Attending to values at stake when a child is dying: A study of pediatric intensive care unit nursing from the perspectives of bereaved parents

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Abstract

Existing literature has identified that health care providers significantly shape the experiences of parents at the end-of-life in the pediatric intensive care unit. However, there is a gap in the literature of the specific nursing influence on parental experiences of a child's death in this context. Employing the interpretive descriptive methodology, this qualitative study was designed to explore parents' moral experiences of nursing care at the end-of-life in the pediatric intensive care unit, and was analyzed through a lens of nursing ethics. Face-to-face, semi-structured interviews were conducted with eleven parents (six mothers and five fathers) of six children who died in a pediatric intensive care unit at a university-affiliated tertiary hospital in Eastern Canada.

Study results revealed close connections between parents' abilities to meaningfully parent a child through their death and the nursing care that they received at the end-of-life, and highlighted the varying helpful guiding roles that nurses adopted at different moments in parental experiences. Results also indicated that parents attributed immense value to feeling that nurses cared-for-and-about their child and the parents themselves, since this made parents feel that their child's death mattered to the nurses whom they had formed relationships with. This study enhances our understanding of the individualized nature of parents' moral experiences of nursing care at the end-of-life in the pediatric intensive care unit, and study results suggest implications for nursing practice, education, and research.

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Chapter 1: Introduction

Background

The death of a child is a devastating experience for parents. In Canada, the common causes of death in children and adolescents include congenital malformations, accidental injuries, suicide, and malignancies (Ornstein, Bowes, Shouldice, Yanchar, & Canadian Paediatric Society, 2013; Statistics Canada, 2016). Of child deaths in Canada, most happen in hospital, and the majority occur in critical care settings such as the pediatric intensive care unit (PICU) (Guertin, Côté-Brisson, Major, & Brisson, 2008; Widger et al., 2016). Children who are admitted to the PICU range in age from neonates through to young adults (Huang & Haresh, 2009). Common illnesses necessitating a PICU admission include traumatic injuries, serious infections, organ failure, or surgeries requiring close postoperative management (Frankel & Kache, 2012). Children who are admitted to the PICU may require mechanical ventilation, invasive intravascular monitoring, and always require frequent attention and interventions from the interdisciplinary PICU team (Frankel & Kache, 2012).

In addition to the care and support that children require during hospitalization in this context, parents also want to feel supported when their child is admitted to the PICU (Dahav & Sjöström-Strand, 2018). Parents have described a child's PICU hospitalization as being extremely stressful, overwhelming, and surreal (Dahav & Sjöström-Strand, 2018; Latour et al., 2011). Parents experience feelings of helplessness because of unfamiliar aspects of the environment, including the life-saving technology and monitoring that are used to support the child, because of alterations to their child's appearance and behavior, and because an admission to the PICU means that their child could die (Dahav & Sjöström-Strand, 2018; Latour et al., 2011). Parents may also experience feelings of powerlessness because they perceive they are

unable to help, comfort, or offer security to their child (Ames, Rennick, & Baillargeon, 2011; Dahav & Sjöström-Strand, 2018; Latour et al., 2011; Meyer, Snelling, & Myren-Manbeck, 1998). Moreover, parents have described feeling uncertain as to how they can interact with their child safely in this context, and thereby appreciate when clinicians orient them to safely provide care to their child during hospitalization (Dahav & Sjöström-Strand, 2018; Latour et al., 2011).

The child's bedside nurse often plays a key role in supporting parents and reducing their distress during a child's admission to the PICU (Ames et al., 2011; Meiers & Tomlinson, 2003). Nurses are involved in the "mundane and ordinary" tasks that exist in the daily lives of patients and their families[1] (Hess, 2003, p. 143). Given the extended amounts of time that nurses spend at the bedside, they are in a unique position to connect with patients and families in comparison to the rest of the interdisciplinary team (Hess, 2003; Wright & Brajtman, 2011). This proximity provides nurses with the opportunity to engage in dialogue with patients and families to understand what is most important to them (Austin, 2008). Conversely, if nurses are physically present at the bedside but are emotionally disengaged, they risk being unable to recognize important aspects of patient and family experiences (Austin, 2001; Austin, Bergum, & Dossetor, 2003). This failure to recognize what is important to parents may prevent parental desires from being accomplished at the end-of-life in the PICU.

The nurse-patient relationship is one of many caregiving relationships (Kleinman, 2012). Caregiving is "almost always a deeply interpersonal, relational practice" (Kleinman, 2012, p. 1551) that is transformative for both the individual providing care and for those receiving care. There are significant moral aspects that are integral to caregiving relationships because "what [matters] most" (Kleinman, 2013, p. 1377) is threatened by the illnesses that people experience.

[1]While the experiences of other family members are important for nurses to consider in the clinical encounter, the focus of this thesis is on the experiences of parents at the end-of-life. I occasionally

Individuals experience illness in a relational context, and "illness is everywhere a profoundly *moral* experience, since sufferers have things of great personal and collective value to gain or lose" (Kleinman & Benson, 2006, emphasis in original, p. 835). Moral experiences comprise the meanings and values that individuals attribute to specific encounters (Hunt & Carnevale, 2012). Given that the things that matter most to parents are achieved within the relational space between caregiver and care recipient, the nurse's ability to form a connection with parents has significant ethical implications.

In the PICU, parents are also recipients of care during their child's hospitalization (Falkenburg, Tibboel, Ganzevoort, Gischler, & van Dijk, 2018). Important moral matters are at stake for parents whose children are admitted to the PICU; the parent-child relationship is often central to a parent's sense of personhood and constitutes a core element of a parent's identity (Gillis & Rennick, 2006; Meert, Briller, Schim, Thurston, & Kabel, 2009). A parent's identity and personhood are threatened in the face of a child's critical illness because of the significant disruptions that often occur to their roles as parents (Dahav & Sjöström-Strand, 2018; Latour et al., 2011), and because of the possibility that their child might die (Gillis & Rennick, 2006). Although stressful, the temporary disruptions to the parental role that occur for parents of children who survive their illness or injury are sometimes perceived as acceptable given that the anticipated outcome is the child's recovery from their critical illness (Butler, Hall, & Copnell, 2018b), and parents are often able to become involved in care when their child's condition stabilizes (Ames et al., 2011; Dahav & Sjöström-Strand, 2018). However, for parents of children who will die during their PICU admission, the threat to a parent's personhood and identity increases significantly if they feel they are impeded from parenting their child as they desire at the end-of-life.

PICU nurses are in an optimal position to facilitate a parent's ability to sustain their parental role (Ames et al., 2011; Butler et al., 2018b). PICU nurses have the opportunity to support parents to participate in their child's care (Bloomer, Endacott, Copnell, & O'Connor, 2015), which, in part, facilitates parents' abilities to perceive that they are able to be "the best parents they can be" (McGraw et al., 2012, p. e251). The ways that nurses interact with children and families can fundamentally shape parental experiences and the meanings that they attribute to their child's hospital admission (Meiers & Brauer, 2008).

The relationships that nurses form, or fail to form, and the ways that they care for children and their parents are especially significant in situations where the nurse is caring for a child at the end-of-life. In the PICU, the end-of-life period encompasses different time frames depending on the way that the child dies. In PICUs in the United States, most children die following the withholding or withdrawal of life sustaining treatment (i.e., not introducing or not augmenting treatments, or discontinuing life-sustaining treatments, respectively) (Burns, Sellers, Meyer, Lewis-Newby, & Truog, 2014). The remainder of children die following unsuccessful cardiopulmonary resuscitation or brain death (Burns et al., 2014). Besides the different circumstances that can precede the death of a child, parental perspectives about the start of the end-of-life period may differ depending on individual, subjective values regarding what constitutes the child "[living] in a way that is meaningful or acceptable" (Feudtner, Zhong, Faerber, Dai, & Feinstein, 2015, p. 534), or in other words, depending on their values surrounding the child's quality of life.

Nurses' abilities to effectively engage with parents at the end-of-life require more than "mechanistic behavioral processes of communication" (Wright & Brajtman, 2011, p. 24). While a nurse may be described as competent if they conduct technical tasks proficiently with a

generally pleasant demeanor, “the inspiration required to know what to say and when to say it to capture the moment must…depend upon some degree of caring *about* the individual as a particular person” (de Raeve, 1996, emphasis added, p. 17-18). If nurses are not willing or able to “connect and be with another in an intersubjective, mutual, and authentic way” (Wright & Brajtman, 2011, p. 24) then there is a risk that the things that matter most to parents will remain unidentified and unrealized.

Parents have asserted the central importance of remaining involved in their child’s care as the child is dying; fulfillment of this need is fundamental to parents’ abilities to cope with their child’s death during bereavement (Price, Jordan, Prior, & Parkes, 2011). Parents’ experiences of their child’s death can be negatively influenced by clinicians’ actions and behaviors; parents who perceived that health care providers communicated insensitively or who felt that their parenting expertise in caring for their child was disregarded have reported significant emotional distress related to these elements during bereavement (Contro, Larson, Scofield, Sourkes, & Cohen, 2002). In the PICU specifically, parents have also identified that health care providers significantly influence their experiences of their child’s death (Butler et al., 2018b; Falkenburg et al., 2018).

While there have been studies examining the influence of nursing care on parents’ experiences in the PICU when children survive, and although there have been studies exploring the relationships formed between clinicians (including physicians, nurses and other team members) and parents at the end-of-life, there has not been an in-depth examination specifically exploring the influence of nurses on parents’ experiences of a child’s death in the PICU. Given what we know about the integral influence that nurses have on parental experiences of a child’s PICU hospitalization when the child survives (Meiers & Tomlinson, 2003), and the significant

moral matters that are at stake for these parents in all circumstances (Gillis & Rennick, 2006), it is necessary to gain a better understanding of parents' moral experiences of end-of-life nursing care in this context. It is important to understand the ways in which these nurses meaningfully engage with parents while providing end-of-life care; such understanding will offer an evidence base to support nurses in their efforts to be most helpful to parents during the death of a child. Therefore, the research question guiding this study was as follows: How do parents interpret and describe the influence of nurses on their moral experiences of their child's death in the PICU?

Purpose of the Research Study

The purpose of this study was to solicit parents' perspectives about their moral experiences of their child's death in the PICU, focusing specifically on perspectives about how nursing care influences these experiences.

