COMPANIONING END-OF-LIFE:
NURSES' EXPERIENCES OF CARING FOR THE CHILD WHO IS DYING THROUGH A RELATIONAL ETHICS LENS

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Abstract

Caring for children who are dying requires exploration to understand and validate the meaning of this lived experience for nurses. This study uses a qualitative descriptive method to answer the research question: *What is the meaning of caring for a dying child for nurses within their collective ethical commitments and responsibilities in neonatal and paediatric intensive care units?* Relational ethics was the theoretical framework guiding this study, where semi-structured interviews were conducted with eleven intensive care nurses. Participants were also asked to provide an image that reflected the meaning of providing this care. Findings are presented in five thematic patterns: *a) Careful cultivation of a team approach shapes end-of-life decisions; b) Resilience and affirming of self as nurse arise with alleviating suffering; c) Navigating sustained turmoil; d) Willingly sojourning in loving presence; and, e) Facilitating and valuing a family's role in their experience of end-of-life.*

DEDICATION

This thesis is dedicated to all of the nurses who continue to provide care at the bedside for children who are dying and their families with patience and compassion, especially those who participated in this study and helped to articulate the sheer magnitude of the impact of this caring relationship through their words and images.

It is also dedicated to my late grandfather, who taught me the value of holding hands during scary moments, as he always held my hand during the scariest scenes of our favourite movie. While providing nursing care to many patients and their families at end-of-life, I have witnessed the power of physical touch during life's scariest moments, which goes beyond any words I could have possibly found to say.

Finally, it is also dedicated to my parents and sister, who have taught me the value of working with passion, dedication, and to continue to pursue my dreams. This work would not have been possible without their ongoing support and patience.

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Chapter One: INTRODUCTION

Nurses in paediatric intensive care settings encounter deaths of children proportionately more often than do nurses in other areas of acute care (Canadian Institute for Health Information, 2016, p. 21), and yet we continue to have limited understanding about how these experiences shape and impact these nurses' meaning of caring. In the caring relationship between nurses, the children who are dying, and the families of these children, nurses may encounter a variety of care approaches by different healthcare team members that conflict and add layers of complexity when approaching conversations regarding end-of-life; these conflicts can create fragmented encounters that bring about colliding opinions and ideas (Breuner & Moreno, 2011; Levetown, 2008). The conflicting approaches to end-of-life care can have a mystifying effect on nurses trying to preserve quality of life from a holistic and humanistic approach. In addition to healthcare team members' conflicting approaches to end-of-life care, Breuner and Moreno (2011) describe the challenging conversations encountered by paediatric nurses delivering palliative care as partially due to the added layers of complexity when also caring for parents of children who are sick. For instance, parents can have hopes and dreams, a sense of desperation and complete dedication to meeting their child's needs that extend beyond the healthcare team's curative options (Breuner & Moreno, 2011). At the same time, the joint position statement on palliative care nursing by the Canadian Nurses' Association asserts a different approach from a cure focus and expects that nurses are to be advocates for patients by promoting "dignity, hope, quality of life, and relief of suffering" (Canadian Nurses' Association, Canadian Hospice Palliative Care Association, 2015, p. 2). Though this is a well-defined role expectation for nurses, formal training processes that teach how to provide this care are lacking.

Uniquely, nurses in Canadian neonatal and paediatric intensive care units (here after, NICU and PICU) set out to accomplish holistic goals of palliative care within the context of sterile, highly technologically-advanced patient care units, with patients often too young to voice their own concerns, while at the same time balancing the needs of the families of these children. This approach is largely attributed to the strong emphasis on family-centered care in Canadian paediatric centres (Canadian Patient Safety Institute, 2015) which still have high rates of palliative care being provided in the sterile environment of the intensive care unit. Inevitably, these end-of-life (hereafter, EOL) caring experiences contribute to the formation of philosophical foundations for how nurses care, process the impact of this care, and develop as human beings and nursing professionals. The context of EOL care in Canadian NICUs and PICUs is complex; there exists an interplay between fiscal limitations of public healthcare, variable levels of organizational support, interdisciplinary team communication, nursing education and training, and the input of families. These complexities can lead to challenges with nurses' abilities to care for dying children and their families in a way that is consistent with their values and beliefs, and potentially leading to moral distress. The Canadian Nurses Association (CNA) defined moral distress in their 2002 *Code of Ethics for Registered Nurses* as:

> *Situations in which nurses cannot fulfil their ethical obligations and commitments (i.e. their moral agency), or they fail to pursue what they believe to be the right course of action, or fail to live up to their own expectation of ethical practice, for one or more of the following reasons: error in judgement, insufficient personal resolve or other circumstances truly beyond their control (Webster & Baylis, 2000). They may feel guilt, concern or a distaste as a result.* (CNA, 2002, p. 6)

As the death of a child can be considered beyond control of nurses, moral distress and vulnerability are inevitably occupational hazards when providing care in this healthcare context. As such, it is imperative that we begin to understand not only how nurses provide care *for* children who are dying, but how nurses care *with* children and their families facing death in a world reality layered beyond linear approaches to care (Bergum & Dossetor, 2005), and how this relational approach can lay a foundation for nurses' own philosophy of caring. This research may also enhance understanding about nursing burnout and work-related stress. In a 2003 publication, the CNA identified the physical and emotional toll of moral distress experienced by nurses resulting in nurses missing the most of time at work due to sickness and disability out of any other occupational group (p. 2)

As a paediatric critical care nurse providing care at the bedside for many children at EOL, and given the gap in the literature and the ethical implications of this lived experience, I was interested in engaging nurses in an exploration of the meaning of caring for children at EOL using a relational ethics lens (Bergum & Dossetor, 2005). I wanted to also add an arts-based component where participants were invited to capture the essence of their experience through an image or photograph. Through creative expression, it may be possible to derive a stronger sense of meaning of the experience that goes beyond spoken words. The involvement of arts in this qualitative research is a significant effort to be fully embodied in the research. It also supports the tenet of embodiment in the relational ethics conceptual framework, which allows the researcher to consider the context of the participants' perceptions and reactions of the phenomenon being described (Barbour, 2011). Furthermore, representing the meaning of the phenomenon through artistic expression highlights the relationship of this experiencing of nurses caring with the world—a connection between the physical and emotional aspects of this experience (Barbour, 2011). This is eloquently described by Karen Barbour in her book *Dancing Across the Stage,* which highlights the value of being fully immersed in arts-based research to reflect embodied knowledge. This exploration of nurses' experience of caring for children at

EOL may also provide valuable insight for the nursing profession to identify supports for quality paediatric EOL care.

Chapter Two: LITERATURE REVIEW

In chapter two, the literature search strategies for this study are presented along with the literature review and identified gaps in current research.

Search Strategies for Literature Review

The search strategy for the literature review was conducted in two phases and focused on EOL care in paediatrics and then on relational ethics. Both phases of the search were conducted using CINAHL, Google Scholar and Medline (Ovid and PubMed) databases. Studies pertaining to EOL care and relational ethics were limited to those between the years 2001 and 2018, with the exception of one EOL study in 1998. For the relational ethics search, the review also included textbook resources. Search terms for the online database were developed from practice knowledge and those most often cited in the literature. For the review about EOL, key words included “end-of-life or palliative”; “paediatric or child”; “nursing or nurse”, with the “AND” and “OR” Boolean operators to further enhance search results. Hand-searching of the journal articles’ references was done to target relevant studies that expanded further on the ideas highlighted by the key words. In addition to formal literature searches, I attended two conferences focusing on palliative care, including the *2018 International Perinatal Bereavement Conference* in St. Louis, Missouri, and the *2018 Bereavement Ontario Network Annual Conference* in Orillia, Ontario. I took notes during workshops hosted by nurses with expertise in neonatal and paediatric palliative care, and attended plenary sessions hosted by nurse researchers. This immersion enabled me to identify other study examples and researchers who had expertise in the areas of perinatal and paediatric bereavement, the approach of relational caring, and the nursing caring experience during EOL.

For the second part of the review focused on relational ethics, key words included "relational ethics"; "nursing care"; and "relational practice". Inclusion criteria included articles published in the last ten years with abstracts and topics focused on the concept of EOL care from the perspective of nurses, EOL care, paediatric nursing, and critical care nursing. Key word searches were modified based on emerging ideas that appeared in the literature. Emerging themes in the literature included: *the perspective of parents in EOL care, good professional communication in EOL care, resources for professional support, challenges to providing EOL care in critical care units* and *challenges to providing EOL care in paediatrics*. I also used the textbook resource by Bergum and Dossetor (2005), *Relational Ethics: The Full Meaning of Respect.*

Findings from the Literature Review

Gaps in Current Nursing Literature Regarding Care at End-of-Life

Most research about nursing care at EOL focuses on the adult population (Bloomer, Moss & Cross, 2011; Hebert, Moore & Rooney, 2011; Adams, Bailey Jr., Anderson, & Docherty, 2011). Seven studies pertaining to EOL care with the adult patient population were examined for this study. Existing research yields insight into the stress and burnout amongst nurses caring for adult patients at EOL (Ranse et al., 2012). It was also found that burnout is alleviated by providing nurses resources during palliative care, good communication between families and healthcare professionals, and debriefing in situations where the patient died (Jones & FitzGerald, 1998). Ranse et al (2012) and Jones and FitzGerald (1998) focused on nurses providing EOL care for adults in intensive care. One study focused on the behavioural aspects of nurses in adult intensive care at EOL, with an emphasis on how they defined quality indicators for palliative care in the ICU environment (Clarke et al, 2003). Though these studies show valuable insight into the importance of practicing good communication and using clear and easily understood language to broach the subject of death with families, the perspectives studied were those solely of nurses with clinical expertise, which may leave gaps in understanding the caring experience for nurses of varying degrees of expertise. These studies focused on quality indicators of good EOL care, which outline behavioural aspects of care and resource accessibility. Though helpful to inform practice, these results based on quality indicators of care were primarily centred on patient outcomes and did not explore the meaning of providing EOL care for nurses, or how this care might affect nurses. While these studies provided foundational understanding of the complexity of care within this environment, there is a differing dynamic in a paediatric setting, where parents weigh in heavily on the decision-making process.

Of seven studies exploring EOL during paediatric care, five studies focused on the paediatric nurse perspective during EOL. Two of these paediatric studies focused primarily on oncological patients and the effects of EOL care on parents (Mulyowa, 2017; Mullen, Reynolds, Larson, 2015). These studies identified that nurses are important in providing good quality EOL care, and that programs supporting EOL care are effective in guiding this provision of care, and allowing families of children who are dying from cancer to cope. A third paediatric study in 2018 by Santoro and Bennett went beyond the discovery of the importance of the nursing role in EOL, and conducted a review of the literature that highlighted the significant lack of effective shared-decision making in paediatric EOL, one of the key aspects of employing a relational ethics caring philosophy during EOL. The researchers identified two aspects of paediatric EOL care that might correlate with this lack of a strong shared decision-making model being employed in an effective manner in paediatrics: the limitations of "age and cognitive reasoning perspective" (Santoro & Bennett, 2018, p. 42). Essentially, children may not have the wherewithal to both vocalize and advocate for themselves with decision making. Further to this, there is a lack of research about this shared caring perspective during *paediatric* EOL care in general, outside of an oncology context, which was the focus of most of the literature cited in Santoro and Bennet's review.

Conflicts within the Landscape of Nursing Care at End-of-Life

As nurses provide support for both the child and the family at the bedside, the families of children in hospital at EOL are continually faced with difficult decisions regarding their input in directing goals of care. As a matter of course then, nurses exposed to frequent patient deaths experience high rates of moral distress and burnout, as evidenced in the literature about both adult and child deaths in hospital (Jones & FitzGerald, 1998; Ranse, Yates & Coyer, 2012; Stayer & Lockhart, 2016). As Browning (2013) points out, the potential for moral distress and burnout increases as aggressive modes of treatment are explored for these patients (p. 144). With the influence of medical technology in intensive care settings, aggressive modes of treatment can be sought as parents seek out a curative means as a last resort. A recent example heavily publicized in the media is the case of Charlie Gard, whose parents sought medical help for a mitochondrial DNA deletion syndrome, which does not have any definitive treatment at this time (Triggle, 2017). Without a definitive treatment, Charlie spent months of his life in an intensive care unit supported by highly technically advanced equipment to prolong his life, while parents fought the terminal prognosis given to them by healthcare practitioners, trying to find a cure for their son. This desperation to choose a curative path instead of a palliative path for a child is one not uncommon for parents of children who are dying in an intensive care unit. As traditional models of medical care still dominate intensive care settings, conflict between curative and comfort measures for dying children foster tensions and create ethical dilemmas regarding how nurses are expected to care for children who are dying (Ranse et al, 2012, p. 5).

Boyd, Merkh, Rutledge and Randall (2011) elaborate on how the frequent and constant care nurses provide for patients at EOL place them in ideal positions to discuss issues surrounding EOL processes with families and patients. In a 2018 study, Ali explored how experienced nurses often carry out tasks, caring interactions and interpretations on autopilot. Alternatively, novice nurses may be so preoccupied with attempting to understand the vast array of procedures, tasks and new skills in intensive care settings, that they may only be half engaged in listening to patients (Ali, 2018). Levetown (2008) stresses that poor communication amongst the healthcare team and between the healthcare team and families can cause sentiments of "anger, regret, and result in compromised outcomes for the patient and family….and for the practitioner" (p. e1441).

