variables and nurses' attitudes toward death and caring for dying patients?</p> <p>Key Findings Factors such as the past, personal and professional experiences effect nurses in both the end-of-life care they provide and their attitudes towards death and dying. The past experiences described within this study include level of education and palliative training they have received. The past experiences include the social demographics of the nurse including age and religion; professional experience is described as</p>

<p>the months and years of nursing experience and the amount of time in contact with terminally ill patients.</p> <p>Author/APA Reference: Gaudio, F., Zaider, T.I., Brier, M., Kissane, D.W. (2011). Challenges in providing family-centered support to families in palliative care. <i>Palliative Medicine</i>, 26(8), 1025-1033.</p> <p>Research Methodology: Quantitative study</p> <p>Sample: 144 families and individuals</p> <p>Research Question: To examine the therapists' techniques used in assessing 'at risk' families in palliative care to better illuminate what helps and what remains challenging.</p> <p>Key Findings Supporting the family as a whole can be a challenge, and it is noted that for a family caring for someone who is dying can create greater sense of meaning and connection, conversely, it can create significant distress and negative psychiatric health.</p>
<p>Author/APA Reference: Kent, B., Anderson, N., & Owens, R. (2012). Nurses' early experiences with patient death: The results of an on-line survey of Registered Nurses in New Zealand. <i>International Journal of Nursing Studies</i>, 49(10), 1255-1265.</p> <p>Research Methodology: Mixed-method study</p> <p>Sample: 174 nurses</p> <p>Research Question: What are the clinical circumstances, impact and challenges and rewards of nurses' early experiences with patient death?</p> <p>Key Findings The first experiences a nurse has with patient death are known to be stressful, with some experiences being described by them as being good learning, rewarding, distressing or causing guilt and helplessness.</p>
<p>Author/APA Reference: Maunder, E. (2006). Emotion work in the palliative nursing care of children and young people. <i>International Journal of Palliative Nursing</i>, 12(1), 27-33.</p> <p>Research Methodology: Literature Review</p> <p>Research Question: What emotion work is involved in palliative care provision for children and families?</p> <p>Key Findings When a nurse feels that he/she has provided appropriate care of a high quality to the best of his/her ability, this can help the nurse deal with the emotion work involved in caring for a dying child. There must be systems in place that enable nurses to feel that others are supportive of them so that they can be there for others.</p>
<p>Author/APA Reference: Morgan, D. (2009). Caring for dying children: assessing the needs of the pediatric palliative care nurse. <i>Pediatric Nursing</i>, 35(2), 86-90.</p> <p>Research Methodology: Discussion article</p> <p>Research Question: What is the history and current status of pediatric palliative care, the experiences of nurses caring for dying children, the impact of providing palliative care on the hospital staff, and possible interventions by the advanced practice nurse to influence more positive patient care and nursing staff job satisfaction and retention?</p> <p>Key Findings The concept of palliative care originally evolved from the hospice philosophy of meeting gaps in care for seriously ill and dying patients. The World Health Organization(WHO) describes palliative care for children as the active total care of the child's body, mind, and spirit, as well as a means of providing support to the family. The literature identifies multiple barriers to good palliative care, including attitudinal, clinical, educational, institutional, regulatory, and financial barriers.</p>
<p>Author/APA Reference: Mutto, E.M., Errázquin, A., Rabhansl, M.M., & Villar, M.J. (2010). Nursing education: the</p>

experience, attitudes, and impact of caring for dying patients by undergraduate Argentinian nursing students. *Journal of Palliative Medicine*, 13(2), 1445-50.

Research Methodology: Mixed-methods study

Sample: 680 undergraduate nursing students

Research Question:

The goals of the study were to establish: (1) undergraduate nursing students' experience and attitude toward dying patients and training in end-of-life issues, (2) students' wishes regarding care of terminally ill patients and their future caring approaches in the relationships with them, and (3) the opinion about the quantity and content of end-of-life care in the curriculum.