Researcher's Personal Stance

My interest in exploring this topic arose from my clinical practice as a novice nurse working in the PICU. When I applied for my master's degree and began thinking about a topic to explore for my thesis, I had been working for about a year and a half in this setting. I had always had an interest in palliative care and felt it was very important to develop skills in the delivery of end-of-life care; however, I had not had any formal training in PICU end-of-life nursing care. I had only observed some of the ways that my colleagues delivered such care, and how parents could be affected by the death of a child. For example, on my first day of orientation to this unit, a child was admitted urgently from the emergency room and was being resuscitated as he arrived to the PICU, but died minutes after arriving to the unit. I saw his mother cry out in anguish and fall to the floor in the hallway outside his room when she realized he had died. I began to question how I might be able to best support parents during these extremely difficult moments.

I continued working part time as a bedside nurse during my graduate degree, and had my first encounters with parents who were experiencing the death of a child during this time. Although I have gained experience working with these families, I have often questioned if I was offering the best support that could be provided given parents' unique circumstances and backgrounds. In my own clinical practice, I often struggle trying to determine the best ways to support parents. Some questions I ask myself include: should I be present in the room with parents to convey my support? If a parent says they do not want to hold their child when treatment withdrawal occurs, will they regret this later? If I emphasize the importance of this action, am I 'forcing' the parent to conform to my own perception of a 'good' experience of their child's death? If I continue speaking to a child who has experienced brain death (as I would with other children who are unresponsive), will parents see this as respectful or will this worsen their feelings of ambiguity about whether the child is alive in braindeath?

The uncertainty that I experienced (and continue to experience) in clinical practice led me to wonder if there had been any research done to examine the influence of nurses during these moments in the PICU that might support my practice and interventions at the end-of-life. Before embarking on this study, I was certain that nurses would significantly influence the experiences of parents because of our positioning at the bedside. My experiences in this setting led me to want to learn more about *how* nurses affect parents' experiences of a child's death in the PICU.

Chapter 2: Review of the Literature

Introduction

In the following chapter, I review literature that served as the foundation to my research study. I will begin by examining parents' conceptions of being a good parent of a seriously ill child in different contexts and, more specifically, of realizing a parental role in the PICU. Then, I will explore what is already known about parental experiences of child death in the PICU, including the priorities that parents have identified at the end-of-life in this setting. I will explore parents' perceptions of the ways that clinicians' actions influence the attainment of parental priorities, and I will also examine other important supports and resources that many parents desire to accompany their child through their death.

In 2015, Butler, Hall, Willetts, and Copnell published a metasynthesis exploring family experiences of PICU death, but found limited empirical studies exploring family member's experiences other than parents, and so this study only pertained to parental experiences. I read the primary studies that were identified in this metasynthesis and included them in the following literature review. I identified additional studies after the metasynthesis was published using the same search terms that were originally employed (Butler et al., 2015). I examined all of the studies about parental experiences of PICU death to identify instances where parents mentioned the influence of nurses on their experiences. Additional quantitative studies related to this topic were identified by reading the reference lists of the primary qualitative studies, and were included since I wanted to examine different sources of relevant literature from the field (Thorne, 2016), rather than solely considering qualitative inquiries. Most studies have examined different aspects of the experiences of parents at the end-of-life in the PICU without explicitly exploring the influence of nursing care; however, parents often directly referred to the ways that nurses

shaped their experiences in this context. In the literature, the influence of non-nurse clinicians was also mentioned by parents; however, given the aim of my study, I will primarily focus on parents' perspectives of nurses and nursing interventions in the PICU.

The priorities of parents at the end-of-life in the PICU will be described below, and include the parent's ability to realize their role as a parent by being present and providing care to their child, by forming trusting relationships with the clinicians caring for their child, and by being informed about their child's prognosis and care as their child proceeds throughout their hospitalization. Parental priorities at the end-of-life also include having control over the environment in their child's room, assuring that their child is recognized as a unique individual and receives optimal comfort care, having access to spiritual support as required, and having enough time to say goodbye to their child. I will also outline descriptions of the meanings that parents attribute to being parents after death, and parents' needs for end-of-life care after discharge from the hospital (i.e., bereavement support). Finally, the recent literature exploring parent-clinician relationships at the end-of-life, including parental interactions with, and perceptions of PICU clinicians will be examined. In the last few sections of this chapter, I will speak to studies that explicitly explored characteristics of the relationships between parents and PICU health care providers at the end-of-life, as these studies more closely relate to my research.

What it Means to be a Good Parent to a Seriously Ill Child

The meaning of being a 'good' parent to a seriously ill child has been explored with parents who are facing important decisions related to their child's illness. From parents' perspectives, this label is not used to judge the quality of one's parenting abilities, but is rather meant to reflect the "core values" that one believes constitute being a parent (Rushton, 1994, p. 77). For parents to perceive they are able to be a 'good' parent, they must remain faithful to their

"core commitments," which are the commitments that "have a privileged status in their lives because they reflect what is most important to them, give them reasons for living, and determine their moral identity" (Rushton, 1994, p. 97). For parents of neonates with life threatening congenital disorders, these core commitments included being physically and emotionally present for their infant, and making unique contributions to their child's life and health (Rushton, 1994); these parents perceived that their abilities to make informed and selfless decisions, to persevere for their child, and to pursue positive outcomes when faced with difficult treatment decisions were all integral to their conceptions of being good parents (Rushton, 1994).

Similarly, parents of children with incurable cancer described that the most important aspects of being a good parent involved making well-informed decisions in the child's best interests while putting the child's needs above their own, meeting the child's basic needs (e.g., by providing food and clothing), remaining physically present with the child to convey their support and love, and acting as their child's advocate (Hinds et al., 2009). When faced with treatment decisions in the PICU context, parents prioritized focusing on the child's quality of life, advocating for their child, putting their child's needs above their own, and making informed decisions (October, Fisher, Feudtner, & Hinds, 2014). Although the parents in these studies had children of varying ages with diverse illnesses, they all had similar conceptions of what it meant to be a good parent when faced with such decisions. Across care settings, parents require staff to support their abilities to make informed decisions for their children and to promote their sense of self as 'good' parents (Hinds et al., 2009; October et al., 2014; Rushton, 1994). When clinicians respect parents' choices in these situations, they promote parents' feelings of competence when there are few remaining occasions for parents to feel this way (Hinds et al., 2009; Rushton, 1994).

To be able to focus on being a good parent in life threatening situations, parents need to perceive that health care providers continue to provide the same quality of care regardless of the child's prognosis (Hinds et al., 2009; October et al., 2014). For parents of children who did not survive their illness, being a good parent meant feeling that they had done everything within their power to assure their child lived a life with happiness, and with the least amount of pain and suffering possible (Woodgate, 2006). In addition to parents' abilities to promote their child's quality of life prior to death, parents have described their presence during their child's death as an integral moment in their relationships with their children; their presence and perceptions of positively contributing to their child's well being during these moments were viewed as their final opportunity to be a good parent (Woodgate, 2006).

The Parental Role in the PICU

Many of the core commitments that parents have described contribute to their abilities to be 'good' parents (e.g., being physical and emotionally present, making informed, selfless decisions, and advocating for their child) are also aspects of the parental role in the PICU from the perspectives of parents. In a qualitative study of seven parents (five mothers and two fathers) of seven children who recovered from their illness in a Canadian PICU, Ames and colleagues (2011) explored the meaning of the parental role from parents' perspectives using in-depth, semi structured interviews; the themes identified in this qualitative study will be used to frame part of the following literature review of parents' experiences of a child's death in the PICU.

Parents whose children are admitted to the PICU have suggested that the parental role in this context consists of the ability to be present and participate in their child's care, to form trusting relationships with PICU clinicians, and to be knowledgeable about their child's prognosis and treatments as the individual who "'knows' the child best" (Ames et al., 2011, p.

146-47). With a child who is hospitalized in the PICU, parents feel the need to know they are making unique, significant contributions to their child's care (i.e., that they are able to be 'good' parents) and while being physically present is important, parents often experience feelings of helplessness when they are unable to concretely participate in their child's care (Ames et al., 2011). Parents are often only able to begin participating in care once their child's condition has stabilized, but this is still perceived as difficult because parents often feel unsure as to how they can safely interact with their child (Ames et al., 2011).

Parents recognize that their child's critical condition requires care informed by medical and clinical expertise; however, parents also have unique knowledge of their child that others do not possess, and to form trusting relationships with clinicians during hospitalization in the PICU, they require that health care providers inquire about and acknowledge this expertise (Ames et al., 2011). Additional interactions that contribute to building relationships of trust in this context include parents' direct observations of staff interactions with their children to assess the quality of care provision, and when parents feel that clinicians encourage them to take care of themselves (Ames et al., 2011). Parents also require information about their child's physiological condition, including information about how to read their child's vital signs monitoring to know what is normal for their child; moreover, they need explanations of the interventions and care that are being provided, and they require anticipatory information so that they know what to expect during their child's PICU stay (Ames et al., 2011).

I will now further explore specific aspects of the parental role at the end-of-life in the PICU, as revealed by the perspectives of parents.

Physical Presence.

Proximity to one's child is an important aspect of fulfilling one's parental role, and when a child is nearing death, this is often of utmost importance (Falkenburg et al., 2016; McGraw et al., 2012; Meert, Briller, Schim, & Thurston, 2008; Meert, Thurston, & Briller, 2005; Meyer, Ritholz, Burns, & Truog, 2006). Parents often find that the monitoring and life-sustaining technology surrounding their child creates a barrier to intimate contact; however, nurses can promote parents' abilities to feel close to their child by providing a large bed so that parents may lie next to their child (Falkenburg et al., 2016), or by showing parents how they can safely interact with their child (McGraw et al., 2012). In circumstances where infants are hospitalized immediately following birth, parents may not know how to be with their child, and may subsequently feel "out of sync with the parent role" (McGraw et al., 2012, p. e353) as a result. In such instances, the guidance of bedside nurses can be invaluable. Parents of an infant who was hospitalized in the PICU described how their child's nurse informed them as to how they could connect with their child:

> All we could really do was to touch him. We…didn't know how to comfort him. He was sedated. You know, the thing I remember the most was the one nurse who said that, 'He likes to have his head rubbed.' That was really important to us. (McGraw et al., 2012, p. e353)

Although the above study was focused on parenting at the end-of-life in the PICU, assertions such as these highlight the intimate connection between nursing care and parents' abilities to meaningfully interact with their children. Had this nurse not offered this information to these parents, they may have lacked the opportunity to offer support to their infant before his death.