The Impact of Providing End-of-Life Care

Jonas-Simpson, McMahon, Watson and Andrews (2010) emphasized that though caring for families of babies who are dying is challenging, it holds value for nurses. Additionally, this study cited the importance of having supportive colleagues through this caring experience. Limbo and Kobler (2010) reviewed literature specific to supporting nurses who care for families experiencing early infant loss. According to these authors, the use of relationship-based care is required in order for outcomes to be significant to those families faced with grief associated with the death of their child (Limbo & Kobler). The relationship with families is critical to understanding how to best support grieving families within the context of their needs and values. According to Limbo and Kobler, "nurses must find meaningful ways of self-care as a way of reinvesting in future relationships with other grieving families" (p. 316).

A study by Bloomer, O’Connor, Copnell and Endacott, (2015) examined neonatal and paediatric intensive care units that provide care for children and neonates at EOL. This study focused on the logistics of preparation for and provision of care at EOL, including a component that involved the nursing perspective on this process. Emphasis was put on understanding that good communication between nurses and families might facilitate shorter, more effective grieving for parents following death (Bloomer et al., 2015, p. 88). Bloomer et al.’s (2015) study identified attention to biomedical language as paramount to facilitating preparation of parents for the death of a child. Another paediatric-focused, meta-synthesis study from the perspective of nurses providing EOL care identified central themes existing in the research on palliative care, including “journey to death”, “a lifelong burden”, “challenges to delivering care”, “maintaining self”, and “crossing boundaries” (Stayer & Lockhart, 2016). Stressful and burdensome undertones remain embedded in these themes, suggesting the need for further examination of the lived experiences of nurses in these situations. Significantly, Stayer and Lockhart (2016) suggest that future research should embark on a search for a richer understanding of what is needed as a platform to support the grief and coping of nurses on an individual level, and to help alleviate the toll of this stress (p. 355). In their study of NICU nurses’ experience caring during EOL for patients and their families, Ives-Baine et al. (2013) highlight the importance of “conscious engagement” (p. 301) as an important part of establishing a therapeutic relationship during EOL care. The conceptualization of this relationship by Ives-Baine et al. (2013) was identified as a pattern woven from “conscious engagement, reflection and reframing and dialogue” (p. 300). With this foundation in exploring the experience of caring during EOL through engagement, the current study looks to explore how nurses can be in a therapeutic relationship with patients, whilst validating their own grief, and enabling validation through this nursing caring experience.

To go beyond a meta-synthesis study and derive personal testaments about what this experience of caring for a dying child means to nurses in the context of their environment, the degree of uncertainty experienced during EOL care, the engagement between healthcare team and the nurses with the families and the patients who are dying, the reciprocal respect between patients' families and nurses, and in the fully embodied awareness that incorporates arts-based expression is to begin to address this void in the current understanding the experiences of nursing who provide paediatric EOL care. Thus, this current study seeks to build on the research conducted to date, to fill the gap by exploring the meaning of ICU nurses' experiences caring for the dying child and families, from a relational ethics theoretical perspective, while incorporating the arts for deeper reflection and expression of lived experience.

Chapter Three: CONCEPTUAL FRAMEWORK

Bergum and Dossetor's (2005) relational ethics is the conceptual framework guiding this study. Relational ethics focuses on knowing how to act and appropriately approach situations within the context of a relationship with a concrete other (Pollard, 2015). This framework stems from the work of a nurse and physician team from the University of Alberta, in Canada, Vangie Bergum and Dr. John Dossetor. Bergum and Dossetor's Relational Ethic Project evaluated how daily care decisions were made within the ethical commitments founded between health care providers, their patients and the families of these patients (Upasen, 2017, p. 3). This work gave recognition to the concept that, as health care providers, care decisions are being made within the context of a relationship. This conceptual framework considers the relationships between nurses and paediatric patients with their families, and examines the growth, healing and caring effects of this interdependent relationship. Nurses are understood to provide care to patients with the family-centered care that fosters a *care with* instead of *care for* approach (Pollard, 2015). Nurses providing care in the paediatric setting recognize their patients as individuals who have an important role in their health care decisions, especially regarding EOL. Central to this study and the exploration of lived experiences of nurses caring for children who are dying are the tenets of relational ethics: "mutual respect" (Bergum & Dossetor, 2005, p. 215); "engagement" (p. 213); "embodiment" (p. 212); "interdependent environment" (p. 218) and "uncertainty" (Pollard, 2015, p. 367).

Mutual respect is the reciprocal act on the part of patients sharing vulnerabilities, and healthcare practitioners honouring these vulnerabilities (Bergum & Dossetor, 2005, p. 215). As such, patients learn to be open and willing to respect these professionals, and, professionals learn to respect the patients and their intimate and vulnerable emotions and experiences (p. 215).

Engagement is defined as the acknowledgement that people naturally establish relationships, in essence, a reciprocal commitment with other individuals, wherein each individual must be accountable for her/his actions and decisions (p. 213). In the context of health care, this engagement refers to the importance of understanding the communal approach to decision-making, that is in stark contrasts to the more traditional top-down model of health care professional to patient (p. 213). Engagement is modeled after Raymond Duff's (1987) "close-up ethics" that invites healthcare practitioners to reject the traditionally-held power dynamic, with enforcement of control over patients, and instead is meant to understand the value systems and cultural beliefs of patients to drive care decisions (p. 212). According to Bergum and Dossetor (2005), the tenet of *embodied space* refers to the relational space bridging opposing worlds of rationality and spirituality, so that feelings and emotions can be valued in a more personal landscape that acknowledges the reality of others (pp. 153-155). The *environment* tenet of relational ethics is that of the healthcare environment (p. 218). In Canada, this involves the landscape of universal healthcare, which includes both limitations and advantages in regard to access to resources including pharmaceuticals. Bergum and Dossetor point to how this publicly-funded system breeds a common sense of concern for fellow beings in the context of ethics. The tenet *uncertainty* involves the choice to understand what might be best for the patient amidst differing perspectives, beliefs and competing frameworks (McPherson et al, 2004). The term uncertainty emphasizes that humility is necessary to confront situations involving ambiguity in ethical decisions (2005). With the central tenets of mutual respect, engagement, embodiment, environment and uncertainty, nursing care is guided to "no longer be interpreted as caring for the patient. Nurses must care *with* the patient," (Pollard, 2015, p. 367), and focus on the development of a relationship with a "concrete other" (Bergum & Dossetor, 2005; Pollard, 2015). In the development of this relationship, nurses may also begin to anticipate and perceive needs and obstacles for the provision of good EOL care (Kirkoff & Beckstrand, 2000). As researcher, I was informed by relational ethics throughout the research processes including the interpretative process, so that I could understand the phenomenon of this caring relationship, while being aware of my own critical care background in nursing, and within the context of each participant's environment, personal experiences and values expressed during interviews.

Research Question

The research question guiding this study is: *What is the meaning of caring for a dying child for nurses within their collective ethical commitments and responsibilities in neonatal and paediatric intensive care units?*

Chapter Four: METHODOLOGY

A descriptive exploratory method outlined by Parse (2001) was used to answer the research question. Parse (2001) recommends the descriptive exploratory method to explore phenomena about lived experience, and in this study, nurses' experiences of caring for dying children and their families at EOL. The descriptive exploratory method enables researchers to delve into the layers of experience beneath academic and professional discussion surrounding the phenomena to uncover conceptual ideas, perspectives and meanings beyond the concrete information obtained from a more positivist approach. Additionally, the medium of visual expression through a photograph can be used as a tool for a deepened expression of the participants' inner emotions (Radley, Hodgetts & Cullen, 2005). The use of the arts as creative outlets enables a dynamic approach to understand the view of the participant in trying to convey context of an experience (Radley et al., 2005). The arts-based component in this study was used to invite deeper reflection and understanding of the lived experience as well as creatively represent participants' experiences. Given the descriptive exploratory research method is not grounded in a particular theoretical framework, researchers are free to choose one to guide their study (Parse, 2001). Thus, the research objectives were developed based on the themes of Bergum and Dossetors' (2005) relational ethics theoretical framework. Subsequently interview questions were developed for each objective (see Table 1).

Participant Recruitment and Ethical Considerations

Purposive sampling was used in this study. This type of sampling allows for the most information-rich sampling to occur, with those selected having sufficient knowledge and experience in EOL care of children in a critical care environment (Palinkas et al, 2015). The inclusion criteria were nurses who worked in Canadian paediatric or neonatal intensive care settings, who had experience caring for a dying child. Exclusion criteria were any nurses who did not have experience in working in one of these settings, or those who did work in these settings but did not have experience caring for a dying child. No limits were placed on the years of experience, age, province or gender of these participants, as these would potentially restrict the range of perspectives and depth of understanding of this phenomenon.

Eleven nurses volunteered to participate in this study. All participants were Canadian, nine were female and one was male. They included four nurses in Ontario working in paediatric intensive care units, three nurses in Alberta working in neonatal intensive care units, and three nurses work in paediatric intensive care units in British Columbia. The four nurses from Ontario were interviewed in person, and the six nurses from Alberta and British Columbia were interviewed via Webinar. One female nurse working in both paediatric and neonatal intensive care units from British Columbia was unable to participate in an interview but participated in this study by providing a photograph along with a written description of the meaning of her caring experience at EOL. Participants were recruited through use of a public research Facebook page (Appendix A) specific to this study, and through purposive sampling, with a snowballing component, where selected participants in the study were asked to suggest other participants appropriate for the study (Groenewald, 2004). Ten participants interviewed achieved data saturation, defined by Bowen (2008) as the point at which enough data are obtained to answer the research question and when repetition is occurring in the data (Parse, 2001).

Once REB approval was received from York University, informed consent was obtained for participants by the principal investigator, Karlie DeAngelis, a Registered Nurse in candidacy for the Master of Science in Nursing degree with York University (Appendix B). Informed consent included information about the voluntary nature of participation, the purpose of the research, the right to ask the researcher to stop the interview at any time, and the right to confidentiality. The only risk of participating was the emotional vulnerability to which nurses were exposed during interviews, which was mitigated by reminding participants that they could stop at any time without any repercussions. In fact, participants stated that they found the interview to be very therapeutic rather than upsetting.

Data Gathering

Data gathering involved an approximately 60-minute video-recorded, semi-structured interview in person or via Skype webinar for out-of-province participants. Interview questions were developed for each of the research objectives and can be found in Table 1.

Table 1

Study Objectives with Interview Questions

Objective 1: To understand how nurses experience mutual respect. *What is it like when children and parents share deeply vulnerable thoughts, aspirations and frustrations? How, if at all, does this sharing impact mutual respect in your relationship with children and their families? Do you feel mutual respect from other members of the interprofessional team? Please explain why or why not.*
Objective 2: To understand how nurses experience engagement with paediatric patients, their families, and the interprofessional care team *Please describe one experience of engagement with a dying child and his/her family: What did this experience mean for you as a nurse? What is your experience with the interprofessional team in the decision-making process during end-of-life?*
Objective 3: To understand how embodiment with patients and their families is practiced by nurses in the context of end-of-life care. *Based on your previous knowledge and experiences with children dying, how do you provide care in a way that brings your whole being to the relationship? Do you ever have moments that you just know something, or have a gut feeling/intuition/ "Spidey senses" without your patients verbalizing what this "something" is? Tell me about this experience.*
Objective 4: To understand the influence of the environment on paediatric EOL nursing care. *In the context of your care environment, how are decisions for critically ill children who are dying made? What is it like for you to provide nursing care for children who are dying and their families in this environment?*

Objective 5: To understand the nursing experience of providing care in a context of uncertainty with respect to decision-making outcomes at end-of-life for children.
Please describe how an experience caring for a dying child brought about differing ideas of what should be done. How do you provide care in a context where there is uncertainty and you do not necessarily agree with decisions that have been made about the child's end-of-life care?

Interviews were transcribed verbatim for in-depth analysis and exploration of themes. Interviews ranged from 46 minutes in length to 1 hour and 35 minutes in length. Transcription of the interviews yielded a total of 146 pages of data that were transcribed by the principal investigator. Participants also contributed one image depicting a visual artistic expression of what their experience of caring for a dying child signified to them, sent by email. Participants were advised to not include confidentiality-breaching materials, including names and demographic information of patients, or pictures including patients or family members. Demographic data collected for nurse participants in this study included hospital area in which they practice and province in which they practice (Table 2).

Table 2
Demographic Data of Participants

Participant Number	Province	Gender	Area of Practice
1	Ontario	Female	Paediatric Cardiac Critical Care Unit
2	Ontario	Female	Paediatric Cardiac Critical Care Unit
3	Ontario	Male	Paediatric Cardiac Critical Care Unit
4	Ontario	Female	Paediatric Cardiac Critical Care Unit
5	Alberta	Female	Neonatal Intensive Care Unit
6	Alberta	Female	Neonatal Intensive Care Unit
7	Alberta	Female	Neonatal Intensive Care Unit
8	British Columbia	Female	Paediatric Intensive Care Unit
9	British Columbia	Female	Paediatric Intensive Care Unit
10	British Columbia	Female	Paediatric Intensive Care Unit
11- submitted image with written description only	British Columbia	Female	Paediatric Intensive Care Unit AND Neonatal Intensive Care Unit

Data Analysis

The interview transcripts were analyzed following the data gathering process. Braun and Clarke's (2006) thematic analysis was used to name and categorize themes and subthemes in participant responses. According to Vaismoradi, Turunen and Bondas (2013), the significance of choosing thematic analysis in qualitative descriptive studies is in its emphasis on context to derive meaning of themes, which is consistent with the qualitative descriptive method outlined by Parse (2001). Braun and Clarke's (2006) analysis method is used to name themes not by frequency of occurrences in narratives, rather by the patterns which emerge from the detailed integration and analysis of the data. Written and verbal descriptions of the submitted visual images and photographs reflecting participants' caring experiences at EOL were also included in the overall analysis of codes to derive thematic patterns.