Key Findings

It has been shown that nurses with greater exposure to dying patients, more years in practice, more experience and more hours of palliative care education, tend to have more positive attitudes toward death and caring for dying patients than those with less exposure. However, when nurses are exposed to care of the dying without receiving a systematic death education, they suffer a higher incidence of death anxiety and develop negative attitudes toward care of the dying. Also, they limit their involvement in death-related situations, and are more likely to withdraw from the care of the dying.

Author/APA Reference:

Papadatou, D. (1997). Training health professionals in caring for dying children and grieving families. *Death Studies*, 21(6), 575-600.

Research Methodology: Discussion paper, literature review

Key Findings

Death in children is rare, often not talked about; however, there is a need for proper education for people caring for pediatric palliative care patients and their families.

Author/APA Reference:

Rushton, C. H., Reder, E., Hall, B., Comello, K., Sellers, D. E., & Hutton, N. (2006).

Interdisciplinary interventions to improve pediatric palliative care and reduce health care professional suffering. *Journal of Palliative Medicine*, 9(4), 922-933.

Research Methodology: discussion paper about a qualitative study

Sample: 100 participants

Key Findings

Although families reported satisfaction with the care provided for their dying child, health care professionals expressed significant levels of distress. Strategies developed within the hospital included palliative rounds and bereavement debriefings.

Author/APA Reference:

Youngblood, A.Q., Zinkan, J.L., Tofil, N.M., & White, M.L. (2012). Academic Education.

Multidisciplinary simulation in pediatric critical care: The death of a child. *Critical Care Nurse*, 32(3), 55-61.

Research Methodology: Discussion, based on a simulation scenario developed for the multidisciplinary team in an Alabama hospital

Key Findings

Health care providers are trained to care for the living. They may complete their education and enter the workforce without ever experiencing the death of a patient. Simulation of stressful pediatrics medical events such as a death can help prepare the multidisciplinary team for their roles when events do occur in the practice setting.

Appendix C

Timeline for Capstone Project

Dates	Timeline Events
October 2012-February 2013	<ul style="list-style-type: none"> -Develop research question, begin literature search and meet with thesis committee. -Participate in capstone seminars on a monthly basis
March 2013	<ul style="list-style-type: none"> -Complete the first draft of the thesis proposal and send to my primary reviewer (Dr. Sheryl Reimer Kirkham) for feedback -Continue editing and reviewing thesis proposal with primary review (Dr. Sheryl Reimer Kirkham) and secondary reviewer (Dr. Gwen Rempel).
April 2013	<ul style="list-style-type: none"> -Develop an information document for prospective study participants. -Continue literature review and developing the background for the study to add to the final thesis. -Develop interview guide, debrief guide and potential focus group script.
May 2013	<ul style="list-style-type: none"> -The goal is for the final draft to be written and approved by the end of the month. -The Research Ethics Board (REB) forms will be completed by me while my proposal review is occurring and be ready for submission to TWU and CREBA by the end of the month. -Finalize recruitment materials (email and poster). -Contact unit managers on each of the proposed units to obtain authorization to recruit nurses for research study pending REB approval.
June 2013	<ul style="list-style-type: none"> -Submit REB to TWU and CREBA. -After obtaining REB approval begin recruitment of study participants and arrange appointments for interviews.
August-September 2013	<ul style="list-style-type: none"> -Conduct interviews. -Start data analysis after each interview. -Obtain feedback from primary reviewer on initial data analysis for first 1-2 interviews.
November 2013	<ul style="list-style-type: none"> -Complete last two interviews -Continue data analysis, coding, and initial identification of themes and patterns.
December 2013-January	<ul style="list-style-type: none"> -Begin writing chapters of final thesis
February-April 2013	<ul style="list-style-type: none"> -Chapters 1-5 complete with several revisions
May 2014	<ul style="list-style-type: none"> -Completion of Chapter 6, thesis reviewed by Primary and Secondary Reviewers in its entirety, further revisions done. -Submission of complete draft (all chapters) to 3rd reviewer

June 2014	-Thesis defense and revisions of the document for final approval by committee members.
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Appendix D

Questions and Script for Interview

Thank-you so much for your participation in this project. Your participation is important to the project and will benefit other nurses and ultimately, pediatric patients and their families who are receiving palliative care.