In other instances, clinicians may also cause parents to feel disconnected from their child when present at the bedside. One mother described how she was prevented from being able to remain as close to her child as she would have liked since "sometimes I was told not to touch her and this was very painful…I felt a distance between me and her to avoid medical complications" (Lamiani, Giannini, Fossati, Prandi, & Vegni, 2013, p. 1337). In this instance it was not specified which staff member communicated this to this mother. However, it appears that this health care provider prevented this mother from meaningfully interacting with her child, which created painful memories of her hospitalization. In a qualitative study of thirty-three parents (61% percent mothers) of twenty six children in a PICU in the United States, another mother described how a nurse negatively affected her ability to bond with her child before his death when, in relation to the effects of a medication the child was receiving, the nurse stated that the child "probably can't see much anyway…it's probably just a blur" and how this "insensitive" comment detracted from this mother's ability to feel close to her son during these important moments (Meert et al., 2005, p. 423).

In addition to being at the child's bedside and connecting to the child through touch, studies suggest that many parents want to have "unlimited access" to their child, which includes the need to be present during urgent and critical events or interventions (Meert et al., 2005, p. 422). The ability to be present at the time of the child's death is critically important for some parents (Lamiani et al., 2013; Meert et al., 2009). When a parent who wants to be with their child during this time is unable to be present, it can create additional feelings of grief, loss, and regret. For example, in a study of the parents of eight children (seven mothers and five fathers) in an Italian PICU, one mother described the additional loss she experienced following her inability to be present when her child died, stating that "the fact that they called us when the child was

already dead was horrible. I had accepted the thought that my son could die...but not being there in that moment it was devastating" (Lamiani et al., 2013, p. 1340). This mother wished she had been called in time to be present for her child's death. In some situations, parents are physically present at the bedside but are unable to have the type of contact that they want with their child; some parents have described wanting to hold their child before their death but being unable to do so (Abib El Halal et al., 2013). However, the reasons for the parent's perceived inability to hold their child were unclear in this study conducted by Abib El Halal and colleagues (2013) in a PICU in Brazil, and there was no information regarding the conversations that occurred (if any) regarding this desire with the nurses caring for the child.

Participation in Care.

It is evident that a parent's ability to be physically present during significant moments is important, and this ability is intimately linked with a parent's ability to participate in their child's care. Literature suggests that parents want to be able to participate in their child's care in any way that they can, they need to be acknowledged for the unique contributions they make to their child's care, and they need clinicians to guide them to safely provide this care (Brooten et al., 2013; Butler, Hall, & Copnell, 2018a; Meert et al., 2009; Meert, Briller, et al., 2008; Merk & Merk, 2013; Meyer et al., 2006; Yorke, 2011). Parents have described that in some moments, nurses guided them to care for their child (McGraw et al., 2012; Yorke, 2011), while in other circumstances, unspecified PICU clinicians made parents feel displaced from their roles as primary caregivers to their children, thereby contributing to feelings of helplessness during their child's hospitalization (Lamiani et al., 2013). Some parents have also described that they want explanations as to the types of care they can provide to their child in this setting. In a mixed-methods study of twenty-three parents and guardians of fourteen children in the United States

(no additional demographic characteristics are provided by this author), one father expressed lacking confidence and feeling uncertain about the types of care he could provide to help keep his son comfortable (Yorke, 2011); this father would have benefitted from explicit communication and support from nurses to provide care to his son.

Forming Trusting Relationships with Clinicians.

When nurses support a parent's desire to provide care to their child, they promote the formation of trusting relationships at the end-of-life. Parents have described the importance of forming trusting relationships at the end-of-life in the PICU (Brooten et al., 2013; Meert et al., 2009; Meert et al., 2005; Merk & Merk, 2013; Yorke, 2011). Parents often feel vulnerable when their child is admitted to the PICU because they are thrust into a situation where they are relying on individuals whom they have never met before to take care of their child (Meert et al., 2005; Merk & Merk, 2013). For children who did not survive their illness, the development of trust between parents and clinicians was crucial because it contributed both to parents' comfort levels with the care that was provided at the end-of-life, and to perceptions that parents made the right decisions when reflecting back on their child's death (Meert et al., 2009). Trusting relationships may depend on a parent's perception that clinicians are providing care in the child's best interests (Meert et al., 2009).

For children who are hospitalized for extended periods of time, trust is fostered when consistent caregivers are assigned to provide care to children (Brooten et al., 2013; Yorke, 2011). This consistency is important to parents, as they are able to get to know the nurses who are taking care of their children, and subsequently feel assured that nurses are able to provide care competently and confidently (Brooten et al., 2013). Moreover, parents perceive that their child's needs are better attended to with primary nursing; one father described how primary nursing

benefitted his son and felt that the nurses were "his [son's] team. They had shifts…I was very glad to see the same person when I [came] in. Then I just didn't feel like they were assigning nurses to whoever's needed…that they have actually knowledge of his special symptoms" (Yorke, 2011, p. 99). When parents develop trusting relationships with nurses, they feel confident taking short moments of respite from the bedside since they feel their child will be well cared for in their absence (Brooten et al., 2013; McGraw et al., 2012). Although many parents feel they are able to develop trusting relationships with nurses as a result of the familiarity and consistency of their child's nursing assignments, the specific ways that trust features within nurse-parent relationships at the end-of-life in shorter term hospitalizations has not been explicitly explored in this context.

Being Informed.

Besides consistency in care providers, parents feel they are able to better trust clinicians when they perceive that clinicians communicate honestly about their child's prognosis (Meert et al., 2005). Most of the literature pertaining to the provision of information and communication at the end-of-life in the PICU surrounds conversations between parents and physicians regarding the child's prognosis and parental decision-making (e.g., Gordon et al., 2009; Meert, Eggly, et al., 2008). In a qualitative study of fifteen parents (nine mothers and six fathers) of thirteen children, some parents described that when information was not clearly communicated by physicians, nurses provided additional explanations and translated medical terminology so that they were better able to assimilate and understand the information (Abib El Halal et al., 2013). Parents have described that clinicians communicate effectively when information is delivered honestly, clearly and consistently (Falkenburg et al., 2018; Gordon et al., 2009; Lamiani et al., 2013; K. Macdonald, Latour, & Storm, 2001; Meert et al., 2009; Meert, Eggly, et al., 2008;

Meert et al., 2005; Meyer, Burns, Griffith, & Truog, 2002; Meyer et al., 2006; Yorke, 2011), and have described that the affect and timing through which professionals communicate information is also very important (Gordon et al., 2009; Meert et al., 2009; Meert, Eggly, et al., 2008).

Parents need to be well informed about and understand their child's prognosis and care plan so that they can fulfill their responsibilities as primary decision-makers for their children (Gordon et al., 2009; McGraw et al., 2012; Meert et al., 2009; Meert, Eggly, et al., 2008; Yorke, 2011). The ability to continue fulfilling this responsibility directly contributes to parents' perceptions that they are able to continue being 'good' parents to their child in the PICU. In most settings, parents want to retain their roles as primary decision-makers; however, while some parents want to be informed about the care plan, they do not wish to be the ultimate decision-makers for decisions that will likely result in their child's death (e.g., treatment withdrawal) (Lamiani et al., 2013).

Communication that is honest, clear, and consistent.

In many studies, parents have cited the importance of being provided information that is honest and realistic, so that false hope is not created and parents can anticipate the outcome of their child's illness (Butler, Copnell, & Hall, 2018; Gordon et al., 2009; K. Macdonald et al., 2001; Meert et al., 2009; Meert, Eggly, et al., 2008; Meert et al., 2005; Meyer et al., 2006). One parent highlighted this need by expressing that "I would have much rather they told me her chances were slim [for survival]" rather than falsely perceiving that their child would survive hospitalization because prognostic information was withheld (Yorke, 2011, p. 11). Parents have also described that anticipatory information is helpful so that they know what to expect as their child nears death (Lamiani et al., 2013; Meert, Eggly, et al., 2008). In a secondary analysis of qualitative interviews with fifty-six parents of forty eight-children who died in PICUs in the

United States, one parent[2] explained that "they told us exactly what was coming and what to expect, and that was really helpful in preparing ourselves psychologically" (Meert, Eggly, et al., 2008, p. 4). The health care provider who offered these explanations was not explicitly identified in this study. Regardless of which professional (e.g. nurse, physician, social worker) provided this parent with these explanations, this type of information before the child's death can be helpful so that parents have the opportunity to prepare for and anticipate what will happen to their child at the end-of-life.

Parents also need information to be communicated clearly, which entails clinicians using terminology that parents can understand, and assuring that parents have grasped the significance of the information that is being provided to them (Gordon et al., 2009; Meert, Eggly, et al., 2008; Meert et al., 2005; Meyer et al., 2002; Yorke, 2011). The latter aspect is especially necessary for the effective exchange of information. One mother emphasized how her son's nurses communicated information to her without ascertaining her understanding of its significance:

> [The nurse] called me at midnight to tell me that his urine output was low…I was not alert enough to say, 'Well what does that mean?' And then the next morning, the nurse called before she got off her shift to tell me the same thing. It did not occur to me that he [my son] is going to die today (Meert et al., 2005, p. 423).

In this instance, although it is impossible to know the nurse's reasoning behind communicating this information, what is clear is that, in situations like this, parents need biomedical information to be interpreted; it is extremely important to gauge a parent's understanding of the meaning of physiological changes to their child, because what might be an obvious sign of clinical

[2] I refer to study participants as 'parents' when the authors of the original inquiry do not specify whether the parent was a mother or a father.

deterioration to a health care provider might carry little weight or significance for a parent who does not have the same familiarity or knowledge base.

In addition to honesty and clarity in communication, many parents want clinicians – both within the PICU as well as outside consultants – to provide consistent information (Meert et al., 2009; Meert, Eggly, et al., 2008; Meyer et al., 2006; Yorke, 2011). When different and sometimes conflicting perspectives and opinions are shared with parents about the best course of treatment, parents' confidence in their child's caregivers is reduced, which contributes to feelings of distress and confusion (Meyer et al., 2006).