The thematic analysis process is non-linear and requires careful consideration of whether themes are directly relatable and significant to the research question at hand (Braun & Clarke, 2006). The transcription was first read in its entirety by the researcher. Following this initial reading, the data were analyzed, first, by each objective across all ten interviews, and codes were named that represented underlying essences. Codes were written down and analyzed for sub-theme emergence across each of the five objectives. The emerging codes and subthemes were then read as a cohesive group to understand if there were threads that repeated throughout all five objectives. Once these threads exposed overarching subtheme developments, the subthemes were further analyzed as a group for thematic patterns, which Braun and Clarke (2006) characterize in the third step of their thematic analysis as the organization into broader themes instead of patterns. The original themes were presented with data to my thesis committee members and in describing the nuanced meaning of each theme, I was able to finalize the naming of themes.

Validity, Credibility and Transferability

As the key focus of this study is an interpretation of the meaning of experiences of nurses caring for children at EOL, the findings are not meant to be widely generalizable to nurses, rather the findings may be transferrable to other settings within Canadian neonatal and paediatric ICUs, given that participants in this study spanned three provinces. The researcher also engaged in reflexivity, as a means of understanding influence and position as it relates to the phenomenon being examined, to add credibility to the findings of this qualitative inquiry (Streubert & Carpenter, 2011, p. 32). As a paediatric critical care nurse, I have personally experienced caring for children who are dying in the intensive care setting many times, and engaged in self-reflection throughout the study, with careful attention to the interpretation of codes, sub-themes and thematic patterns determined through the analysis of the data. Though reflexivity described by Streubert and Carpenter focuses on the acknowledgment and intended separation of one's own viewpoints from the data being analyzed, having experienced the lived phenomenon described by participants also allowed me a deep, empathic understanding of what nurses discussed. In this way, I was able to enter into the space of the interview with a self-awareness that focused on asking questions related to what was being said, and not based on my own bias based on my experiences (Streubert & Carpenter, 2011). The inclusion of an arts-based approach in this study further enhanced the internal validity of the findings, as the visual images, along with their descriptions, were enriched by the descriptive vividness of the findings. Descriptive vividness in qualitative methodology, as explained by Nancy Burns (1989), is enhanced when the reader is given clear expressions of the lived experience and in this study, this is enhanced even further with the inclusion of the arts as creative expressions of lived experience.

Chapter Five: FINDINGS

Themes are represented in five thematic patterns. Thematic pattern is the term used to identify the findings in this study. Jonas-Simpson, Pilkington, MacDonald and McMahon, (2013), defined thematic patterns as “interconnected patterns woven throughout the data like a tapestry” (p. 4). Referring to findings as thematic patterns is consistent with the conceptual framework of relational ethics, as there is an understanding of the balanced interplay between individuals who derive meaning with consideration for context and connection. The thematic patterns identified were: *1) Careful cultivation of a team approach shapes end-of-life decisions; 2) Resilience and affirming of self as nurse arise with alleviating suffering; 3) Navigating sustained turmoil; 4) Willingly sojourning in loving presence;* and, *5) Facilitating and valuing the family’s role in their experience of EOL* (see Appendix C and Table 3).

Imagery of End-of-Life Nursing Care

Visual images including photographs, with the corresponding narratives from each participant are incorporated in the findings of this study. The corresponding codes identified in the visual images were derived, analyzed and ultimately were included within their respective thematic pattern. The images were submitted by eight of the eleven nurses who participated in this study. Participants were asked to share a visual representation of what an EOL caring experience means to them when a child is dying. The images reflected underlying thematic patterns that were consistent with the nurses’ verbal expressions from their interviews. The sub-themes of “protect”, “comfort”, “create connection”, and the “celebration of life” are all reflected with greater depth through the participants’ chosen images. The nurses’ descriptions of the meanings of each of these images can be found below the images, throughout the presentation of the thematic patterns as well as in Appendix D.

Thematic Patterns

Careful Cultivation of a Team Approach Shapes End-of-Life Decisions

The first thematic pattern reflects how nurses attributed great importance to their role in carefully cultivating the interdisciplinary team approach during EOL; understanding that this care approach shapes the decisions made by families of children who are dying. This theme reflects the sub-themes: *importance of nurses helping families navigate the healthcare system*, *nursing help in the development of team cohesion*, and the *value of language in the provision of care by nurses and members of the healthcare team*. These are represented in Figure 1 below:

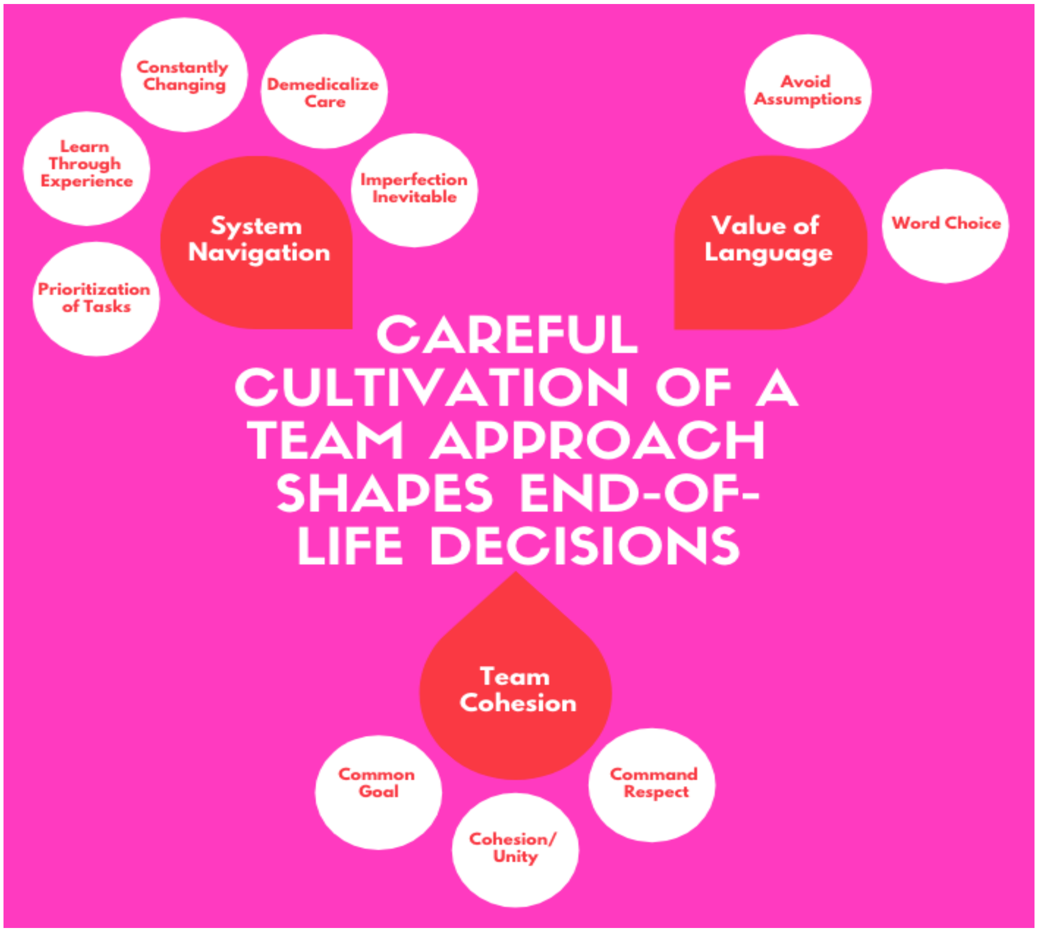

Figure 1: Thematic Pattern 1, Careful Cultivation of a Team Approach Shapes End-of-Life Decisions

Nurses were asked about their experiences engaging with the interdisciplinary team members in terms of decision-making involvement, feelings of mutual respect, and how conflicting ideas of what should be done for the patient are addressed in their area of practice. In some instances, where nurses spoke of their role in engaging at end-of-life, they spoke about how their position at the bedside enabled them insight into vulnerabilities expressed by families that enhanced understanding of the family's wishes not otherwise known by the medical team. During these intimate moments, nurses compassionately listened to the emotions, worries and frustrations of families. One participant's statement exemplifies this in the following quote:

> *I mean we do really have a fantastic social worker, and a fantastic palliative care team... But sometimes they're not there at 3 o'clock in the morning. Sometimes when these things happen we have to call them in from home and those sorts of things. You know, we don't have social work coverage 24 hours a day. And so, if those people aren't there, you just have to sort of step in as much as you can.*

When ideas regarding decision-making varied even within a family, nurses found themselves at the crux of helping these families navigate conflicting emotions. One participant stated:

> *You know sometimes parents disclose feelings to us as nurses, when they're alone with their child, or you know, when their spouse isn't there, or when the grandparents aren't there. Because sometimes there's a really big difference in the way different families are thinking about approaching the situation. And sometimes, you know, even right now we have a situation where one parent is pretty much ready to let go, and the other parent is absolutely insistent that we're not going to let go. And so, I feel like they… you know I think they might express that they know, they understand, they can see it happen, but their spouse isn't really there yet. And so, I think just [families feel] safe in terms of they feel like a confidence in terms of, we're not going to um…you know sort of maybe like outright share their feelings. But hopefully we're going to maybe advocate for them. Find their voice with other families to be able to get how they feel out there.*

Nurses described their experiences with the interdisciplinary team as being one that required "avoiding assumptions" by the interdisciplinary team about what families may want. There was also a need to "command respect" from the team if there were noticeable differences in the medical team's approach to how the nurses felt their patient's status was evolving, and if the approach conflicted with the family's desires. When there were noticeable conflicting emotions and sentiments being expressed by the medical team, which often focused on a curative approach, nurses were left feeling frustrated that these attempts to persevere in a curing mode were futile. Nurses also noted that families take longer to accept the ultimate outcome of the patient's impending death when a curative approach is prolonged. Nurses felt their role was to help "de-medicalize care", to accept that "imperfection is inevitable" with regards to the caring relationship, and that their team engagement and approach to EOL with families was "constantly changing" as they were "learning from experience". One nurse's emotional description of the image she submitted depicts a cove, symbolic of her responsibility to protect patients during EOL, shown in Figure 2.

Figure 2: The Cove

Submitted by: Registered Nurse, Neonatal Intensive Care Unit

Source: Garaev, Y. Retrieved from: https://unsplash.com/photos/kNIDFv5ee_g

"This is a picture of a cove. It's a picture of a body of water and some mountains...kind of a nature scape. [The name is significant to me] as a nurse...and how I view us as comforters and protectors, particularly in such an intimate space. It's also calming for me to think about the aspect of nature...I wanted to use a picture my sister took, but I ended up going with a free stock photo instead of going with my sister's [photo].

The participants noted that families were very impressionable in their decision-making based on the language and word choice of those providing care, citing that asking about specific emotions of the family, for example, the question, “what are you feeling at this moment?”, did more to yield how families were shaping their decisions regarding EOL than merely asking, “how are you doing?”. Participants also spoke of positive experiences when they felt cohesion and unity with the team at large, with the common goal of wanting the best for the patient. The cohesion that comes with working toward a common goal by all involved in care was noted by several participants to be helpful to families when it came to accept the ultimate outcome of death. This idea is noted in this statement from one participant:

> *I think everyone was very unified and everyone was up to date and involved in the situation pretty much starting from the initial code, right until the very end. Everyone saw all the efforts that we did as a team, and I think at the end, everyone could accept all of the decisions for what it was.*

Resilience and Affirming of Self as Nurse Arise with Alleviating Suffering

The second thematic pattern reflects the gravity of the suffering experienced by both the families and patients for whom they cared, and nurses as caregivers. What sustained these participants in providing this care was the ability to alleviate suffering by: finding moments to “celebrate life” with the patients and families, being able to “fulfill wishes” of the patients and families (no matter how small), and “making their last breaths count”. Part of this feeling of alleviating suffering was expressed by one NICU nurse who describes how she is able to bring normalcy into the relationship of parents of newborn infants who are dying:

> *I think that one of the most important things...if parents start to share things that are really vulnerable, scary for them etcetera... then I really do try to focus them on the welcoming piece first. In that, you know, it’s important for them to bathe their baby, and put a diaper on them for the first and probably last time and put clothing on them. And do important things like read them a book or sing them a song, otherwise if things had gone differently. And do all of those things as a welcoming instead of a farewell.*

Participants indicated a need to "carry inner joy" despite their own grief. They were able to find meaning in their work by persevering with their efforts to comfort and alleviate the suffering of those children and families in their care. The concepts represented with this theme are shown in the Figure 3:

Figure 3: Thematic Pattern 2, Resilience and Affirming of Self as Nurse Arise with Alleviating Suffering

The following quote describes how the intention to alleviate suffering and connect with a patient and his/her family was foundational to; shaping their experience and facilitating both the nurses' and families' growth:

> *And, you know, they are part of my life. Not in the same way that I'm grieving them in the same way that their parents are, sure. I do let them be kind of…without sounding too weird or hippy or airy fairy here… I do let them be part of my life too. I feel like that way it allows me to find celebration and joy in the ways that they touched my life, instead of feeling so focused on the grief piece. Or how terribly tragic it is that this happened.*

These sentiments of being impacted by the experience, and at the same time finding the motivation to continue as a nurse were characterized as resilience and a sense of validation. Figure 4 is a strong example of acknowledging the resilience expressed by one nurse participant in this study, through her description of a tattoo depicting the gladiolus flower:

Figure 4: Gladiolus Flower Tattoo

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

"The gladiolus flower, also known as the sword lily, represents strong character, remembrance and focus. The flower of the warrior signifies commemoration, devotion, and loyalty. It reminds me of the tough battles I've faced as a cardiac nurse and that something beautiful can grow from every beating heart through every challenge."