1. Can you share your experiences caring for palliative children and their families?

2. When did you decide you wanted to become a pediatric nurse?

Prompt: Did you choose this area knowing that pediatric death would be something you would encounter?

Prompt: Did you receive advice in your undergraduate education about areas to work as a registered nurse?

3. Can you describe some of the challenges you experienced in caring for a palliative child?

Prompt: Were some of these challenges emotional and/or organizational?

Prompt: Did you experience some of the same challenges in caring for the family?

4. What coping strategies did you use when providing care?

Prompt: Were there personal coping strategies you used?

Prompt: Were there coping strategies you used from your education?

Prompt: Were there strategies in place in your workplace to help with coping?

5. What personal supports do novice nurses use when providing end-of-life care to children?

6. How did your practice environment influence your care of the palliative patient and their family?

7. How did your undergraduate education prepare you to provide end-of-life care?

Prompt: Did you have any specific courses/seminars on caring for the dying patient?

Prompt: Was any of your educational preparation focused on pediatric patient death?

8. Do you see yourself continuing to work in this specialty area for an extended period of time?

Prompt: What factors may cause you to seek work in another area?

9. Did you receive any training after graduation to help provide palliative care?

Prompt: Does your workplace provide any additional training?

Prompt: Did you receive mentorship in your practice area when providing palliative care?

Prompt: Have you taken any additional courses or certifications to prepare you to provide end-of-life care?

Prompt: Were there any barriers that prevented you from receiving additional training?

10. Overall, how do you see this experience influencing your work as a nurse?

Appendix E

Demographic Data 1

Demographic Data

Thank-you so much for your participation in this project. Your participation is important to the project and will benefit other nurses and ultimately, pediatric patients and their families who are receiving palliative care.

1. Assigned Participant Identification:
2. Age: <25 years old
 25-35 years old
 35-45 years old
 >45 years old
3. Sex: Male
 Female
4. Pediatric Nursing Experience: Less than 6 months
 6 months to 1 year
 1-2 years
5. Number of children palliative care was provided to : 1
 2
 3 or more

Demographic Data 2

Demographic Data

Thank-you so much for your participation in this project. Your participation is important to the project and will benefit other nurses and ultimately, pediatric patients and their families who are receiving palliative care.

1. Assigned Participant Identification:

2. Age: <25 years old
 25-35 years old
 35-45 years old
 >45 years old

3. Sex: Male
 Female

4. Pediatric Nursing Experience: Less than 6 months
 6 months to 1 year
 1-2 years
 > 2 years

5. Number of children palliative care was provided to : 1
 2
 3 or more

Appendix F

Recruitment Poster 1



Registered Nurses: You are Invited to Participate in a Pediatric Palliative Care Study



I am seeking nurse participants to take part in a research study. The purpose of this study is to explore: The Experiences of Novice Nurses Caring for Palliative Children and Families. This is my Masters of Nursing Thesis project.

If you are a registered nurse who graduated within the last two years of and have directly provided care to a palliative or dying child, you are invited to participate in a 45-minute interview that will take place outside of work hours. Specifically, I hope to learn more about the impact of providing palliative care for the first time on novice nurses, the existing personal and workplace supports that were available to them and the educational preparation they may have had prior to providing palliative care to a child and family.

To volunteer for this study or to request further information please contact:

Elizabeth Cernigoy RN, BScN

403-393-5783

Elizabeth.Cernigoy@mytwu.ca

** A \$5 gift card will be provided as a token of appreciation for your participation in the study*

Ethics ID: 13314 and 13630

This study has received Ethics Approval from: Community Research Ethics Board of Alberta & Trinity Western University

Date of Ethics Approval: Monday, July 29, 2013

Recruitment Poster 2



Registered Nurses: You are Invited to Participate in a Pediatric Palliative Care Study



I am seeking nurse participants to take part in the final round of interviews in a research study. The purpose of this study is to explore: The Experiences of Novice Nurses Caring for Palliative Children and Families. This is my Masters of Nursing Thesis project.

If you are a registered nurse who graduated within the last three years and cared for a palliative or dying child, you are invited to participate in a 45-minute interview that will take place outside of work hours.