Respect and professionalism in communication.

All of these aspects of communication and information delivery are important; however, even if a clinician provides clear and honest information, parents can be negatively affected if this information is delivered without emotion or without regard for the seriousness of the situation (Butler et al., 2018; Gordon et al., 2009). Parents have described that clinicians communicate respectfully when they deliver information sensitively and use language that acknowledges the child as a human being and not solely in relation to their illness (Gordon et al., 2009; Meert et al., 2009; Meert, Eggly, et al., 2008). When such respect is lacking, parents perceive that their child is viewed as a "routine clinical case" (Gordon et al., 2009, p. 11). One parent described this feeling after a physician communicated that their child would not survive, saying the physician "came across very cold…Just the way he presented the information in such a matter-of-fact tone…It's like he did not have a concept that he was talking about a human being" (Meert, Eggly, et al., 2008, p. 4). When health care providers convey such a 'tone', it makes parents feel that the identity of their child and the significance of their experience are being disregarded. Closely related to respect is what some parents have described as

communicating ‘professionally’; professional communication in this sense involves clinicians considering the timing of the information they are providing (Gordon et al., 2009). In a qualitative study of fifty-one interviews with bereaved parents, a parent provided an example of unprofessional communication, describing that one of their child’s physicians informed them of their child’s brain death while simultaneously inquiring about the parent’s feelings about organ donation; this parent found this simultaneity extremely inappropriate (Gordon et al., 2009).

Being informed in relation to one’s parental role.

Many parents feel it is their responsibility to advocate for their children, and this is an important aspect of their role in the PICU (McGraw et al., 2012; Meert et al., 2005; Meyer et al., 2006). To be able to advocate effectively for one’s child, parents feel that they need to understand their child’s condition, treatments and interventions (Gordon et al., 2009; Meert, Eggly, et al., 2008; Yorke, 2011). Parents also require this information so that they can make decisions that align with what they value as best for their child. In a qualitative study of fifty-six parents (thirty-seven mothers, seventeen fathers and two legal guardians) in a PICU in the United States, one parent expressed the importance of being provided such information, saying, “I told them, you just let me know when it’s that time. You guys know if there’s nothing else you can do, I just don’t want her to bear the pain. If she’s suffering, I would just rather make the decision to let her go” (Meert, Eggly, et al., 2008, p. 4). Parents often want to maintain authority for their child’s well-being, and want clinicians to support the decisions that they make for their child (Meert et al., 2009; Yorke, 2011). When parents feel that they are able to understand the care plan, they have described feeling like they are part of the PICU team (Gordon et al., 2009). Parents want to have authority and retain their decision-making capacities for their child at the end-of-life.

In addition to being able to fulfill their roles as parents at the end-of-life in the PICU, parents may desire control over the environment at their child's bedside – including the ability to welcome as many family members and friends as desired, or to have intimate time alone with their child – parents want their child's personhood to be recognized, parents desire access to religious supports to address any spiritual concerns, and parents desire feeling unrushed following the child's death. These priorities are discussed in the following sections.

Environment

Parents want to feel that they are able to stay comfortably at their child's bedside (Butler, Copnell, & Hall, 2017a; Meert et al., 2009; Meert, Briller, et al., 2008), that they have privacy when desired at the end-of-life (Lamiani et al., 2013; Macnab, Northway, Ryall, Scott, & Straw, 2003; McGraw et al., 2012; Meert et al., 2009; Meert, Eggly, et al., 2008; Meyer et al., 2006; Yorke, 2011) and that they are able to have family and friends at the bedside for emotional and practical support when required (Meert et al., 2009; Meert, Briller et al., 2008; Meert et al., 2005; Merk & Merk, 2013). Additionally, they expect clinicians to foster a respectful environment through the ways that they work elsewhere on the unit (e.g., working with a solemn attitude throughout the unit) (Meert et al., 2009; Meert et al., 2005). Certain physical spaces and items need to be available for parents to feel they are able to stay comfortably with their child at the end-of-life. Parents want facilities for self-care that are located on the unit (including a place to shower, store valuables, sleep and eat) so that they do not have to leave their child's bedside for longer than necessary, they require adequate space for family and friends, and desire control over the amount of noise, lights and temperature in their child's room (Butler et al., 2017a; Meert et al., 2009; Meert, Briller, et al., 2008). The types of care that nurses provide to the child at the

end-of-life, and the ways that nurse welcome parents' presence and incorporate them into the child's care also contribute to parents' comfort in this context.

Parents also want to be able to control who is present at their child's bedside at the end-of-life (McGraw et al., 2012). Most PICUs have restricted policies for visitation, and some parents have described that such rules should be adjusted in the moments leading up to their child's death (Butler et al., 2018; Meert, Briller, et al., 2008; Merk & Merk, 2013). Some members of a parent's social circle offer crucial emotional support to parents; parents have reported that they find that sharing their experience of their child's critical illness with these individuals assists them to comprehend that their child is in fact going to die (Meert, Briller, et al., 2008). Other parents have described the instrumental assistance that family and friends can offer through the provision of meals, or offering to stay at the child's bedside so that the parent can take short breaks, but be reassured that their child is not left alone (Meert et al., 2009; Meert et al., 2005).

The presence of others is not always welcomed however; in certain instances, parents want be alone with their child. Privacy is especially valued when the child's death is imminent since parents may desire uninterrupted time during these moments (Meert et al., 2009; Meert, Briller, et al., 2008; Meyer et al., 2006). In the literature, parents have often attributed their abilities to have privacy at the end-of-life as dependent on their child's nurse. In a study that used open-ended, anonymous questionnaires to collect data from fifty-six parents, one parent described that their nurse "was so kind and compassionate. She stayed in the room with us but also gave us our space, which was really good" (Meyer et al., 2006, p. 652). While this parent valued this nurse's presence, the concrete ways through which the nurse fostered this parent's

privacy were not further described in this study; this is a limitation of the chosen data collection method.

In other instances, parents have described the negative consequences of nurses' presence at the bedside when it was not wanted or needed (Lamiani et al., 2013; McGraw et al., 2012; Meert et al., 2009; Meert et al., 2005). One parent described how, when their child was actively dying, the nurse "ruined the whole moment for us" by entering the child's room unannounced and giving the parents "some kind of a weird dirty look" (Meert et al., 2009, p. 728). Although it is clear that this parent remembers this nursing encounter in a way that was devastating, the authors did not provide additional details about this interaction; across the literature that I reviewed, authors often do not provide sufficient narrative detail to provide the reader with an idea of the context in which such devastating or meaningful interactions between parents and nurses occur.

In a study of seventeen mothers and one father conducted in a PICU in the northeastern United States, another mother expressed how she felt she was prevented from sharing intimate moments with her daughter when it mattered most to her:

> I couldn't do that with [pause] [crying] all the nurses… Everybody in and out, you can't have those private moments. And I just wished I had got in bed with her one time and gave her that last hug before she became incoherent. I never got that chance because it's so damn busy in there. (McGraw et al., p. e353)

It is evident that significant regrets can result when parents feel unable to have private time to meaningfully connect with their child at the end-of-life.

Parents' desires for respect and privacy continue through the child's death and during the postmortem period. Parents have described appreciating when health care providers foster a

"sacred atmosphere" by being respectful, as this acknowledges the impact of the loss that they are experiencing (Meert et al., 2009, p. 727). Clinicians influence the ways that parents live the experiences of their child's death through the manner that they carry themselves on the unit in general (Meert et al., 2009; Meert et al., 2005). One father explained that such respect entailed that "everybody was very sad...life does go on and people have jobs to do and everyone went about their business very quietly. Everybody was very solemn" (Meert et al., 2009, p. 728).

Fostering a respectful environment also occurs when clinicians demonstrate compassion and have caring attitudes at the end-of-life (Brooten et al., 2013; Meert et al., 2009; Meert et al., 2005; Meyer et al., 2006). While parents appreciate professionalism in the provision of information as described earlier, they have also described appreciating what they perceive to be authentic emotional expression from health care providers, since the expression of such emotions reflected care beyond what they expected of clinicians in their professional roles (Meyer et al., 2006). One father expressed that "knowing that your loved one was in somebody's hands that cared" made him feel that "everything possible" was done to help his child (Meert et al., 2005, p. 425). Some parents have expressed that staff (Meert et al., 2009), and nurses in particular (Meyer et al., 2002) foster important connections with parents at the end-of-life, almost as though they are a part of their families. However, the conversations and interactions that foster these bonds between nurses and parents have not been thoroughly described in these studies.

The child's personhood

Nurses also convey compassion and caring when they acknowledge the child's personhood while they provide care. In addition to wanting their child to be free of pain and distress (Brooten et al., 2013; Meert et al., 2005; Meyer et al., 2002; Yorke, 2011), parents want their child to be acknowledged as a unique individual who has "social worth" (Meert et al., 2009,

p. 726). One parent described how the nurse acknowledged their daughter's personhood as the nurse provided care to the child: "she [the nurse] was just really gentle and she talked to her while she was doing it and that kinda helped me feel more comfortable" (Yorke, 2011, p. 99). Parents appreciate when clinicians try to get to know the child beyond their illness by finding out about their personalities (Butler et al., 2018; McGraw et al., 2012) and when they address the child by name regardless of their age or level of consciousness (Falkenburg et al., 2018; Meert et al., 2009). When parents perceive that clinicians acknowledge their child's personhood, they feel that their child receives dignified and respectful care (Butler et al., 2018; Meert et al., 2005).

Spiritual support

Some parents have religious or spiritual beliefs and therefore find comfort from prayer, religious rituals or referral to spiritual texts (Meert et al., 2009; Meert et al., 2005; Meyer et al., 2002; Meyer et al., 2006; Robinson, Thiel, Backus, & Meyer, 2006). For parents with specific spiritual beliefs, the ability to perform certain rituals at the end-of-life can, for example, support the child's personhood by fostering the child's transition to the afterlife (Meert et al., 2005). Parents have most often referred to the support of hospital chaplains or individuals from their communities as helpful to offer spiritual support when it is needed (Meert et al., 2009); however, some parents have reported being offended by hospital professionals who approach them offering prayer during these intimate moments, especially if these individuals do not share their spiritual or religious views (Meert et al., 2005). Parents have also described the support they feel when they know that people in their social circles and health care providers are praying on their child's behalf (Meert et al., 2005; Meyer et al., 2006).