From these described experiences and images, the pattern that emerged related to the phenomenon at hand was that of resilience and the affirmation of both personal and professional self through the ability to alleviate patient and family suffering.

Navigating Sustained Turmoil

The third thematic pattern, *navigating sustained turmoil*, became apparent throughout each interview. Nurses caring for children during EOL were subjected to, and experiencing the effects of "turbulent emotions". Several of the participants in this study cried during their interviews. The impact of this caring experience was noticed through this expression of outward grief of the caregiver, and also through expressed sentiments of “feeling undervalued”, a “lack of control”, and “raw emotions”. This theme, with corresponding subthemes and concepts, are depicted in Figure 5:

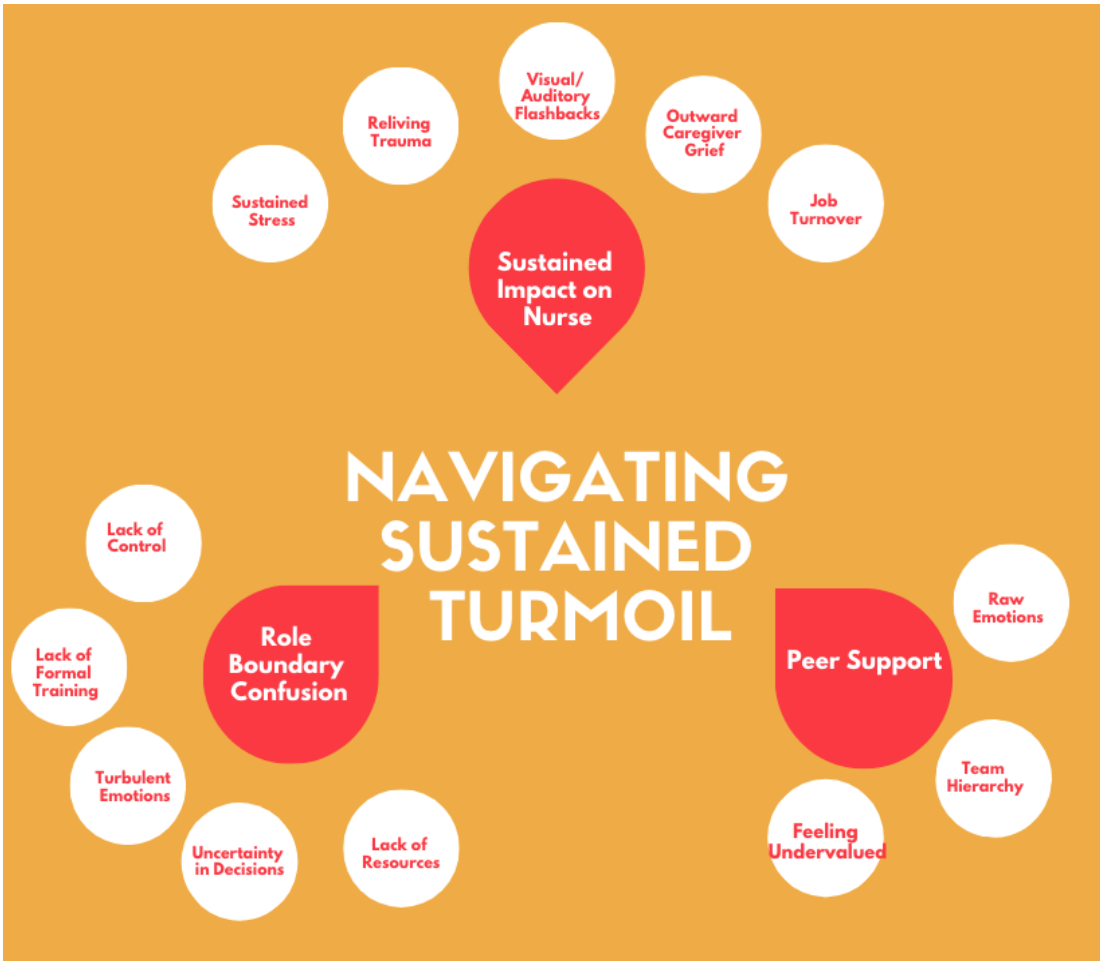

Figure 5: Thematic Pattern 3, Navigating Sustained Turmoil

In the following image, one nurse, recognizing the tragedy of the death of a child was reminded of the wider impact of this death on all care providers during EOL with the Thumbprint Tree in Figure 6.

Figure 6: The Thumbprint Tree

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

Source: DovDesigns, Etsy. Retrieved from: https://www.pinterest.ca/pin/216313588323616104/?lp=true

"This was taken from the internet (so this isn't one of my patients), but it's similar to the ones we use for patients in our unit. The thing that I always liked was the tree with all the thumbprints. Because even such a small baby that may have only lived 3 days…you can see the lives they've touched in such a short time. Even if they weren't able to take the baby home and leave the hospital. It makes the life not seem…I think the biggest fear is carrying a child for, you know, 9 months, and then they pass away in those few days is that it doesn't feel wasted. That that life meant something and it wasn't for a waste. And that you've made an impact even in such a small being."

One nurse spoke of a particularly traumatic, unsuccessful resuscitation in which she had participated, during which the physician made repeated attempts to intubate a newborn infant despite being asked multiple times by the nurses and respiratory therapists present to redirect care to comfort measures:

> *And at some point, [the baby's] pain has to mean something. And it's not acceptable that he's bleeding out of every facial orifice, and that his parents are going to meet him looking like that. And a comment was made, that "well if she didn't want to meet him like that, [the mother] shouldn't have done drugs".*

This nurse spoke of the emotional and professional impact of this incident, and others similar to it, in the following quote:

> *And so, there were a number of incidents that kind of all happened at the same time that kind of prompted me to get really involved and to do my charge [nurse] training. And to get into a position where I could be an influence. But that was one of them. And I drafted a letter to management after that and just said: "The way this happened made me feel not only as a non-valued member of the team, but also like a core component...one of the core components of nursing… which was advocacy, was not my job. My job was to listen to the doctor and do what he said. And I don't appreciate the way that he approached the baby, the way that he approached the parents, the situation."*

Participants in this study spoke of many of their colleagues seeking other career paths, as their own units experienced high rates of job turnover possibly due to a lack of formal training in EOL care, a lack of resources, and a feeling of powerlessness due to the team hierarchy where physicians are at the top of the decision-making hierarchy. Three of the participants in particular cited sustained emotional stress with flashbacks to particularly traumatic deaths of patients, and a crippling fear of seeing their patients' families in public settings. During one traumatic resuscitation, one nurse spoke of her memories of the incident and what was evolving:

> *And there was that period where everyone just kind of had to accept that this was happening. And the parents were very much involved in it. Watching everything we were doing, and then it was just like tears and emotions, and I really can't get the mom's screaming out of my head. It's really hard to.*

Participants spoke of feeling uncertain of how they could appropriately separate themselves from their work with families during EOL, to return home to their partners and children with any sense of normalcy. This thread of role boundary confusion seemed to be noticeable through several of the interviews conducted. Participants spoke of their need for peer support, including that of their managers, and one nurse cried when speaking of the emotional stress of seeing her colleagues subject to repeated yelling, name-calling and accusations of nurses by parents of dying children. In an effort to recognize the grief experienced by nurses after the death of a patient, one nurse submitted an image that represented the process of remembering to recognize the impact of this death through Memory Beads at her hospital (Figure 7).

Figure 7: Memory Beads

Submitted by: Registered Nurse, Neonatal Intensive Care Unit, Alberta

"...a picture of my memory beads from Peds Oncology. In the last few years I was there, we all got better at debriefing and talking about the deaths as they happened. We would have a tea time and pick a bead to remember the sweet love. I only have 8 beads on it as we only did it for about the last 2 of the 22 years I was there. I have not continued it in NICU...something to think about!"

Another nurse spoke of the acceptance of the final outcome in death, and the importance of learning to cope with the emotional impact of this work:

> *It truly is being able to see that there really is a need to see beyond you being the final authority...that there is no black and white of doing palliative care nursing. But that it is an open and changing field constantly. And a willingness to be able to read those around you, reading the family, reading the patient, reading them all where everyone's at is a huge gifting and ability and it needs…it's a hard task and it takes a lot of emotional energy, but it needs to be done.*

Willingly Sojourning in Loving Presence

The fourth thematic pattern reflected the data describing the power of creating connections with a child who is dying and his or her family and the nurses' willingness to sojourn with them in loving presence. Participants described the importance of sincerity, practicing with "maternal instincts", being "open" and "approachable" with families, and "giving space" to families to allow them to express themselves in ways that were meaningful to them. These concepts are shown in Figure 8 with their corresponding subthemes in the theme development:

Figure 8: Thematic Pattern 4, Willingly Sojourning in Loving Presence

One nurse spoke of this relationship: *"I think it must start with mutual respect for the family and absolute awareness of where they're at and where their struggle is. And a willingness to enter into that space with them,*". Participants spoke of practicing with "intuition" and being led by "inexplicable" forces that allowed them to know when to be silent and how and when to practice physical touch in the context of EOL care. One example of the power of this physical touch was evident in this quote from one NICU nurse participant:

> *I just felt like as soon as I took him out of his bed and held him for the rest of the shift…and I just did my charting while I held him...I, maybe this is my imagination...I felt like he was more relaxed, and he struggled less. And it honestly…it was a very powerful learning experience for me, that even a non-verbal patient can experience actual real…I don't know...I feel like yea…engagement is the right word for it. That he can interact with me. And get comfort from what's a very basic offering. And in this EOL scenario, that's the strongest example I can think of where I felt very engaged with a baby.*

The term "companioning" came across as a means of explaining the feeling that EOL care was a journey that began before and lasted after the physical death of the patient. Being aware of one's physical presence and sensing when to "shift priorities" with respect to care capacity (e.g. from a curative or assessment-focused approach to one that emphasizes comfort and privacy for the patient and his or her family) was also spoken of as important in EOL care. This awareness of physical presence in sojourning a family's journey at EOL is visually represented in Figure 9, a baby's encapsulated feet with a mother's embrace:

Figure 9: Mother's Hands Encapsulating Baby's Feet

Submitted by: Registered Nurse, Neonatal and Paediatric Intensive Care Units

Source: Beautiful Beginnings Midwifery and Birth Centre, 2015. Retrieved from: https://beautifulbeginningsmidwifery.com/services.php

"I have chosen a photo of a mother's hands encapsulating her baby's feet. I chose this because I feel that the parent's role in caregiving and sheltering their child does not end once they face a time of suffering, pain or dying. The caregiver must continue to show compassion and support with their child. In the NICU this can be done by simply holding them close until the very end. Some caregivers or parents do not feel comfortable holding their child or accepting their child's disease process, but the strength of their spiritual and physical presence during this time is powerful."