To volunteer for this study or to request further information please contact:

Elizabeth Cernigoy RN, BScN

403-393-5783

Elizabeth.Cernigoy@mytwu.ca

** A \$5 gift card will be provided as a token of appreciation for your participation in the study**

Ethics ID: 1314 and 13610

This study has received Ethics Approval from: Community Research Ethics Board of Alberta and Trinity Western University

Date of Ethics Approval: July 29, 2013

Appendix G

Information Letter and Consent

Information Letter and Consent: Nurse Interviews

The Experiences of Novice Nurses Caring for Palliative Children and Families

Principal Investigator: Elizabeth Cernigoy
Master of Science in Nursing (MSN) Student
School of Nursing
Trinity Western University
7600 Glover Road Langley, BC V2Y 1Y1 Canada
Elizabeth.Cernigoy@mytwu.ca 403.393.5783

This research is related to Elizabeth Cernigoy's MSN thesis.

Faculty Advisor for this research study: Dr. Sheryl Reimer-Kirkham
School of Nursing
Trinity Western University
7600 Glover Road Langley, BC V2Y 1Y1 Canada
sheryl.kirkham@twu.ca 604.513.2121 x3239

Purpose

The purpose of this project is to explore the experiences of novice nurses who are caring for palliative children and their families. The nursing care of children requires a family centered approach and expertise about growth and development by the registered nurse. As novice nurses, the care of a child can be overwhelming, not to mention the care of a child who requires end-of-life care. There are few literature examples that focus upon the experience of the novice nurse in caring for children who are dying. This qualitative study will endeavor to explore these experiences and address the current as well as needed supports for novice nurses who choose to practice in this field.

You have been asked to participate in this study as a pediatric nurse working in a setting where pediatric palliative care is provided.

Procedures

In this study, you will be asked to complete a demographic data form and an interview.

The data collection will be performed through conducting face-to-face interviews with 8-12 nurses. Each interview will be conducted by Elizabeth Cernigoy. The interviews will be 45 minutes in length, and conducted with nurses living in the Alberta, outside of work time. The population focus will be novice nurses within two years of graduation. The interviews will be audio-recorded and transcribed by Elizabeth. Although an interview guide has been created, the questions will be open-ended and focus on

your experiences providing palliative care to children and families. You may request to have the audio-recorder turned off at any time during the interview.

If you would like a copy of the transcribed interview you may request for Elizabeth Cernigoy to provide you with a typed, 1-2 page summary. The final report is expected to be completed by December 2013. This will be made available to participants and an invitation will be extended to each nursing unit participating in the study for results to be shared in an interactive format with nursing staff.

Potential Risks for Participant(s)

There is a risk of emotional distress when interviewing novice nurses about their first experiences with pediatric death. If you are distressed, the researcher will use empathy and active listening skills. You will also be provided with the contact information for the Employee Assistance Program at your hospital.

Potential Benefits for Participant(s)/Society

Nurses often benefit from reflecting on their practice, and discussing it with another nurse. The researcher will share the findings at each recruitment site, and this may inform future clinical education and supports for novice nurses. In addition, the findings will inform the local baccalaureate curriculum (where the researcher teaches). The findings of the study will be published in a peer-reviewed journal, and presented at a nursing conference.

Confidentiality

Any information that is obtained in connection with this study and that might identify you, will remain confidential and will only be accessible to the principal investigator (Elizabeth Cernigoy) and her thesis supervisor (Dr. Sheryl Reimer-Kirkham). This information will only be disclosed with your permission. Demographic information, audiotapes, transcribed interviews and notes will be assigned an identification code and pseudonym and will be kept in a locked filing cabinet. Any digital information will be stored in a password-protected computer. These records will be kept for seven years.

Remuneration

A \$5 honorarium gift card will be provided as a token of appreciation for your participation in the study. Should you choose to withdraw from the study, you can keep the gift card.

Contact for Information

If you have any questions or desire further information with respect to this study, you may contact Elizabeth Cernigoy (principal investigator) or Dr. Sheryl Reimer-Kirkham (faculty advisor) using the contact information provided at the beginning of this consent form.