Some parents want to be able to seek counsel from religious leaders in their communities before they are able to make decisions at the end-of-life, and feel that this guidance is invaluable

in their perceptions that they are making the right decisions for their child (Meyer et al., 2006). Other parents' religious or spiritual beliefs will affect expectations about care of the body after death; some religions require burial before a certain amount of time has elapsed after death, while others may require the body to be "intact", influencing parents' opinions about autopsy or organ donation (Meert et al., 2009, p. 722).

Time: Being able to say goodbye

After a child has died, parents have described feeling an "altered sense of time and the need to not feel rushed" (Meert et al., 2009, p. 727) so that they can say goodbye to their child (Falkenburg et al., 2016; Lamiani et al., 2011; Yorke, 2011). During these moments, parents may want to hold their child, but often need to be explicitly told that they can do so by clinicians (Butler et al., 2018b; Macnab et al., 2003). Parents also want time to make decisions about postmortem care of the body – and whether they would like to participate in this care – to assemble family members, and to grieve in the presence of their child's body (Meert et al., 2009). During these moments, parents may want nurses to remove the medical equipment that is connected to their child (Abib El Halal et al., 2013); some parents may have never seen their child free of such equipment. In parents' final moments on the unit, nurses can assist parents who want to hold or bathe and dress their child after death, and to allow parents the time and space to feel unrushed in these activities (Butler et al., 2018b; Falkenburg et al., 2016) Postmortem care of the body involves rituals that allow parents to begin to say goodbye to their child, while acknowledging the child as a valued human being.

Being a parent after death

Thus far I have discussed different parental priorities at the end-of-life in the PICU. I will now examine some of the ways that parents fulfill their parental role after a child's death, and their desire for continued support once they return home.

The bond between parent and child transcends the child's death (Robinson et al., 2006), and parents maintain this bond by remembering their child and attempting to make meaning of their child's life and death (Macnab et al., 2003; Meert et al., 2009; Meert et al., 2005; Meyer et al., 2006; Yorke, 2011). Parents often find it helpful when they are offered the option of collecting mementos such as clothing, items from the hospitalization such as blankets or the child's bracelet, hand and foot prints, or a lock of their child's hair; they feel that these items help them maintain a connection with their child after death (Macnab et al., 2003; Meert et al., 2009). To remember their child and maintain a relationship with them, some parents attend hospital memorials, adapt events or holidays to acknowledge their child (e.g., celebrating the child's birthday each year, or recognizing the anniversary of the child's death), envision what their child's life would be like in the present, continue to have conversations with their child, and feel the desire to talk to others about their child's life and death (Meert et al., 2005). One father expressed "I didn't even want to forget the pain because I feel like if I lose it, then I'm kind of forgetting her" (Meert et al., 2005, p. 423), highlighting his desire to continue to think about and maintain a connection to his daughter. Other parents attempt to find meaning in their child's death by considering the good their children brought to their lives and to the lives of others (Meert et al., 2005). Examples of ways that parents search for meaning include consenting to organ donation so that others may benefit from their child's death, or through participation in

studies with the hopes of improving the experiences of parents who will lose a child (Yorke, 2011).

Clinician support after death

Some parents form important relationships with their child's health care providers during the child's hospitalization; however, these relationships often end abruptly after the parents return home following their child's death. For some parents, the immediate cessation of relationships with their child's caregivers contributes to additional feelings of grief and loss (Merk & Merk, 2013). Some parents have explained that staff efforts to maintain contact after death were valued because they conveyed that clinicians were still thinking about their child and them after they left the hospital (Meert et al., 2009; Meert et al., 2005). Parents have described that they also want practical information about the types of physical and emotional reactions they might experience as they grieve the loss of their child (Yorke, 2011). Others desire meetings with the child's physician to clarify the events leading up to their child's death (Meert et al., 2005), and some parents have explained that they felt supported when they received continued reassurance from staff that they made the right decisions for their child (Merk & Merk, 2013). Such reassurance can support parents' perceptions that they were 'good' parents to their children.

Inquiries that have specifically examined parental perceptions of PICU clinicians

Some of the aforementioned studies examined components of parent-nurse or parent-clinician relationships at the end-of-life in the PICU, and more recently, studies have explicitly explored characteristics of the relationships between clinicians and parents during a child's hospitalization (Butler et al., 2017a, 2018, 2018a, 2018b), parents' desires to have "meaningful" interactions with health care providers (Falkenburg et al., 2018, p. 2), and parents' perceptions of the quality of care provision based on clinician interventions and behaviors at the end-of-life

(Butler et al., 2018). Parents' perceptions about health care providers in general have been examined in these studies, and have therefore included physicians, nurses, social workers, and other allied health care providers. I will examine these studies in more detail since these inquiries more closely relate to my study as they aimed to elucidate parental perspectives of health care providers at the end-of-life in the PICU.

The evolving nature of parent-clinician relationships.

Initial hospitalization.

In a study of twenty-six parents (eighteen mothers and eight fathers) of eighteen children in four Australian PICUs exploring parents' perceptions of parental roles and the roles of their health care providers, parents described that their relationships with clinicians changed as their needs and concerns shift throughout the child's PICU hospitalization (Butler et al., 2018b). Initially, parents expressed that their priority was their child's survival, so they relied on "expert" clinicians to save their child's life while simultaneously "relinquishing care of their child" since they did not want to interfere with life-saving care (Butler et al., 2018b, p. 93). Parents described that they relied on clinicians during this phase of hospitalization to obtain information about the functions of different personnel and the procedures of the PICU (Butler et al., 2018b). This perception of the clinician as expert persisted until parents recognized that their child would not recover from their illness, and parents subsequently described their desire to "reconstruct" their role to "[mirror] their normal parental role with their child as much as possible" (Butler et al., 2018b, p. e28).

Knowledge of impending death.

Parents described that their abilities to parent their child in the ways that they desired were primarily dependent on the staff assigned to their child's care (Butler, et al., 2018b). When

parents perceived they were unable to parent their children as they wanted, they were made to feel like visitors rather than parents, and they perceived that staff "demonstrated ownership over the child" (Butler, et al., 2018a, p. e30). Conversely, when staff fostered parental roles, parents described feeling like they were working *with* clinicians; one mother described that her daughter's nurse fostered her ability to parent her child since the nurse "was overseeing the medical stuff" but otherwise supported her ability to bathe her child (Butler et al., 2018a, p. e30). Parents also expressed that continuity in their child's caregivers promoted their abilities to be parents in the PICU (Butler et al., 2018a). Most parents felt that the primary role of clinicians during this time was to manage technical aspects of the child's care to sustain the child's life until parents were ready to withdraw treatment, while some other parents expected their child's nurses to provide affection to their child when they were unable to be at the bedside (Butler et al., 2018a).

Imminent death and hospital discharge.

Parents described that as their child neared death, they required clinicians to adopt an expert role once again since they were unacquainted with the processes linked to treatment withdrawal and postmortem care (Butler et al., 2018b). After the child's death, parents expressed that they required continued support when they returned home; when parent-clinician relationships ended once they left the hospital, parents experienced feelings of abandonment, whereas when clinicians maintained contact, some parents described feeling that their child "meant something" to health care providers, and how this was important to them (Butler et al., 2018b, p. 95). The contact and support that most parents found helpful involved clinicians attending the child's funeral, providing bereavement resources to parents, clarifying parents'

questions about their child's death, or offering psychosocial support; the frequency and intensity of such supports decreased as time elapsed after the child's death (Butler et al., 2018b).

Meaningful interactions with clinicians.

In contrast to those parents who felt that clinicians' primary responsibilities at the end-of-life entailed managing practical components of a child's medical care (Butler et al., 2018a), in a qualitative study of thirty-six parents (sixteen couples and three mothers) of twenty children who died in a PICU in the Netherlands, parents highlighted the importance of the meaningful interactions that they had with health care providers (Falkenburg et al., 2018). These interactions consisted of staff conveying the commitment they had to promoting the child's well-being, the support that staff offered, and the personal connections that clinicians fostered with parents during the child's hospitalization (Falkenburg et al., 2018). Parents described that the commitment and the associated "relentless efforts" of physicians were important because these efforts made them feel that everything was being done to save the child's life (Falkenburg et al., 2018, p. e160). Additionally, parents found that clinicians were supportive when they demonstrated concern for their well-being, in addition to that of their child, by assuring that parents could remain comfortably at their child's bedside (Falkenburg et al., 2018).

Parents have also described the importance of the personal connections that they formed primarily with nurses during their child's hospitalization; for parents, these connections entailed getting to know staff as individuals by having "normal conversations" with nurses that were not focused on the nurse in their professional role (Falkenburg et al., 2018, p. e160). Parents also appreciated when they were able to share emotions with various health care providers, and felt that the personal links that were established led to health care providers understanding their experiences more thoroughly than their own families and friends (Falkenburg et al., 2018). What

was most meaningful to these parents was the ability to form relationships with clinicians that transcended the traditional parent-health care provider boundaries (Falkenburg et al., 2018). Parents had positive memories of the clinicians who conveyed their commitment to children, and who formed personal links with parents during a child's hospitalization (Falkenburg et al., 2018).

Parents' perceptions of 'good' and 'bad' health care providers.

Some parents have also "judged the quality" of PICU health care providers based on the degree to which parents perceived that staff supported the "maintenance of the parental role" (Butler et al., 2018, p. 20), which in the context of this study, meant that health care providers encouraged parents' presence at the bedside, involved parents in care, shared information, and sustained the child's humanity; parents viewed different PICU clinicians – including nurses, physicians, social workers, physiotherapists, and spiritual care professionals – positively or negatively, depending on how they felt supported in their roles as parents at the end-of-life (Butler et al., 2018). Parents felt clinicians were 'good' when they perceived that health care providers were calm and confident in the manner that they provided care, when they supported parents through the child's death, attempted to engage in collaborative partnerships so that parents felt trusted and involved in their child's care, and able to maintain proximity to their child (Butler et al., 2018). Parents also valued clinicians who cared for them, which entailed that staff remained present and allowed parents to express any emotions that they wanted to express, that they sensitively offered temporary distractions from the situation, and that clinicians encouraged parents to take care of themselves (Butler et al., 2018).