Part of this thematic pattern was derived in Figure 10, The Knitted Octopus, representing comfort provided to the dying child for this nurse participant:

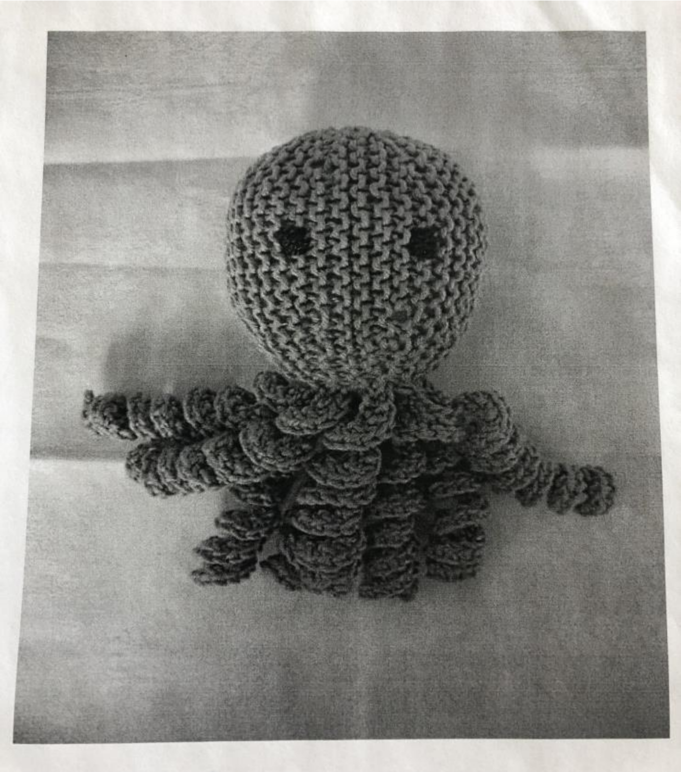

Figure 10: The Knitted Octopus

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

"The photo I have is this knitted octopus and I guess for people who aren't aware…a lot of times parents have been getting these octopi for really small babies as kind of a comfort measure…they need to hold onto things and they need to grab things and so they put them into the crib or the incubator because it's something that's soft, warm and comfortable and allows them to grab onto it. And the reason I brought this is because it reminds me of an experience I had with a child who passed away a couple of months ago and I looked after him since the day he was born…he passed away after a couple of months and numerous surgeries. I was very close with the mother and the big thing I remember is at the very end when he was palliated, he still had the octopus from the very beginning. He was still awake and holding and grabbing onto the octopus. I felt that after everything he had gone through, it was still a source of comfort to him. It was something familiar and something that his parents had bought for him. These are usually very custom things, so it was something they had really considered. And I guess what resonated with me is the fact that…our goal is that we can't necessarily do anything with a child that's going to pass. Within paediatrics, we usually do everything we possibly can, and medically can to keep a child alive. But when we finally decide that the only thing we can do is let them pass, truly the only thing we can do is provide comfort. Comfort for the child and comfort for the parents, and the imagery just reminded me that a lot of the times we don't know what to say or what to do, but if we focus on the fact that our goal is not to provide answers, we can't resolve grief for families- grief is natural and is something that's going to happen for parents. They're going to lose someone they truly love. Truly our only goal is to provide comfort, and to allow them to know that their child who passed was loved by them and the people who cared for them,

> *and that their passing was not something that was painful, but something that was done in a way that maintained the child's dignity and maintained the child's spirit, and ended in a way that the parents will remember probably never as a positive experience, but maybe as an experience that was less painful. That's why I go back to this octopus- his goal is to provide comfort for the child. And I think as nurses, it's our goal to provide comfort for the family and the patient that is passing.*"

Sub-themes derived from analysis included a sense of relatability, allowing for mindful presence, and creating connection with patients through an "innate knowing". The thematic pattern of willingly entering into this journey with patients in loving presence is beautifully captured in the following excerpt from an interview with one participant:

> *And it's been a big journey for me of learning how to cope with it and how to realize that this is their journey, and this is going to become the fabric of who they are. Each sketch is going to be woven in a way that's going to become their story. And I can't take that away from them. I can't take away from who they are and who they're becoming. Instead I can choose to walk with them, not trying to do everything perfect and to be exactly what they need, but to be just present with them. To just be. The willingness to just be with them. Because really, there is no perfect way to come to EOL. There is no perfect way to say goodbye to a child and…* (begins crying) *there is no perfect way to say goodbye to a child, but to be surrounded by people who are willing to just let you come to the realization you need to... to express what you need to, to be sheltered, to be cared for...that's really what the family needs.*

Facilitating and Valuing the Family's Role in their Experience of EOL

This thematic pattern links with a central view of nurses in this study, that is, their role as "facilitator" in the caring relationship. Participants spoke of facilitating the grief of families in their care by "offering follow-up", "mobilizing their resources" as early as possible, and creating opportunities for families to engage in "meaningful moments", which included legacy-making activities. One example of a legacy-making activity, described by a nurse participant from British Columbia, was the making of hand and foot molds for patients during EOL, with the patients' families present. Participants continually expressed ways in which they went beyond the expectations of their role, staying after their shift was over to be with the family, physically moving the patient's bed to accommodate for parents who wanted to lie in bed with their child, providing care for patients who were dying “around the family” as they grieved, and acting to protect and be a “gatekeeper” of the private moments between patients and their families from other interdisciplinary team members wanting to assess patients. Participants expressed a keen awareness that they were the bridge between patient families and the interdisciplinary teams, ensuring families were both aware of the medical team’s plan and goals, and that families’ voices were heard during team discussions surrounding the patients’ plan of care. For example, one participant said:

> *I think one of the biggest things is educating the parents and involving them and making them a fixture basically in the environment and telling them. Especially if they have other kids and can’t be there 24/7, telling them: “Be here as much as you can. You’re the expert on your baby. We only take care of them for a shift and then we might be off for 3 days. You’re here every day, for an hour or you know hours every day, so you know if something’s off with your baby. Mention it.” Because often the first catch of sepsis, the parents will say: “Hey, I don’t think she’s herself,” or whatever. And I think inviting parents into that space and empowering them to be part of the environment is actually really important. And yeah, I think whether you’re in a bedside role or a charge role, kind of making the team gel is kind of big piece of nursing.*

Participants used terms such as “empower”, “avoid false hope”, “advocate” and “allow autonomy” as ways they fostered a family’s understanding of this caring experience and the ultimate goals of care. One nurse in this study expressed the feeling of being responsible for ensuring care decisions were made for and with the family during EOL:

> *It’s a hard responsibility, for being responsible for…making sure parents have a really clear understanding of what [death is] going to look like. But I guess they can’t really understand unless we paint that picture for them. And if they still choose that they want that, and they feel like that’s what’s best for their child, I think that we need to be much better at getting on board and saying, ‘Okay let’s support you in this. Let’s, you know...we’re going to continue doing CPR every hour because you’re the decision maker, and you have the right to change your mind at any time. And just because you said, ‘Yes’ to this now, it doesn’t mean ‘Yes’ forever. You can say, ‘No’ at any time.’*

In this nurse’s statement: “continue doing CPR every hour”, she identifies a complicated, conflicting request of the family for resuscitating a dying patient repeatedly, because it is the family's wish to perform this and it is their right to drive this decision. Another nurse spoke of how she facilitated the family's role through providing many opportunities for conversations to understand the family's values and goals. In Figure 11, the nurse participant describes the responsibility she felt to making the environment adapt to the family's needs at EOL, as part of this facilitative effort:

Figure 11: Mountain View from a Patient's Room

Submitted by: Registered Nurse, Paediatric Intensive Care Unit

"I attached a photo taken from one of our patient rooms. The picture is small and may not accurately reflect the beautiful view of the mountains and city below. The death of a child in hospital is horrendous for everyone involved. The importance of proving a comfortable environment during this most-difficult time is imperative. Whenever possible, the dying patient will be placed in a quiet room, away from other patients and families. Family and friends are welcomed into the room and end-of-life options discussed. Some examples of environment customization are sleeping arrangements for family members in the room; Dimmed lights and music; opportunities for prayer and spiritual customs; the patient's bed is arranged in a manner to encourage a parent of sibling to lie in the bed with them."

This concerted effort toward facilitating a family's role in the end-of-life care was sustained through the nurses' "do anything" to help approach. Figure 12, the EOL heart, is described by the nurse as a memento of remembrance provided by nurses to families whose child has died:

Figure 12: End-of-Life Heart

Submitted by: Registered Nurse, Paediatric Intensive Care Unit

"This is a memento bracelet that our PICU offers to families after their child has passed away; the smaller heart stays on the child's wrist or ankle and the larger usually stays with the parents or loved guardians. To me it symbolizes the family-centered care approach that is so important to have when caring for critically ill children. I feel very fortunate to be a part of a unit that prioritizes this approach and strives to enhance the meaning of each child and family's end-of-life experience. This memento is always so well-received with the families and means a great deal to them, as it does to us nurses caring for these children.

Participants felt the ability to engage with patients and their families was necessary, not only for clear patterns of communication to be established, but also to ensure they were guiding these families in what was the right direction for them: *"We talk to the parents, we explain what's going on, we teach them what we know so that they're part of the team as well, so that they have* *as much knowledge as the team going forward".* This final theme is depicted with corresponding concepts and subthemes in Figure 13:

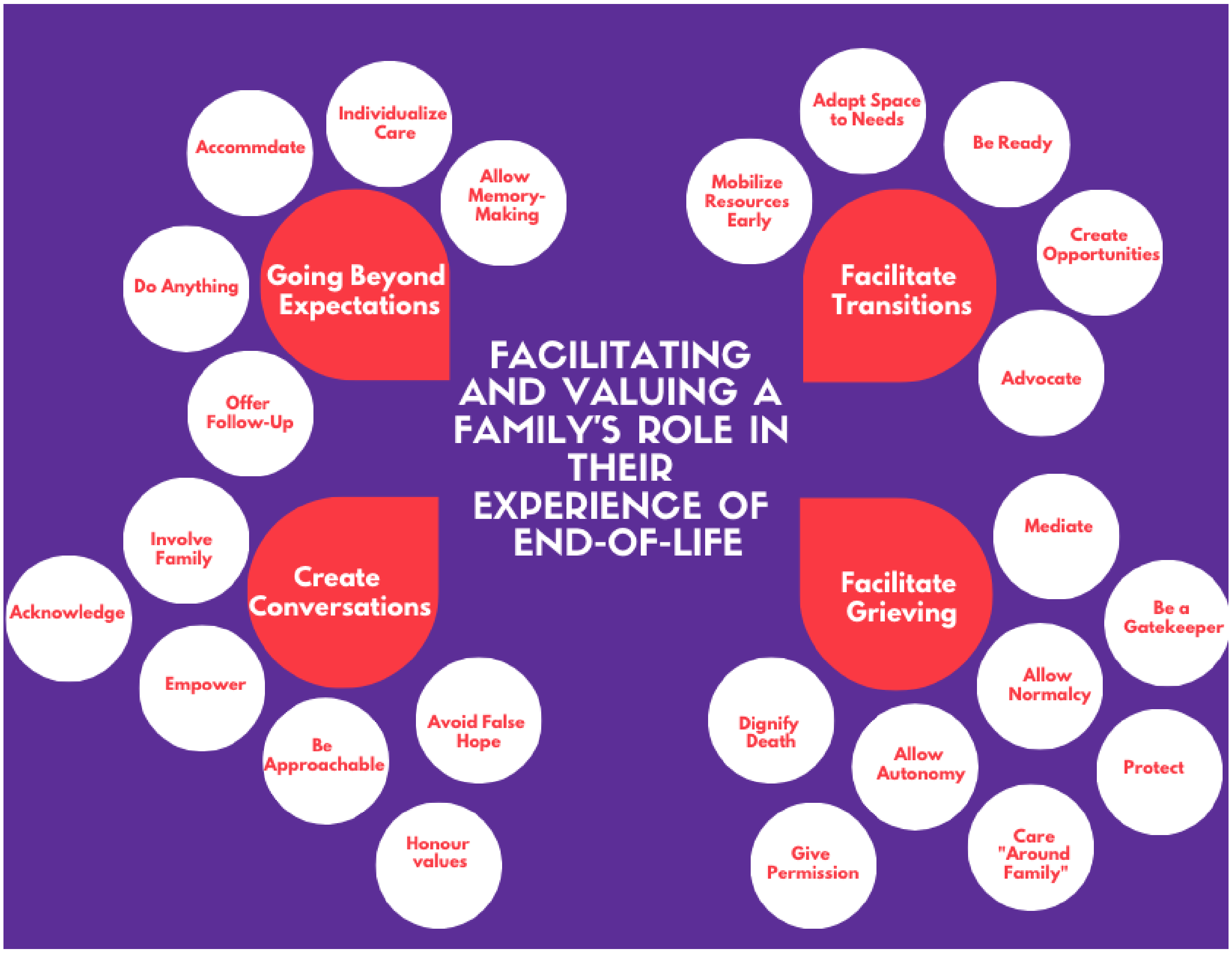

Figure 13: Thematic Pattern 5, Facilitating and Valuing a Family's Role in Their Experience of End-of-Life

Thematic patterns are supported with additional quotes in Table 3 below.

Table 3

Thematic Patterns with Additional Supporting Quotes

Careful cultivation of a team approach shapes end-of -life decisions

- "*We nursed around the family. And I think that at the end stages, that's kind of what we have to do...So making the environment adapt to what the parents need. And what stage they're in"*
- *"I think, you know when you're dealing with end-of-life, without a doubt there is more stress. And everybody wants…you know first of all you want the outcome to be good, and, you know, meaning that…ultimately the patient will make it and survive. But um….so you're very aware that it's a fragile situation. And you're all working hard.*

And I believe everyone is doing it with their best effort possible. You're all working hard to make that happen."