Contact for Concerns

The Community Research Ethics Board of Alberta (CREBA) has granted ethics approval of this project. If you have any complaints or concerns about the ethical conduct of this project, please contact:

Community Research Ethics Board of Alberta (CREBA)

Suite 1500, 10104 - 103 AVE

Edmonton AB, T5J 4A7

Phone: (780) 423-5727 / Toll-free: 1-877-423-5727 / Email: health@albertainnovates.ca

Additionally, if you have any concerns about your treatment or rights as a research participant, you may contact Ms. Sue Funk in the Office of Research, Trinity Western University at 604-513-2142 or sue.funk@twu.ca.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate in any or all parts or withdraw from the study at any time without any consequences or explanation. If you choose to withdraw from this study, please contact either Elizabeth Cernigoy or Dr. Sheryl Reimer-Kirkham (contact information for both persons is provided at the beginning of this consent form).

If you withdraw from the study prior to completion of the initial interview, your data will not be used in the study; if you withdraw anytime after completion of the initial interview, your study data will be included in the study unless you request that it not be used, in which case your data will be removed from the study.

Signature

Your signature below indicates that you have had your questions about the study answered to your satisfaction and have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study and that your responses may be put in anonymous form (using identification codes and pseudonyms) and kept for further use for a period of 7 years after the completion of this study.

Research Participant Signature: _____ Date: _____

Printed Name of the Research Participant signing above:

Appendix H

Code Book

1. Family variations

- a) Knowledge
- b) Values and beliefs
- c) Structure and parenting philosophy
- d) Psychosocial and spiritual needs
- e) Socioeconomic status and culture
- f) Child's demographics
- g) Involvement
- h) Acceptance

2. Resources and responses of the nurse

- a) Helplessness
- b) Awareness
- c) Empathy
- d) Caring
- e) Sadness
- f) Overwhelmed
- g) Angry and frustrated
- h) Relieved
- i) Afraid
- j) Ongoing distress
- k) Avoidance

3. Family centered strategies

- a) Relational practice
- b) Going out of their way to meet all needs
- c) Advocacy
- d) Family participation and collaboration

4. Coping strategies

- a) Personal reflection
- b) Talking with non-colleagues
- c) Discussing with colleagues
- d) Debriefing
- e) Meetings with leadership team
- f) Acknowledgment that nurses are human
- g) Self-care activities

5. Experiences in providing palliative care

- a) Prior career advisement
- b) Mentorship
- c) Personal experiences with palliative care
- d) Comfort with death
- e) Knowing/not knowing what to say
- f) Concern for the families
- g) Reflections on the quality of life for the child and family
- h) Preparedness
- i) Theoretical knowledge of end-of-life care
- j) Understanding of the physical aspects of end-of-life care
- k) Understanding the levels of palliative care
- l) Roles within the interdisciplinary team

6. Barriers/supports to developing pediatric palliative care knowledge

- a) Accessibility of workshops
- b) Information provided in the workplace
- c) Information integrated into undergraduate education
- d) Scheduling
- e) Availability

7. Experiences during undergraduate education

- a) General concepts of family nursing and pediatrics
- b) Clinical experiences with a patient death
- c) Curriculum that included palliative care
- d) Learning nursing skills that relate to end-of-life care
- e) Pediatric-specific palliative care information/experiences

8. Context

- a) Practice area
- b) Unit culture
- c) Societal norms

Appendix I

Complete List of CASN's ETPCs for Palliative and End-of-Life Care

1. Uses requisite relational skills to support decision-making and negotiate modes of palliative and end-of-life care on an ongoing basis.
2. Demonstrates knowledge of grief and bereavement to support others from a cross-cultural perspective.
3. Demonstrates knowledge and skill in holistic, family-centered nursing care of persons at end-of-life who are experiencing pain and other symptoms.
4. Recognizes and responds to the unique end-of-life needs of various populations, such as elders, children, multicultural populations, those with cognitive impairment, language barriers, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and marginalized populations.
5. Applies ethical knowledge skillfully when caring for persons at end-of-life and their families while attending to one's own responses such as moral distress and dilemmas, and successes with end-of-life decision making.
6. Demonstrates the ability to attend to psychosocial and practical issues such as planning for death at home and after death care relevant to the person and the family members.
7. Identifies the full range and continuum of palliative and end-of-life care services, resources and the settings in which they are available, such as home care.
8. Educates and mentors patients and family members on care needs, identifying the need for respite for family members, and safely and appropriately delegating care to other caregivers and care providers.
9. Demonstrates the ability to collaborate effectively to address the patient and family members' priorities within an integrated inter-professional team, including non-professional health care providers, and the patient himself or herself.