Parents viewed clinicians most positively when they displayed compassion; compassionate clinicians had "a bit more of a caring demeanor", were respectful, and displayed emotions in response to the child's death which made parents feel that "they had invested

something in us" (Butler et al., 2018, p. 22). Conversely, there were several actions and behaviors that parents considered negatively. Whereas parents appreciated clinicians who provided clear information, they felt that on occasion, clinicians withheld information, or communicated tactlessly and without emotion (Butler et al., 2018). Moreover, parents found that some clinicians mismanaged their hope by either removing it too soon, or by promoting hope falsely (Butler et al., 2018).

Parents did not appreciate when they felt that clinicians discounted their decision-making, or whom they perceived to be "arrogant", since this made parents feel inferior to certain clinicians; for example, one mother had the impression that her child's health care providers thought she was "stupid" because of the "looks" they gave her when she contemplated certain medical decisions (Butler et al., 2018, p. 22). Parents also found it difficult when they perceived that clinicians were dismissing their concerns as this inhibited parents' abilities to advocate for their child (Butler et al., 2018); parents felt that some staff perceived that they were overly concerned about insignificant issues, while others felt that medical staff adopted an attitude that suggested they were more knowledgeable than parents. Finally, some parents were made to feel that their child was less important than others following statements made by physicians that suggested they prioritized care of children who would survive hospitalization. For example, one parent described that a physician spoke of how the PICU team "[had] more important people to deal with, doesn't look like [child] is going to survive" (Butler et al., 2018, p. 22). The interactions that parents have with clinicians at the end-of-life are often very impactful; studies have detailed parents' recollections of health care providers, and memories of these interactions often remain a source of comfort or distress long after the child's death (Falkenburg et al., 2018; Meert et al., 2009).

Summary

In this chapter, I have reviewed the literature of bereaved parents' experiences of a child's death in the PICU, I presented the meaning of the parental role from parents' perspectives in this context, and I discussed the central importance that parents ascribe to their ability to fulfill their parental roles so they are able to be 'good' parents to their children at the end-of-life. I highlighted that parents feel they fulfill their parental role in this context when they are able to remain present at their child's bedside, to provide care to their child, and to take responsibility for their child's well-being. Parents' abilities to accomplish these components of their parental role are intimately linked to the health care providers that are caring for their child; clinicians can promote parents' perceptions that they are able to be parents in the PICU through the ways that they partner with parents and welcome them at the child's bedside, and through their ability and willingness to offer timely information so that parents retain their decisional responsibilities by making well-informed decisions in their child's best interests. Clinicians also influence parents' experiences positively at the end-of-life when they demonstrate confidence and competence in care provision, when they respect the child by acknowledging their individuality, and when they help parents through postmortem care.

Additionally, this literature demonstrates the importance that parents attribute to having access to different supports and resources so that they can comfortably accompany their child at the end-of-life, including personal and spiritual supports, as well as adequate facilities and physical spaces to promote self-care. This literature explored some of the ways that parents redefine their roles as parents once their child has died, and how for many parents, end-of-life care should not conclude when they leave the hospital; many parents have described the desire for continued contact with those who cared for their child in hospital once they returned home.

In the aforementioned metasynthesis on parents' experiences of PICU death, Butler et al. (2015) identified a main theme of 'reclaiming parenthood', which described the challenges that parents experienced when attempting to maintain their roles as parents, and the ways that parents attempted to reclaim this role during their child's PICU hospitalization (p. e964). This framing of the parental role by Butler and colleagues (2015) implies that this role is dichotomous, and that you are either a parent or you are not a parent. In comparison, my literature review provides a subtler, nuanced perspective about the parental role that also integrates the conception of being a 'good' parent at the end-of-life. Overall, my literature review offers the perspective that the parental role is not regained or maintained, but is realized to different degrees when various facets of the parental role or the priorities of parents are supported (or not). Additionally, Butler et al. (2015) have suggested that parents had to work to 'reclaim' their role. Based on my literature review, I argue that the onus is not solely on parents to 'reclaim' this role, but that clinicians (including nurses specifically) must also help parents *fulfill* aspects of the parental role that they consider to be important.

Although there have been studies that have more recently begun to explore characteristics of parent-clinician relationships and parents' perceptions of health care providers at the end-of-life in the PICU, to my knowledge, there has not been an explicit exploration of the ways that nurses influence parental moral experiences at the end-of-life in this context. Moral experiences consist of features of experience that make a person feel something is right and wrong, good or bad, make individuals feel "remorse, guilt, responsibility, justice, or distressed or fulfilled conscience…[and are] rooted in social and cultural contexts and relationships" (Carnevale et al., 2006; Hunt, 2009, p. 519). Recall, for example, the mother who had "accepted" that her son was going to die, but was devastated that she was unable to be present at the time of her child's death

when she was called back to the hospital after he had died (Lamiani et al., 2013, p. 1340). It is likely that this mother experienced remorse following her inability to be present during this important moment following the (in)actions of her child's health care providers. In another setting, primary nurses influenced a father's moral experience positively by providing 'good' care to his son, which he felt meant that they knew his son's unique characteristics and subsequently provided better care than nurses who had not cared for his child in the past (Yorke, 2011). These examples, among many others that are outlined in this literature review, indicate that the concerns and priorities of parents at the end-of-life in the PICU are morally significant even if they have not been explicitly identified as such.

It is evident that nurses significantly affect parents' moral experiences, given the strong nursing influence that appears within some parental accounts in studies that were focused more generally on parents' experiences of end-of-life care. It is also clear – yet it is still a gap in the literature – that the needs and priorities of parents at the end-of-life have significant moral implications; it is important to acknowledge the moral significance of these priorities to appreciate how they relate to people's values and core commitments (Hunt & Carnevale, 2012). Thus, given the influence that nurses have at the end-of-life, further research, analyzed through a lens of nursing ethics to account for the ethical significance of parental experiences, is needed to expand our knowledge regarding PICU nursing care during this time.

Chapter 3: Methodology

This chapter provides an overview of the methodology used to explore the research question guiding the study. I will first examine the project's qualitative research design and the philosophical underpinnings that orient this study. Then, I will discuss the study's theoretical scaffolding and methods, including the setting, sample, data collection and analysis, the dimensions that were considered to promote rigor, and the ethical considerations that were addressed when designing and conducting the study.

Research Design

Since I wanted to gain a better understanding of the subjective, experiential perspectives of parents regarding the ways that PICU nurses shape their moral experiences at the end-of-life, I chose interpretive description (Thorne, 2016; Thorne, Reimer Kirkham, & Macdonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004) as the qualitative research methodology for this study. Interpretive description was conceived as a methodology for applied health researchers to explore questions that arise from one's clinical practice in order to produce findings that are pertinent and helpful to practicing nurses (Thorne, 2016; Thorne et al., 2004; Thorne et al., 1997). In interpretive description, a study's purpose should be derived from "real-world" questions, knowledge of the current state of the literature to determine what is known about a topic and what remains to be discovered, and an understanding of the "conceptual and contextual realm within which a target audience is positioned to receive the answer we generate" (Thorne, 2016, p. 40).

In addition to developing a thorough understanding of what is already known about a study topic, researchers must ensure that their personal preconceptions, including their opinions, values, viewpoints and disciplinary orientation, are explicitly recognized and accounted for

throughout the design and conduct of the study (Thorne, 2016). Therefore, I considered and accounted for my preconceptions when conceptualizing this interpretive descriptive study, since this study's research question arose from my clinical practice, or "from the field," and was subsequently developed and refined with a thorough review of the literature (Thorne, 2016, p. 30; Thorne, 2013). An in-depth understanding of the literature is necessary when conceiving a study using this methodology; however, it is also important to recognize that study results need to be grounded within the data, and researchers must therefore also account for the influences that their readings of the literature may have on interpretations of the data (Thorne, 2016). When consideration of these potential influences occurs during a study, researchers will be more likely to develop interpretations that extend beyond the initial frameworks that inspired the project to elucidate the phenomenon in a novel and meaningful way (Thorne et al., 2004).

Researchers who employ this methodology should produce findings that identify common and patterned aspects of the chosen phenomenon, while also appreciating the unique variations that will be discovered (Appleton & King, 1997; Lincoln & Guba, 1985; Thorne et al., 2004). Interpretive description is not merely qualitative description. Instead, ID studies present results in a way that explore the underlying meanings of data beyond what is immediately apparent (Thorne, 2016; Thorne et al., 2004). Interpretation in this methodology draws upon the interpretive hermeneutic tradition, and this does not entail "pure" description; rather, when using interpretive description, the applied researcher attempts to discern links, interactions and commonalities within the experience while considering the context within which these experiences occur (Thorne, 2016, p. 56). Products of interpretive description are intended to generate knowledge that can be used by clinicians in their practice; as Thorne (1997) has asserted, "we seek to understand how people experience certain assaults of the body, mind and

spirit not in and of themselves but because we hope to be able to alleviate unnecessary suffering or harm and promote as much well-being as is possible under the circumstances" (Thorne, 1997, p. 122). In other words, I conducted this research with the hope that it might have practical value to bedside nurses providing end-of-life care in the PICU.

Philosophical underpinnings.

The philosophical underpinnings of interpretive description are aligned with the constructivist, naturalistic paradigm that was first described by Lincoln and Guba in 1985. Thus, researchers who use interpretive description acknowledge that 'truth' is relative (i.e., multiple realities can exist for a given phenomenon that may contradict one another), and that knowledge is constructed through researcher-participant interaction (Lincoln & Guba, 1985; Thorne, 2016; Thorne et al., 1997; Thorne et al., 2004). There is an inseparable connection between the researcher and the participant, as they will inevitably influence one another during the research process (Lincoln & Guba, 1985; Thorne, 2016).