- *"Sometimes you'll say 'How are you doing? How are you actually feeling?', and they'll say, 'Oh I'm fine". And you're like, 'No, what are you feeling? What are your emotions right now in this situation?'. Not 'How are you?'...Because, when you ask someone "how are you?" they'll* say, *"oh I'm good, oh I'm fine", but you're not really asking the question here. "What are your emotions?*" *and "*how are you doing*?" are kind of different. You can be okay in the minute, but you actually are feeling and thinking when you go home about what your fears are"*

Resilience and affirming of self as nurse arise with alleviating suffering

- *"But do you know how to care for yourself emotionally as well as that emotional piece of when you're with that patient, what can you emotionally be giving…the best of yourself in a way that won't wreck yourself too. The ability to give with boundaries still for yourself, the ability to give and pour out without leaving the last drop on the table."*
- *"You have to come to a point where this is not just a job...you are now emotionally invested in [the parents'] experience of their child dying."*
- *"She had faith in my abilities and everything I had worked towards as a nurse...she kind of validated all the effort that I put into being the kind of nurse that I am... you can't fix what happened, but you can know you've done the best you could. To add value to someone else. And that's what keeps you going."*
- *"And, you know, they are part of my life. Not in the same way that I'm grieving them in the same way that their parents are, sure. I do let them be kind of…without sounding too weird or hippy or airy fairy here… I do let them be part of my life too. I feel like that way it allows me to find celebration and joy in the ways that they touched my life, instead of feeling so focused on the grief piece. Or how terribly tragic it is that this happened."*
- *"I think that the parents see that they know the nurses that truly care, and I think that comes back to validate you and kind of gives you the motivation to continue. And I think when people always say "how do nurses deal with this, especially in the ICU" … I think that's a component of it- that you can't fix what happened, but you can know you've done the best you could. To add value to someone else. And that's what keeps you going."*

Navigating sustained turmoil

- *"We can't always just switch off. And I think maybe the greatest thing that we can do is to prepare ourselves when we're going to work with times of mindfulness and meditation, and just centering and focusing. Allowing times for our amygdala to settle down and calm so that we can be fully present in whatever situation presents at work"*
- "*I feel sadly [end-of-life skills] is a piece that's lacking in nursing. That we're not training….. And I just thought, wow, how empowering would that be to have for nurses to have a crisis and trauma course, to know how to meet somebody in the middle of a crisis—to know how to walk with them, talk with them through it. So, I do feel like that is a lacking piece in the nursing training for sure."*

Willingly sojourning in loving presence

- *"And I think it's just sensing the room. It's not having this tunnel vision approach. It's really just looking at everything. Like you're there to be that one person that picks up on the subtle cues that can tell the PICU intensivist that might need a gentler approach to everything"*
- *"I guess that's my concern with how we teach nurses. That's it's not really taught…the touch part, the whole psychological approach, the awareness of presence and being, actual being with a patient. Not in terms of treatment, but being with a patient. Um…companioning is maybe a better word."*
- *"I would say that it's a continual work in progress, a continual reading of personalities and situations."*
- *"I still understood that a baby should die against a heartbeat. Even if it isn't his/her mom's."*

Facilitating and valuing the family's role in their experience of EOL

- *"Everyone is going to be uncertain. But the only way you can find some solution is to explore it with the family. And I think that's kind of what affects my decision-making. I would never want to make a decision based on my preconceived notion of what death and dying are. I would want to know what the family's beliefs are. And that will be really instrumental in deciding what is the right decision to make. And I would advocate for that as well."*
- *"We talk to the parents, we explain what's going on, we teach them what we know so that they're part of the team as well, so that they have as much knowledge as the team going forward."*
- *"I think the limitations are only there if you make the limitations there. I think if you think of nursing as not this black and white thing. Like if you could do these things by stepping on the bed or leaning across the bed and maneuvering around, then why shouldn't you. Like do anything. Also, for these kinds who have been chronic, I think we forget that this is their home. And we are coming in on a daily basis, rotating nurses, and we need to kind of allow that normalcy if they were at home and kind of respect that. It's what you make it to be.*"
- *"I think it's creating even those last hours...it's remembering that even this baby, even if this baby, who is only a few days old…touched peoples' lives, made an impact even if they couldn't talk yet. It's a 'do anything' concept but it's also I guess do anything to provide dignity and respect to the patient but not to put them in harm. But not to keep the patient alive that's asking to go."*
- *"I think one of the biggest things is educating the parents and involving them, and making them a fixture basically in the environment and telling them. Especially if they have other kids and can't be there 24/7, telling them "be here as much as you can. You're the expert on your baby. We only take care of them for a shift and then we might be off for 3 days. You're here every day, for an hour or you know hours every day, so you know if something's off with your baby. Mention it. Cause often the first catch of sepsis, the parents will say "hey I don't think she's herself" or whatever. And I think inviting parents into that space and empowering them to be part of the environment is actually really important. And yeah, I think whether you're in a bedside role or a charge role, kind of making the team gel is kind of big piece of nursing".*

Chapter Six: DISCUSSION

The findings of this study aim to substantively contribute to the identified gaps in current research pertaining to the lived experience of nurses caring for dying children in NICUs and PICUs. Of note, interviews with participants from across Canada help to generate a rich understanding of the experience from the perspective of neonatal and paediatric critical care nurses with varying years of professional experience in a Canadian context, evolving from their verbal interviews, descriptions and images. Beyond the meta-synthesis of Stayer and Lockhart (2016), identifying themes of "lifelong burden", "journey to death", and "challenges in delivering care" (p. 353), this study builds on the negative experiences associated with caring during EOL, contributing the important aspects of validation and mutual sharing in care to existing literature. Also, this research is among the first to explore the deeper meanings of participants' experiences within a relational ethics framework to clarify the embedded concerns and ongoing shortcomings of support and understanding of nurses who care for children who are dying.

The first thematic pattern in this study, *careful cultivation of a team approach shapes end-of-life decisions*, reflects the idea that nurses understand themselves to be poised to help the team and families to achieve *common goals, cohesion and unity,* and provide *system navigation* for decision-making. Leuthner and Jones (2007) present literature they used to create an evidence-based program in which nurses are effectively positioned to assist families with the healthcare team in a fetal palliative care program called the Fetal Concerns Program (p. 272). In this program, they recognize the key aspects of caring at the bedside for patients during palliative care, and consistent with this study, Leuthner and Jones describe nurses as the "bridge among all team members" (p. 276). Leuthner and Jones reference the "extensive anticipatory guidance" (p.

276) nurses provided for families during palliative care, which parallels the *intuitive knowing* and *value of language* participants expressed, which helps families by *avoiding assumptions* and achieving a deep understanding of the impact of *word choice* during provision of EOL care. Further consistency with this thematic pattern, Leuthner and Jones identify that behaviours associated with normal activities could be modeled by the nurse in helping families to understand how to approach their child and make decisions surrounding the plan of care (p. 276). This modeling behaviour is, arguably, one of the most effective tools nurses have to cultivate both the interdisciplinary and families' approach to the child—both physically and emotionally. For example, when nurses call a baby by name, the interdisciplinary team can be reminded of the humanity of the child for whom decisions are being made, and allow parents to voice the concerns for their child who has an identity. While the thematic pattern, *careful cultivation of a team approach shapes end-of-life decisions*, is consistent with Leuthner and Jones, it also contributes new understanding of nurses' role in EOL care being like the work of a conductor in guiding an orchestra through a challenging musical passage. Ultimately, this guidance shapes the experiences, actions and outcome of the passage as a whole. This thematic pattern also links with the relational ethics tenet *engagement*, which encompasses both the anticipatory guidance provided by nurses through verbal cues and listening, as well as the physical presence of the nurse at the bedside throughout the caring experience. Research by Ives Baine et al. (2013) resonates with this tenet of engagement in their study of the experience of nurse caring for NICU patients and their families during EOL, with the identification of the thematic pattern that "conceptualized nurses' relationships as constructed within the pattern of essential engagement by intersecting circles of conscious engagement, dialogue, and reflection and reframing" (p. 300). Of note, Ives Baine et al. (2013) further highlight the differentiating aspect of "conscious

engagement" (p. 301), in their study, that the "idea that one is in an experience, and then reflective about that experience, is imagined as an in-and-out process" (p. 301).

The second thematic pattern, *resilience and affirming of self as nurse arise with alleviating suffering*, was reflected in the language of *carrying inner joy* and *acceptance* of the death of the child. Nurses spoke of marking their course for the *celebration of life* of the child amidst the tumultuous emotions expressed in a pattern of repeated sustained joy that echoed across each participant's interview. Browning (2013) expressed a similar theme in her study with nurses caring for adults at EOL in her theme, *psychological empowerment,* which was defined as: "a mechanism by which people gain mastery of their affairs". In the context of caring for patients during EOL, and adult patients in the study by Browning (2013), this empowerment was realized in direct contrast to the manifestation of moral distress. The conceptual framework used in Browning's study identified four main areas for true empowerment to occur: "meaning, competence, impact and self-determination" (2013, p. 145). Significantly, in Browning's survey, incidents of moral distress correlated negatively with high incidence of psychological empowerment (p. 148). Though Browning's study focused on nurses caring for adult patients in critical care environments, the linkage of "impact" with nurses' ability to alleviate suffering, is consistent with what has been expressively stated by nurses in this paediatric-focused study. It becomes especially important to acknowledge the amount of courage it takes to come to this caring relationship with a true openness and a willingness to journey with a patient during this period of extreme vulnerability and intimate sharing. Jonas-Simpson, McMahon, Watson and Andrews (2010) recognized this courage displayed in caring for families after a perinatal death, expanding on the idea that this nursing caring effort can be challenging, but, through courage, can be valued as a privilege. The relational ethics tenet that links to this thematic pattern, mutual respect, is expanded here with the idea that this involves empowerment of self through care. Mutual respect can then be viewed as respect of self as well as respect for those in nurses' care, which provides grounding for joy in the caring experience during EOL.

The third thematic pattern defined, *navigating sustained turmoil*, includes the idea of moral distress generated by caring for patients during EOL, and this was similar to what researchers found in studies with nurses caring for adults at EOL (Browning, 2013; Ranse et al., 2012). Though focused on the adult population, the "emotional intensity" (p. 7) identified in Ranse et al.'s (2012) study lends significance to the array of turbulent emotions expressed by the PICU and NICU nurses who participated in this study. Participants in this study, likewise, identified the need for peer support and dealing with "raw emotions" and "feeling overwhelmed". Ranse et al. (2012) found that the expectation of nurses in the intensive care setting was that of being "expected to cope with death and dying" (p. 7). The thematic pattern identified in this study, *navigating sustained turmoil* goes beyond the expectation of coping that Ranse et al. describe, to extend this expectation to nurses learning to find their way through the intense grief and emotions that occur in EOL care, to find validation for their care and support from their peers. The relational ethics tenet, *uncertainty*, is best linked to this thematic pattern, as it speaks to the fluctuation in emotions, or "turbulence" in the nursing experience. Additionally, the *uncertainty* is present in the sustained turmoil of these situations which may have tentative and undefined courses. This, for example, could be the uncertainty of how quickly a child may die or how certain the team is that death for the patient is inevitable. In accepting this tenet of uncertainty in EOL care, nurses can begin to develop appreciation for their care in an effort to enhance the quality of patients' lives during this time of extreme vulnerability.

The fourth theme, *willingly sojourning in loving presence,* stems from the courageous effort nurses make to be vulnerable and connect with families during shared grief and the families' anguish, through language of *journeying together, being open*, *sincerity* and *transparency*. This theme strongly reflects the exploratory research conducted by Jonas-Simpson, McMahon, Watson and Andrews. (2010), which focused on the experience of obstetrical nurses who care for families of dying or stillborn babies in one of their thematic findings, that is, "Connecting with Families While Connecting Families with Their Babies Provides Comfort Amid the Unbearable Loss" (p. 19). With the emphasis on connection, this finding articulates the careful balance nurses create between bravely entering into a vulnerable space of emotion with families, and also willingly facilitating the connection between the families and the child who is dying. Jonas-Simpson, McMahon, Watson and Andrews (2010) refer to this balanced interplay in the following statement: "The nurses were both connected with and separate from the families while facilitating the connection of the families with their babies" (p. 19). Like in this current study with paediatric ICU nurses, this theme describes how nurses go beyond the role expectation of delivering safe and effective care, to mindfully creating the emotional connection embodied in compassionate care—loving presence. This thematic pattern links with the relational ethics tenet, *embodiment,* and expands our understanding of it through the creation of this connection.

The fifth thematic pattern, *facilitating and valuing the family's role in their experience of EOL,* is consistent with Limbo and Kobler (2010)'s work, which addresses the importance of the relationship between parents and families of children and the child who died during the perinatal period. Specifically, Limbo and Kobler state: “Nurses who are attentive to learning what is most important to a parent, and subsequently work to incorporate such interventions into their care, foster relationship between parent and child” (2010, p. 318), which fully supports the idea of fostering transitions in the goals of care that best represent and utilize the family’s values. In their article, Limbo and Kobler support the notion of nurses facilitating the experience of EOL, including the grief experienced by families, including the following activities: “inviting parents to spend time with their baby; facilitating legacy creation, ritual, or photography; and including surviving siblings in the baby's living and dying” (Limbo & Kobler, 2010, p. 318). Participants in this current study also expressed this cultivating approach, through language of *being open, being ready, acting as a gatekeeper, creating opportunities* and *adapting the environment to the needs of the families.* This concerted effort by nurses is necessary to allow families to experience this EOL period in a way that is significant to them to love and remember their child. Limbo and Kobler (2010) give specific language to nurses to help identify how to individualize care in statements that include “‘*How are you doing with all of this?”* or *"Tell me a little about what's happened’”* (p. 318). The relational caring tenet that is best reflected here is that of the environment. Nurses adapt, shape, protect and create the environment in whatever way is best suited to the experience of the family during EOL. The relational ethics tenet of the *environment* is expanded in this study to include the physical and emotional “space” in which the family is experiencing loss.

One central pattern that emerged throughout this study, was the idea that nurses’ contribution at EOL is, arguably, most felt through genuine presence, a term described as *companioning* by participants in this study. In the thematic patterns discovered in this study, the words “fostering”, “cultivating”, “sojourning”, “affirming” and “navigating” acknowledge an overarching *companioning togetherness* in what it means to nurses to care for children who are dying and their families. This is where the study's title "*Companioning End-of-Life*" originated. When reflecting on the meaning of this phenomenon, companioning can serve to both acknowledge the grief and emotional turbulence felt by nurses, and to validate their contribution of time, presence and cultivated support during the death of a child.