Appendix J

Relevant to Project CASN ETPCs

RELATIONAL PRACTICE OF THE NOVICE NURSE
ENTRY TO PRACTICE COMPETENCIES FOR END-OF-LIFE CARE

Caring and Self	Caring and Knowledge	Caring and Context	Caring and Family
<p>Competency 2 Demonstrates knowledge of grief and bereavement to support others from a cross-cultural perspective. Indicators: -2.8 Develops the capacity to be in the presence of patient and family members' suffering.</p> <p>Competency 5 Applies ethical knowledge skillfully when caring for persons at end-of-life and their families while attending to one's own responses such as moral distress and dilemmas, and successes with end-of life decision making. Indicators: 5.6. Recognizes and addresses indicators of moral distress in self and in other team members and seeks appropriate support.</p>	<p>Competency 2 Demonstrates knowledge of grief and bereavement to support others from a cross-cultural perspective. Indicators: -2.3 Uses insights gained from personal experiences of loss, bereavement and grief to provide supportive care to others -2.7 Demonstrates understanding of individual, social, cultural and spiritual variables that affect grief.</p> <p>Competency 3 Demonstrates knowledge and skill in holistic, family-centered nursing care of persons at the end of life who are experiencing pain and other symptoms. Indicators: -3.1 Identifies gaps in knowledge, skills and abilities as a first step in acquiring new knowledge, skills and abilities for PEOLC</p>	<p>Competency 4 Recognizes and responds to the unique end-of-life needs of various populations, such as elders, children, multicultural populations, those with cognitive impairment, language barriers, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and marginalized populations. Indicators: -4.1 Recognizes and responds to the unique needs or backgrounds of patients of varying ethnicities, nationalities, cultures, genders, ages and abilities that may affect their experience of palliative and end-of-life care.</p> <p>Competency 5 Applies ethical knowledge skillfully when caring for persons at end-of-life and their families while attending to one's own responses such as moral distress and dilemmas, and successes with end-of life decision making. Indicators: 5.5. Identifies situations in which personal beliefs, attitudes and values result in limitations in the ability</p>	<p>Competency 1 Uses requisite relational skills to support decision making and negotiate modes of palliative and end-of-life care on an ongoing basis. Indicators: - 1.3 Communicates respectfully, empathetically and compassionately with the PEOL patient and family members. - 1.4 Conserves patient and family dignity by facilitating expression of their feelings, needs, hopes, joys, and concerns in planning for palliative and end-of life care. - 1.11 Creates a safe environment to build patient and family members' trust and facilitate palliative and end-of-life decision making.</p> <p>Competency 3 Demonstrates knowledge and skill in holistic, family-centered nursing care of persons at the end of life who are experiencing pain and other symptoms. -3.12 Practices person-centered PEOLC that incorporates the unique contributions of the particular family and community members in routine care giving while</p>

		<p>to be present and care for the patient and family members, and then collaborates with colleagues to develop strategies to ensure optimal care is provided.</p>	<p>also demonstrating general knowledge of pain and symptom management in the PEOL.</p> <p>Competency 4 Recognizes and responds to the unique end-of-life needs of various populations, such as elders, children, multicultural populations, those with cognitive impairment, language barriers, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and marginalized populations.</p> <p>Indicators:</p> <p>-4.2 Identifies who the family is for the PEOL patient, and responds to family members' unique needs and experiences.</p> <p>-4.3 Adapts communication, assessment and information sharing to the unique needs of the PEOL patient and family members to facilitate informed decision-making, and consults with/refers to appropriate supports such as translated documents and interpreters.</p>
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