In constructivist inquiries, 'truth' is sought by exploring the subjective perspectives of study participants in naturalistic settings (Appleton & King 1997; Lincoln & Guba, 1985; Thorne, 2016). The relativist ontology and subjectivist epistemology that characterize constructivism cannot be considered in isolation of one another since knowledge is the consequence of human activity (researcher-participant interaction) (Appleton & King, 1997; Guba, 1990; Lincoln & Guba, 1985; Thorne, 2016). Methodologically, constructivist researchers conduct studies that seek to identify the variances in the constructions held by individuals through the use of hermeneutic and dialectic approaches (Appleton & King, 1997; Guba, 1990; Lincoln & Guba, 1985); the former involves understanding the meaning of constructions beyond a superficial, descriptive level and the latter entails the pursuit of both converging and diverging

thoughts about the study phenomenon, so that conflicting perspectives may be identified (Appleton & King, 1997).

Theoretical Scaffolding

In the following section, I will describe the theoretical frameworks that informed my exploration of my study topic. From the review of the literature, it became evident that parents' priorities at the end-of-life in this context are morally significant and are likely to be influenced within the relationships that parents form with nurses. Thus, I specifically wanted to explore how parents' experiences are shaped in the relational context they share with nurses, and so I considered the moral experience (Hunt & Carnevale, 2011) and relational ethics (Bergum & Dossetor, 2005) frameworks to orient and guide my inquiry. I also considered the caring for-caring about continuum as a manifestation of relational engagement, by highlighting the differences between carrying out a caregiving task as part of a care routine or checklist, as opposed to caregiving that is performed compassionately (Borgstrom & Walter, 2015; de Raeve, 1996; Shogan, 1988).

Moral experience.

The moral experience framework was articulated by Hunt and Carnevale (2011) so that researchers could explore a wide range of morally significant matters that have received less attention in bioethics due to a prevailing focus on ethical quandaries and moral distress. Moral experiences are helpful to consider because, through this frame, ethically important moments are not reduced to high stakes decision-making dilemmas; instead, all interactions and lived moments are considered as ethically relevant where there are values at stake (Hunt & Carnevale, 2012). This framework was conceived to help identify what matters most to individuals and encompasses, "a person's sense that values he or she deem important are being realized or

thwarted in everyday life" (Hunt & Carnevale, 2011, p. 658), and entails an examination of an individual's interpretations of lived encounters "that fall on spectrums of right-wrong, good-bad, or just-unjust" (Hunt & Carnevale, 2012, p. 370), even if the individual is unsure what value to assign to the encounter.

Although parents' *moral* experiences at the end-of-life in the PICU have not been explored in the literature, quotes from parents often imply that their experiences are in fact moral experiences; for example, recall the mother in Chapter 2 who appeared to have experienced significant guilt as a result of her perceived inability to lie in bed with her daughter (p. 24), or the mother who likely experienced regret because she was at home when her child died (p. 14-5). These examples, along with others presented in Chapter 2, highlight the moral significance of parental concerns and priorities at the end-of-life.

A range of moral matters can be highlighted using this framework, as moral experiences include situations where one's values are achieved, hindered or fall somewhere in between opposite ends of the aforementioned spectrums of right, wrong, good, bad and just-unjust (Hunt & Carnevale, 2011). In the PICU, consideration of various facets of moral experience that occur in "mundane and everyday settings" (Hunt & Carnevale, 2011, p. 660) is important. Explicit 'ethical' attention to issues that occur in the PICU are typically limited to treatment decisions and decisional conflict, and the ways that parental beliefs and values factor into these decisions (e.g., Birchley, 2014; Hardart & Devictor, 2016; Harrington Jacobs, 2005; Stringer, 2013). Although these are indeed ethical challenges that are important to explore, there are many other moments when parents' values are at stake that merit our consideration, so that nurses might better be able to offer support during these difficult situations. In the PICU at the end-of-life, all situations and interactions are potentially morally significant (e.g., a parent's desire and ability to

change their infant's diaper can have moral consequences), and a moral experience framework draws attention to what those situations might be.

During data collection, I designed an interview guide that elicited perceptions of what parents regarded as 'good' or 'bad' in their experiences. For example, after parents described an issue that was important to them, I would ask participants how they felt about their ability to accomplish that matter of importance (or not), and how this impacted their experience. These reflective questions yielded rich insights into parents' moral experiences of nursing care, and these insights may not have been obtained had I not asked these specific questions related to moral experiences during the study interviews.

Moral experiences comprise how things matter to someone in relation to their personal values, and are based upon the hermeneutic conception that a person's experiences are best understood from their subjective viewpoints (Hunt & Carnevale, 2012). Although inquiry into moral experiences requires an exploration of individual perspectives, what matters most cannot be adequately understood without reflecting on the relationships and context that these experiences occur within (Hunt & Carnevale, 2011). Overall, the moral experience framework is meant to assist researchers to explore and better comprehend the various morally significant aspects of people's lives (Hunt & Carnevale, 2012), and is therefore a helpful lens to examine the values that are at stake to parents at the end-of-life in the PICU.

Relational ethics.

Given that moral experiences are relational and that there is a link between the realization or thwarting of parental values at the end-of-life in the PICU and the actions (or inactions) of nurses in this setting, it is important to consider how nurses engage with parents and form relationships at the end-of-life. Therefore, the relational ethics framework (Bergum & Dossetor,

2005) can help illuminate the ways that nurses shape the moral experiences of parents in this setting.

The relational ethics framework is based on the assumption that all relationships are moral in health care contexts (Austin, 2008); therefore, “ethical considerations occur in every situation, every encounter, and with every patient” (Bergum, 2013, p. 127). This framework can be helpful to orient researchers and clinicians to consider the importance of the relational space that is shared among patients, families and clinicians, and the relational characteristics that are central to the nursing profession (Wright, Brajtman, & Macdonald, 2018). Moreover, similar to the moral experience framework, relational ethics emphasizes the ethical aspects of meaningful everyday interactions that occur in this relational space (Wright, Brajtman, & Bitzas, 2009). From a relational ethics perspective, there is a shift from solely concentrating “on solving the ethical ‘problem’ to asking the ethical question,” and a shift in focus from the individual as autonomous to appreciating how every person is interdependent and linked to others (Austin et al., 2003, p. 45). Adopting this point of view requires that “one seeks to be sensitive to the particular care situation through the opening of dialogue between and among individuals, the consideration of intuitive responses to persons and issues, and an appreciation of the uncertainty inherent in human circumstances” (Austin et al., 2003, p. 45).

The core elements of relational ethics include environment, embodiment, mutual respect and engagement (Bergum, 2013). This framework highlights the importance of the environment as the ethical space where health care happens (Austin et al., 2003). The environment is “in each of us as a living system that changes through daily action” (Bergum, 2013, p. 129); thus, the health care system is enacted and influenced by the interdependent actions of clinicians, and patients and families, who are all affected in the caregiving encounter (Bergum, 2013). It is

important for nurses to attend to the environment since the context within which health care encounters occur is ethically significant; workplace culture may influence a nurse's ability to be open and respond to moral aspects of their practice (Austin, 2001). The environment encompasses and will shape the nurse's interactions with patients and families, and either promotes or constrains the nurse's ability to get to know their patients (and families) as "whole persons" (Austin et al., 2003, p. 48). Getting to know someone in such a way requires that nurses attempt to engage with patients in the relational space that exists in the clinical environment to appreciate the individual's life and relationships, thereby promoting that person's dignity (Austin et al., 2003).

Embodiment is enacted within the relational space between caregiver and care recipient, and "calls for a healing of the split between mind and body…so that scientific knowledge and human compassion are given equal status" (Austin et al., 2003, p. 47) and "emotion and feeling are understood to be as important to human life as physical signs and symptoms" (Bergum, 2013, p. 132). Relational ethics requires that clinicians encourage the reconnection between the object body and the lived body to remain ethically committed to who an individual is, in addition to attending to the physiological ailments that the individual requires care for (Bergum, 2013). Thus, efforts must be made to genuinely attempt to get to know the person who is being cared for. Embodiment is important to consider in the relational encounter because, as some parents in Chapter 2 described (p. 26), nurses who recognize and address children in their care as unique individuals may lead to parents feeling that their child received dignified, compassionate nursing care at the end-of-life.

In addition to efforts directed toward reconnecting lived body and object body, for ethical practice to occur, clinicians must foster mutual respect in healthcare encounters. Mutual respect

is integral to relational ethics and is the fundamental challenge that underlies relational action (Bergum, 2013). People will inevitably have different perspectives, values and beliefs, and mutual respect requires that they attempt to recognize the value of these varied viewpoints (Bergum, 2013; Wright et al., 2009). Mutual respect is achieved through authentic dialogue and requires efforts from both caregiver and care recipient(s) (Austin et al., 2003) to arrive at a way to "achieve cohabitation or coexistence" between different people with equally worthy perspectives (Bergum, 2013, p. 134). In addition to recognizing the value of the perspectives of others, and trying to get to know the people who clinicians are caring for, the type of knowledge required for ethical care is constructed within the clinician-patient (and family) relationship when both parties attempt to decipher the meaning that the disease holds for the patient (and family) as human beings (Bergum, 1994). In Chapter 2, there were certainly some instances where mutual respect was absent from the relational encounter, and significant consequences ensued for parents. For example, one mother described feeling that her abilities to make decisions for her child at the end-of-life were discounted by clinicians who made her feel 'stupid' (p. 34); perhaps these feelings would have never occurred had the clinicians engaged in conversations with this parent, so that the parent and health care providers could better understand each other's perspectives.

The final component of relational ethics that I will discuss is engagement. Engagement requires efforts to comprehend an individual's situation, viewpoint and vulnerability (Bergum, 2013), and necessitates that clinicians respond openly and sensitively to those in their care for an authentic connection to occur (Austin et al., 2003). Relational engagement occurs when people with diverse perspectives find a way to look at something together, and when a health care provider gains an appreciation for what a patient or family might want in the caregiving

encounter (Bergum, 2013). Although a nurse's proximity at the bedside fosters the conditions for nurses to engage with parents, nurses must conscientiously make the decision to explore what matters most to those in their care. Engagement was evident in one example in Chapter 2, where a nurse supported parents to connect with their child in a meaningful way when they were feeling 'out of sync' with the parental role in the PICU (p. 13).