Chapter Seven: STUDY LIMITATIONS, FUTURE DIRECTIONS AND IMPLICATIONS

Strengths and Limitations

There were several limitations of this study. Of note, most participants who were interviewed for this study practiced in paediatric and neonatal critical care units that were in teaching hospitals that were well-staffed, in large, urban centres. Additionally, all participants practiced in Canadian hospitals which were provincially funded in a public healthcare model. The context of these interpretive findings should be considered, since globally, not all nurses practice within publicly-funded systems, and not all centres caring for children who are dying in critical care settings are in well-resourced areas. This becomes a limitation when the cost of treatment is not publicly funded, and might alter the decision-making process for families who are not able to pay out of pocket for a long hospital stay in critical care, or consider therapies to prolong life. Additionally, nurses participating in this study were 90% female, with only one male who participated. This limits the male perspective in caring for children during EOL, which may have further enriched the depth of the findings. The findings were also limited in that the patients being cared for by nurses were typically too young, too sedated or too critically ill to be able to speak. In less acute centers that are still deemed critical care patient care areas, wherein interactions may include many more conversations between nurses and patients, the findings might be different for how nurses consider their role during end-of-life care.

One strength of this study was the participation by nurses from three different provinces across Canada, increasing transferability of the findings to other Canadian paediatric and neonatal intensive care units. Another poignant strength of this study was the addition of imagery to help yield insights into the experiences of nurses who care for children who are dying as it provides a deeper comprehension of the phenomenon being studied. Finally, the private, semi-structured interviews allowed for rich description, as participants were able to speak openly with the principal investigator about their experiences, without the potential influence of other participants' experiences.

Directions and Implications for Practice and Future Research

In combination with existing research findings, which encourage organizational support and communication for effective, quality EOL care; the rich understandings generated from this study may uncover the deeper underpinnings of current organizational and system shortcomings from the perspective of nurses. New understandings from this study could be used to inform administrators and educators to provide more meaningful support.

Delving into the NICU and PICU nurses' experiences of caring for children at EOL may potentially help inform interventions to lessen feelings of burnout and moral distress among nurses. Future research may also use a relational ethics framework to study experiences of other healthcare providers who are integral to the team caring for paediatric patients at EOL. Additionally, end-of-life conversations critically involve informed-decision making, which means we need to build relationships built on components of relational ethics (mutual respect, embodiment, engagement, etc.) to impart the appropriate information for patients and families to assist them in making these difficult decisions (Holland and Perko, 2018).

Since the scope of paediatrics differs from care for adults in rights of consent, advocacy and the role of family, the focus on the understanding of the lived experience of these healthcare professionals might allow for prevention of healthcare professional burn-out, alleviate tensions between nurses and families, and between nurses and other healthcare professionals, and facilitate therapeutic support that focuses on what is important to nurses at the bedside. The implications of this support extend to an increased sense of satisfaction and attentiveness in provision of care for nurses at the bedside. In the longer term, support and satisfaction might result in retention of nursing staff, and richer awareness for the education and training of future neonatal and paediatric ICU nurses, as well as for nurses providing EOL care in other settings. The most significant immediate impact of this research is a heightened sensitivity to the experience of nurses by co-workers, managers, and other team members. Many nurses in this study expressed their experiences of suffering in silence, or desire for termination of employment or change in practice related to the meanings uncovered by caring for children at EOL. By participating in conversation and artistic expression, like the nurses in this study, nurses may instead find a way to continue on by sharing the emotional impact of this care. The dissemination of these findings is meant to provide a framework of understanding for future practice and research on the role of nurses and other healthcare providers at EOL, and how their responsibility to care can reciprocally affect them. Through the creativity expressed in the images submitted by participants, I would highly recommend that providing opportunities for creative visual expressions be used and expanded on for their role in elaborating on the depth and magnitude of the caring experience during EOL. Ultimately the findings from this study contribute a deeper understanding of the meaning of PICU and NICU nurses' experiences and acknowledge their value in companioning end-of-life with children and families.

Chapter Eight: CONCLUSION

American philosopher, Thomas Kuhn, in his book *The Structure of Scientific Revolutions*, emphasizes the importance of paradigm shifts to progress as a society (Kuhn, 1970). Kuhn emphasized a changed worldview as incumbent to this changed paradigm. A shift in paradigm is the desired outcome of this relational study of EOL care through attempting to gain a rich understanding of EOL care for children by nurses. Currently, the worldview is largely based on assumptions that burn-out and moral distress will result from caring for children who are dying. Nursing studies focus on attempts to alleviate this burnout through organizational help instead of assisting nurses to find personal and professional validation in this work. Based on findings from this study, a worldview is presented where nurses are alleviated from the burden affiliated with EOL caring, and are instead, deriving meaningful outcomes from this relationship.

As frontline care providers, nurses who care for both the family and the child who is dying are a critical part of the professional team with the ability to empower these families when faced with difficult decisions regarding EOL. Nurses are in unique, privileged positions to care for children who are dying, with the child’s family as a sojourner, while courageously embracing their own vulnerability. Burlison et al.’s (2016) research acknowledged the impact of the second victim experience in health care workers, that is the dramatic effect of experiencing work-related trauma on caregiver distress and job turnover. As studies on the work-related trauma affiliated with health care workers continue to expand and evolve, including how organizations can support and limit these effects in their employees, we can see small and slow positive changes toward better patient and caregiver outcomes. It is the intention of this study to go beyond the realm of organizational support, to generate a *mutual sharing relationship* with nurses providing care during EOL to children, that fosters respect and ongoing engagement to support the emotional needs of these nurses.

It would be a mistake to think, given the unique experience of caring for children during EOL, that nurses are not expected to grieve as well. The results of this study recognize that this caring experience is a reciprocal relationship between nurses, patients and their families, and requires careful validation of the gravity of how this can form a nurse’s outlook on his/her career choice and inform interactions at EOL in future. Nurses can reframe interactions from one of "caring for” to one of “caring with” and one that also recognizes and honours nurses’ own grief and experience. Rather than compartmentalizing grief while caring for these families, nurses can be mindful of their presence and their own experiences. In doing so, nurses not only create an opportunity for transformation in acknowledging the impact of a child’s death for grieving families and themselves, but also honour the powerful impact of relational nursing care when companioning EOL with children and their families.

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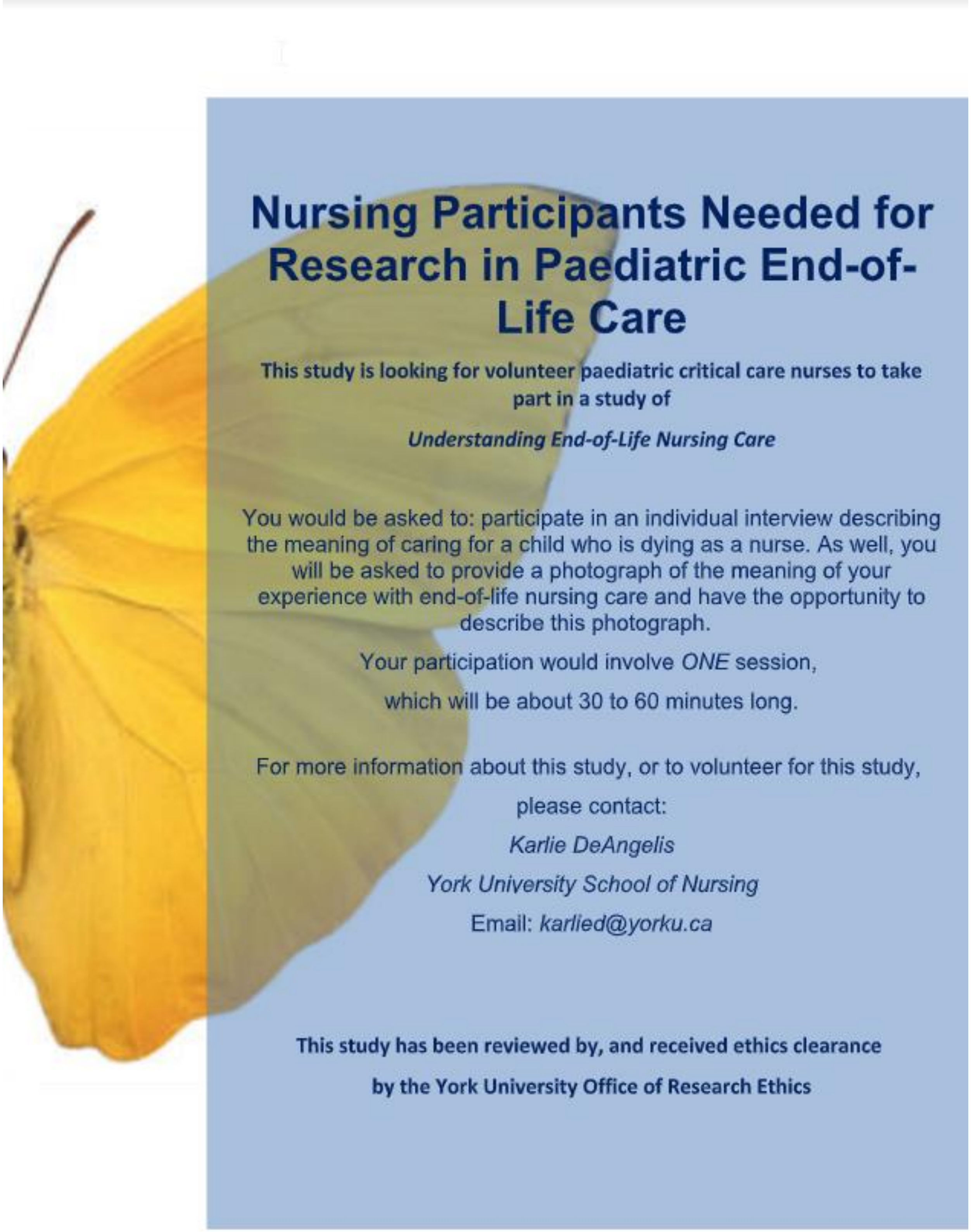
Appendix A: Recruitment Poster



Nursing Participants Needed for Research in Paediatric End-of-Life Care

This study is looking for volunteer paediatric critical care nurses to take part in a study of

Understanding End-of-Life Nursing Care

You would be asked to: participate in an individual interview describing the meaning of caring for a child who is dying as a nurse. As well, you will be asked to provide a photograph of the meaning of your experience with end-of-life nursing care and have the opportunity to describe this photograph.

Your participation would involve *ONE* session,

which will be about 30 to 60 minutes long.

For more information about this study, or to volunteer for this study,

please contact:

Karlie DeAngelis

York University School of Nursing

Email: *karlied@yorku.ca*

This study has been reviewed by, and received ethics clearance

by the York University Office of Research Ethics

Appendix B: Informed Consent Form

Informed Consent Form

Date:

Study Name: Caring for a Child who is Dying: A Relational Ethics Understanding of End-of-Life Nursing Care

Researcher name: The Principal Investigator of this study is Karlie-Carmen DeAngelis, a candidate for the Master of Science in Nursing (2019) degree at York University. Participants may contact the researcher through the following phone number or email at any time should she/he have questions or concerns regarding this study.

Purpose of the Research: This study proposes to study the experience of nurses caring for children with complicated illnesses at end-of-life in the hospital setting. As an exploratory study, video-recorded interviews will be conducted via the internet or in person, and transcripts will be made. Following data collection and interpretation, the study results will be presented as part of a thesis to the faculty of the School of Nursing at York University, and disseminated by presentations at conferences and publication in journals pertaining to end of life care.

What You Will Be Asked to Do in the Research: Participants will be asked to participate in a video-recorded interview with the Principal Investigator, in which they will be asked to describe their experience caring for paediatric patients at end-of-life in hospital. All information collected will be confidential, with no names or identifying information included in the final reports. Participants will also be asked to participate in one form of arts-based expression describing the creative avenues of expression. These include photos that may be taken from the internet, or with an individual iPhone. ***Photos are not to depict any images breaching patient confidentiality.*** These creative expressions will be used in the final report, but participants may opt to keep their identity anonymous. Participants will be asked to provide a short description (1-2 sentences) describing their artistic expression in relation to their caring experience. The approximate time commitment of participating in this study is proposed to be 30-60 minutes for the interview, and 15 minutes for the arts-based expression.

Risks and Discomforts: Potential discomforts of participation in this study include re-examining painful, difficult memories while caring for children at end-of-life. If participants so choose, they may opt out of continuing the interview at any time. Participants' arts-based expression as part of this study is seen as a source of mitigation for the painful memories.

Benefits of the Research and Benefits to You: The exploration of this topic may be of benefit to models of care in hospital for nurses who tend to paediatric patients at end of life. The researcher also hopes that providing an avenue of arts-based expression might yield some therapeutic benefit to the nurses who participate. Understanding the caring experience of nurses during such a vulnerable time might also yield benefits to the healthcare team at large who might better understand the role that nurses play during end-of-life care in hospital.

Voluntary Participation and Withdrawal: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer, to stop participating, or to refuse to answer questions will not influence the nature of the ongoing relationship you may have with the researchers, or the nature of your relationship with York University either now, or in the future. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. Should you wish to withdraw after the study, you will have the option to also withdraw your data up until the analysis is complete.

Confidentiality: Data will be collected by the researcher by video recording. Video recording of the interview will be stored on a personal computer with password access by the Principal Investigator only. Data will be stored until June 2019 following the completion of the study, and both hard copy and electronic recording will be destroyed following the completion of the study. All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Data will be collected through hand written notes and in digitally through webcam and video recording. Your data will be safely stored in a locked facility and only the researcher will have access to this information. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact me or my supervisor, Christine Jonas-Simpson. You may also contact the Graduate Program in the Faculty of Health, Nursing and Environmental Studies.
This research has received ethics review and approval by the Delegated Ethics Review Committee, which is delegated authority to review research ethics protocols by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I consent to participate in the research study entitled, Caring for a Child who is Dying: A Relational Ethics Understanding of Nursing Care conducted by Karlie-Carmen DeAngelis. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature **Date _**

Participant

Signature **Date _**

Principal Investigator

Additional consent (where applicable)

1. **Audio recording**

- I consent to the audio-recording of my interview(s).

1. **Video recording or use of photographs**

I ____________________ consent to the use of images of me (including photographs, video and other moving images), my environment and property in the following ways (please check all that apply):

In academic articles [ ] Yes [ ] No

In print, digital and slide form	[ ] Yes	[ ] No
In academic presentations	[ ] Yes	[ ] No
In media	[ ] Yes	[ ] No
In thesis materials	[ ] Yes	[ ] No

Signature: Date:

____
Participant: (name)

1. Consent to waive anonymity

I, ______________________ consent to the use of my name in the publications arising from this research.

Signature:

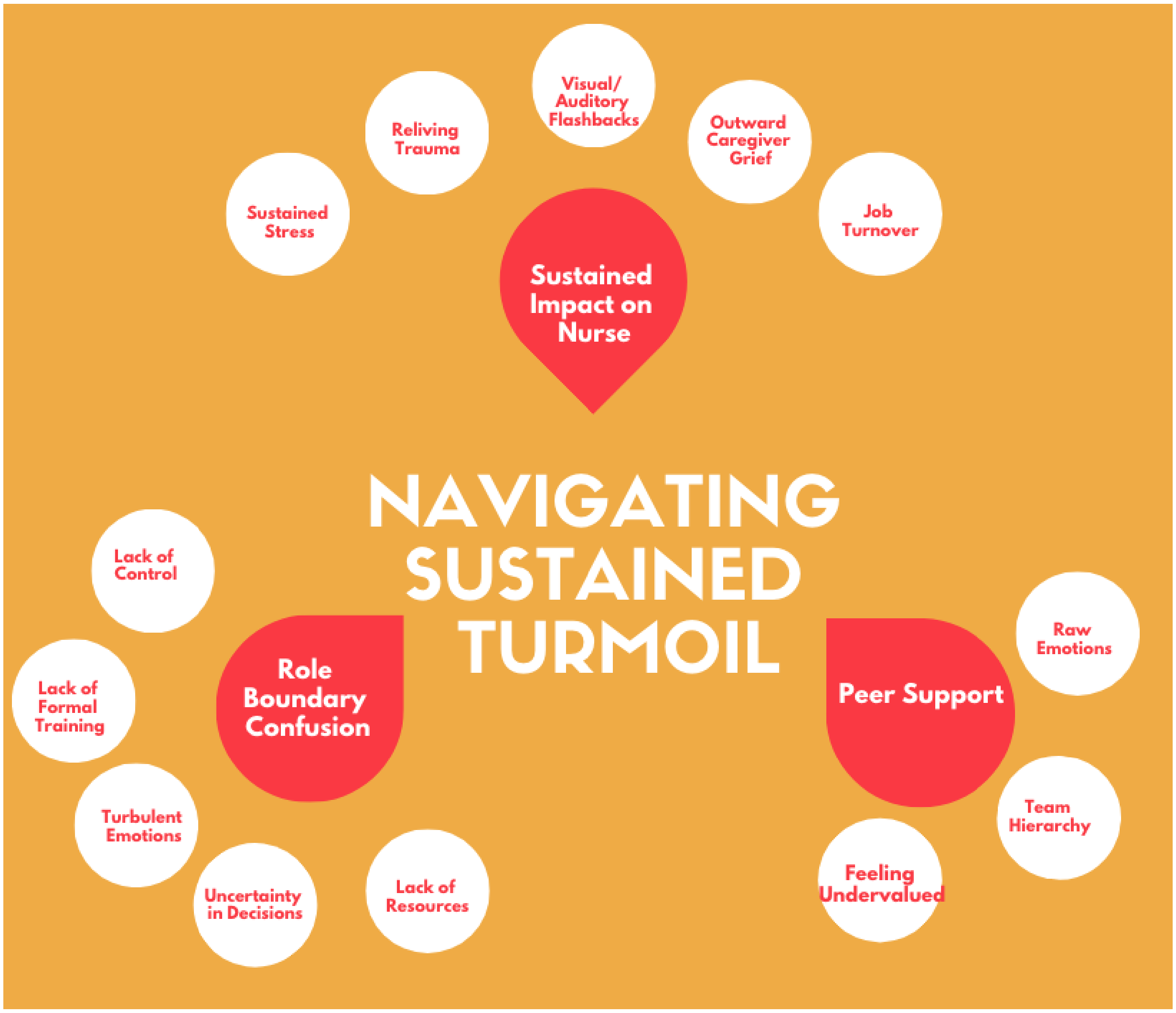
Participant: (name)

Date:

Appendix C: Mapping Thematic Patterns

Thematic Pattern 1: Careful Cultivation of a Team Approach Shapes End-of-Life Decisions

Thematic Pattern 2: Resilience and Affirming of Self as Nurse Arise with Alleviating Suffering



Thematic Pattern 3: Navigating Sustained Turmoil

Thematic Pattern 4: Willingly Sojourning in Loving Presence

Thematic Pattern 5: Facilitating and Valuing a Family's Role in Their Experience of End-of-Life

Appendix D: Imagery at End-of-Life

Image 1: The Cove

Submitted by: Registered Nurse, Neonatal Intensive Care Unit

Source: Garaev, Y. Retrieved from: https://unsplash.com/photos/kNIDFv5ee_g

"This is a picture of a cove. It's a picture of a body of water and some mountains...kind of a nature scape. [The name is significant to me] as a nurse...and how I view us as comforters and protectors, particularly in such an intimate space. It's also calming for me to think about the aspect of nature...I wanted to use a picture my sister took, but I ended up going with a free stock photo instead of going with my sister's [photo]*."*

Image 2: Gladiolus Flower Tattoo

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

“The gladiolus flower, also known as the sword lily, represents strong character, remembrance and focus. The flower of the warrior signifies commemoration, devotion, and loyalty. It reminds me of the tough battles I’ve faced as a cardiac nurse and that something beautiful can grow from every beating heart through every challenge.”

Image 3: The Thumbprint Tree

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

Source: DovDesigns, Etsy. Retrieved from: https://www.pinterest.ca/pin/216313588323616104/?lp=true

“This was taken from the internet (so this isn’t one of my patients), but it’s similar to the ones we use for patients in our unit. The thing that I always liked was the tree with all the thumbprints. Because even such a small baby that may have only lived 3 days…you can see the lives they’ve touched in such a short time. Even if they weren’t able to take the baby home and leave the hospital. It makes the life not seem…I think the biggest fear is carrying a child for, you know, 9 months, and then they pass away in those few days is that it doesn’t feel wasted. That that life meant something, and it wasn’t for a waste. And that you’ve made an impact even in such a small being.

Image 4: Memory Beads

Submitted by: Registered Nurse, Neonatal Intensive Care Unit

"...a picture of my memory beads from Peds Oncology. In the last few years I was there, we all got better at debriefing and talking about the deaths as they happened. We would have a tea time and pick a bead to remember the sweet love. I only have 8 beads on it as we only did it for about the last 2 of the 22 years I was there. I have not continued it in NICU...something to think about!"

Image 5: Mother's Hands Encapsulating Baby's Feet

Submitted by: Registered Nurse, Neonatal and Paediatric Intensive Care Units

Source: Beautiful Beginnings Midwifery and Birth Centre, 2015. Retrieved from: https://beautifulbeginningsmidwifery.com/services.php

"I have chosen a photo of a mother's hands encapsulating her baby's feet. I chose this because I feel that the parent's role in caregiving and sheltering their child does not end once they face a time of suffering, pain or dying. The caregiver must continue to show compassion and support with their child. In the NICU this can be done by simply holding them close until the very end. Some caregivers or parents do not feel comfortable holding their child or accepting their child's disease process, but the strength of their spiritual and physical presence during this time is powerful."

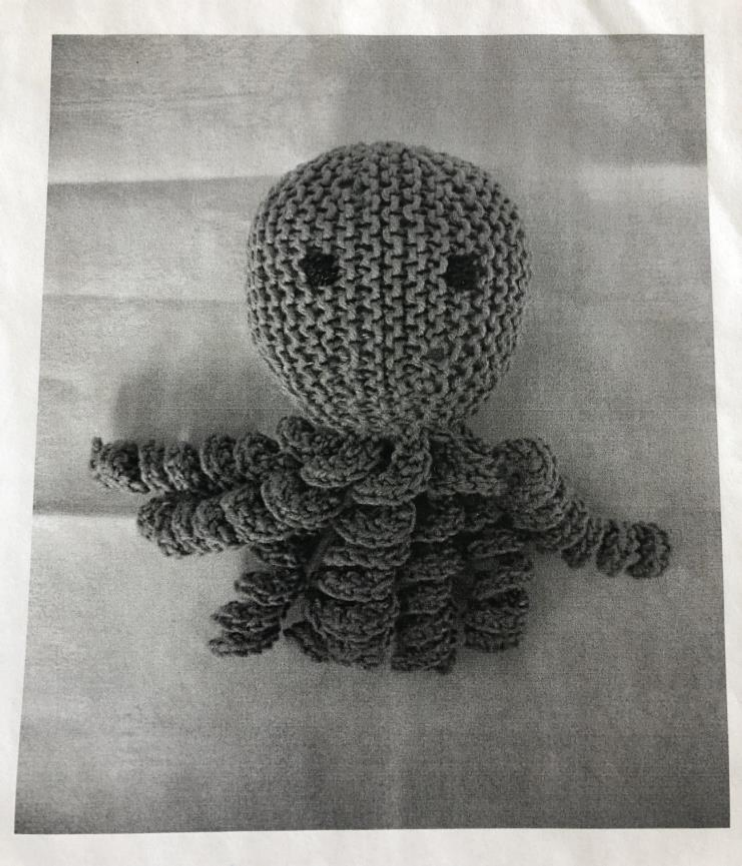


Image 6: The Knitted Octopus

Submitted by: Registered Nurse, Paediatric Cardiac Critical Care Unit

"The photo I have is this knitted octopus and I guess for people who aren't aware…a lot of times parents have been getting these octopi for really small babies as kind of a comfort measure…they need to hold onto things and they need to grab things and so they put them into the crib or the incubator because it's something that's soft, warm and comfortable and allows them to grab onto it. And the reason I brought this is because it reminds me of an experience I had with a child who passed away a couple of months ago and I looked after him since the day he was born…he passed away after a couple of months and numerous surgeries. I was very close with the mother and the big thing I remember is at the very end when he was palliated, he still had the octopus from the very beginning. He was still awake and holding and grabbing onto the octopus. I felt that after everything he had gone through, it was still a source of comfort to him. It was something familiar and something that his parents had bought for him. These are usually very custom things, so it was something they had really considered. And I guess what resonated with me is the fact that…our goal is that we can't necessarily do anything with a child that's going to pass. Within paediatrics, we usually do everything we possibly can, and medically can to keep a child alive. But when we finally decide that the only thing we can do is let them pass, truly the only thing we can do is provide comfort. Comfort for the child and comfort for the parents, and the imagery just reminded me that a lot of the times we don't know what to say or what to do, but if we focus on the fact that our goal is not to provide answers, we can't resolve grief for families- grief is natural and is something that's going to happen for parents. They're

going to lose someone they truly love. Truly our only goal is to provide comfort, and to allow them to know that their child who passed was loved by them and the people who cared for them, and that their passing was not something that was painful, but something that was done in a way that maintained the child's dignity and maintained the child's spirit, and ended in a way that the parents will remember probably never as a positive experience, but maybe as an experience that was less painful. That's why I go back to this octopus- his goal is to provide comfort for the child. And I think as nurses, it's our goal to provide comfort for the family and the patient that is passing."

Image 7: Mountain View from a Patient's Room

Submitted by: Registered Nurse, Paediatric Intensive Care Unit

"I attached a photo taken from one of our patient rooms. The picture is small and may not accurately reflect the beautiful view of the mountains and city below. The death of a child in hospital is horrendous for everyone involved. The importance of proving a comfortable environment during this most-difficult time is imperative. Whenever possible, the dying patient will be placed in a quiet room, away from other patients and families. Family and friends are welcomed into the room and end-of-life options discussed. Some examples of environment customization are sleeping arrangements for family members in the room; Dimmed lights and music; opportunities for prayer and spiritual customs; the patient's bed is arranged in a manner to encourage a parent of sibling to lie in the bed with them."

Image 8: End-of-Life Heart

Submitted by: Registered Nurse, Paediatric Intensive Care Unit

"This is a memento bracelet that our PICU offers to families after their child has passed away; the smaller heart stays on the child's wrist or ankle and the larger usually stays with the parents or loved guardians. To me it symbolizes the family-centered care approach that is so important to have when caring for critically ill children. I feel very fortunate to be a part of a unit that prioritizes this approach and strives to enhance the meaning of each child and family's end-of-life experience. This memento is always so well-received with the families and means a great deal to them, as it does to us nurses caring for these children."