Arguably, technical or practical nursing interventions can be accomplished regardless of a nurse's interest or ability to engage with the patient as a person, and in some settings "where nurses must race to meet the demands of bureaucracy and technology", the adoption of a routinized approach to care and the resulting disengagement that occurs foster circumstances where nurses fail to consider the patient's perspective in caregiving encounters (Austin, 2001, p. 16). In some contexts, disengagement is framed as being professional so that clinicians do not get 'over-involved' (Austin et al., 2003; Bergum, 2013). However, from the perspective of relational ethics, such disengagement is problematic because it creates "a technical relationship, [where] one nurse is interchangeable with another nurse and patients are interchangeable as well, identified according to disease or problem", thereby reducing patients and clinicians to objects rather than people (Bergum, 2013, p. 136). Engagement provides a manner through which meaning can be identified in the caregiving encounter, and promotes the clinician's ability to understand and respond to the moral commitments implied by their caregiving role (Bergum, 2013).

Caring for—caring about: A manifestation of relational engagement.

For ethical practice to occur, nurses require curiosity, intent, capacity, and opportunities to engage with patients (Austin, 2001). Similar to what Austin (2001) described as the adoption of a routinized approach to care, other scholars have differentiated between acts of caring that

lack engagement, and those that are directed toward a moral end (Borgstrom & Walter, 2015; de Raeve, 1996; Shogan, 1988). Distinctions have been made between 'caring for' and 'caring about', where the former "is a task-oriented concept which describes what might be involved in tending for someone or something" while the latter requires acknowledgement of the other in one's care (Shogan, 1988, p. 7). Nurses' abilities to 'care for' their patients at the end-of-life, in this sense, involve technical, measurable tasks such as timely medication administration to promote a child's comfort. The 'care for' portion of this continuum is important because "caring about is not in itself enough to ensure that adequate caring practices will take place" (De Raeve, 1996, p. 12-13). 'Caring about' is a manifestation of engagement in that caregivers take the time to demonstrate compassion, and caring actions are done with a moral purpose in mind; this purpose is identified by engaging with patients and families to identify what matters most to them.

In this section, I discussed the theoretical scaffolding that I considered during this study. An enquiry that uses the moral experience framework can inform clinical practice, in highlighting for nurses what is most at stake (Hunt & Carnevale, 2012) for those that they care for and about. Additionally, the relational ethics framework highlights the significance of the caregiving encounter, and how opportunities to appreciate what matters most to those in one's care occur in the shared relational space between nurses and their patients and families (Wright et al., 2018). These frameworks provided perspectives that helped me gain a more in-depth understanding of the study phenomenon (Thorne, 2016).

Assumptions

As a researcher who aligns with the constructivist paradigm, who views the experiences of parents as moral experiences, who considers encounters between nurses and parents as

ethically significant, and who chose to adopt the interpretive description methodology for this research study, I acknowledge using my prior knowledge and experience as a bedside nurse and the knowledge I have obtained from my review of the literature as foundational to this inquiry (Thorne et al., 1997). As was previously stated regarding my stance as a researcher, I am a nurse who works in the PICU, and I therefore have an awareness of what it means to provide end-of-life care in this setting from a nurse's perspective. The experience and knowledge that I brought to this study meant that I had preconceptions about what I might encounter as I proceeded throughout the study design and data collection, and I therefore explicitly acknowledged and reflected on the influences that these ideas may have (Thorne, 2016). These reflections occurred before I conducted the literature review, and evolved as I gained a more thorough understanding about what is known about the experiences of parents at the end-of-life in the PICU before conducting the study interviews. My assumptions were as follows:

1. In addition to the dramatic, morally ambiguous dilemmas that occur in the health care context, there is moral significance underlying daily nursing practice in the PICU.
2. PICU nurses will significantly shape the moral experiences of parents at the end-of-life because of their proximity at the child's bedside (and parents will shape the moral experiences of nurses).
3. The relationships that nurses form (or fail to form) with parents will have significant ethical implications on the ways that parents live experiences of a child's death in the PICU.
4. The values of nurses and the wide (biomedical) values of the PICU may shape or influence the values and experiences of parents at the end-of-life.

Methods

Setting.

Participants in this study were recruited from a PICU at a university affiliated, tertiary care academic hospital in Eastern Canada. The interdisciplinary team providing care to these critically ill children includes nurses, advanced practice nurses, intensivists, critical care fellows, pediatric medical residents, respiratory therapists (RT), pharmacists, nutritionists, social workers, spiritual care professionals and other allied health professionals; moreover, several services are consulted and collaborate with the PICU team to deliver care to children and their families. There are also often students from various disciplines doing clinical rotations on this unit.

The majority of beds on this unit are for children requiring one-to-one nursing; however, one third of the beds are for children requiring intermediate care. The intermediate care beds are on a separate floor of the hospital, but are staffed by the same interdisciplinary team that works in the PICU. From now on, the intermediate care unit will be referred to as the Step Down Unit (SDU). There are a few key differences between the PICU and the SDU that are worth noting. Although the interdisciplinary team staffs both units, most of the professionals are more often present in the PICU given the acuity of children's conditions in comparison to those that are admitted to the SDU. Therefore, the nurses who staff the SDU are often the only group of clinicians who are physically present on a continuous basis. End-of-life care is delivered in both the PICU and SDU.

The major differences between the PICU and SDU concern the physical characteristics of these units. Children have private rooms on both of these floors, but there are otherwise few similarities between the PICU and SDU. In the PICU, the side of the child's room that faces onto the unit is comprised of a large sliding glass door that allows for continuous observation even

when the door is closed. There is a large curtain inside the room that can be drawn shut to promote privacy, but the curtain and door are most often left open to allow observation of the child. There is a large window in each child's room that faces outside and there are windows between patient rooms with shutters that can be opened or closed (e.g., when nurses are covering two patients in adjoining rooms when their colleague is on a break). This window allows visualization of both children under the nurse's care. Otherwise, these shutters are typically closed. Each room in the PICU otherwise has two large mobile surfaces that have intravenous poles, nursing and respiratory therapy equipment and the vital signs monitors. There is also a nursing cart and table with additional supplies and medications at the bedside, a surface that parents and other family members can use for personal items, a closet for parents' larger personal items and a seat that extends for a parent to sleep on overnight. Additional chairs may be in the room as needed. There is typically a maximum of two family members at the bedside at once (this is a rule of the unit unless there are exceptional circumstances). Additionally, the PICU is a closed unit, so parents must ring a 'doorbell' before being able to enter. Self-care spaces such as a bathroom, showers, and the family room are accessible to parents, and are adjacent to the unit within the locked entrance.

Another difference between the PICU and the SDU is the nurse's physical proximity to the child. Nurses are often assigned to care for one child at a time in the PICU, and although there are two workstations on this unit, nurses always document patient care in the alcoves that are directly outside the child's room so they are able to visualize the child, the monitors and other equipment in the room at all times. In some instances, the nurse will remain inside the room because of the child's unstable medical condition. Thus, in the PICU, a nurse will be present in or near the child's room at all times.

In comparison to the PICU, the SDU has a similar layout to other medical and surgical wards in the hospital, and is an open unit that does not have a locked entrance. The nurses' workspace is in a nursing station in the middle of the unit, the workspace has central monitoring that connects to the vital signs monitors that are in each child's room (the vast majority of children have some type of monitoring on at all times). One nurse is assigned to care for two children at a time while working in the SDU. If nurses are not at the workstation, they are in patient rooms, or will otherwise be found in spaces from which children and their parents are restricted, such as the medication room or the medical supplies room. There is always a minimum of two nurses present on the unit.

In the SDU, there are small alcoves outside each child's room with a small window. There is also a glass window on the door to each room, with curtains on the inside that are often drawn closed for privacy. The curtains may be opened or closed depending on the child's clinical condition, but when they are fully drawn closed, there is no direct visibility into the room from the hallway. Inside each child's room, there is a large window facing outside the hospital, there is a television, a private bathroom (including a shower), a closet for personal storage, a couch for family members to sit or sleep on, and a large chair for the child to sit on, or for family members to sit in while holding the child. Other spaces outside of the room include a dining area, and a playroom with different games and toys for children and siblings.

Sample.

Convenience sampling was used for the study. Potential participants were identified from the mortality statistics of the PICU and the SDU. This sampling method was chosen for a number of reasons: 1) The hospital moved to a new building, and there was a major restructuring of the entire hospital (additionally, bereaved parents had been researched in the previous hospital

setting); 2) There were only 34 eligible sets of parents, and I was concerned about recruitment rates given the sensitivity of the research topic, so I recruited from the entire 'population' that was available at the study site.

There are limitations inherent to this sampling approach since common aspects of experience may be more related to the context (i.e., this specific PICU) rather than to the phenomenon itself (Thorne, 2016), and in heterogeneous populations, there is the risk that one subset of the population might be over or underrepresented (Polit & Beck, 2012). In the PICU setting, I anticipated that there would be differences in parents' moral experiences of nursing care given the heterogeneity of the population of children who are admitted to this unit (e.g. planned versus urgent admissions, ages ranging from neonate up to young adult, chronic versus acute illnesses, parents with previous PICU experience versus no previous experience). While moral experiences are unique to each individual (and there will therefore inevitably be differences between different parents' moral experiences), the experience of a parent of an adolescent who dies unexpectedly from an unintentional injury might differ in comparison to the parent of an infant who has been hospitalized for an extended period of time and then dies following treatment withdrawal. Studying moral experiences are therefore challenging, as the unique characteristics and backgrounds of parents will shape their values and perceptions of what is right or wrong in a particular situation. Despite this challenge, exploring moral experiences allows for consideration of how the PICU context influences the subjective, individual experiences of parents at the end-of-life, while appreciating both the commonalities and differences that may be discovered.

Parents were eligible to participate in the study if they spoke English or French, and if their child died between six to twenty-nine months (the date of the hospital move) prior to

contact for study recruitment. If one of two parents was interested in study participation, they remained eligible for recruitment. Exclusion criteria included if a/the parent(s) were facing allegations of parental misconduct contributing to the child's hospitalization preceding their death or if I had directly cared for the child at the time of death. Once eligible parents were identified, half of the group were randomly selected and were sent recruitment packages. The second half of the group was sent recruitment packages six weeks later. The reason for this staggered approach was two-fold: first, I wanted to avoid a situation where more parents expressed interest than could be included in study participation, and second, I wanted to allow myself time to engage in analysis of earlier interviews before proceeding to complete data collection. Parents were invited to participate on a first come, first served basis.

Eleven parents (all of the parents who wanted to participate) of six children participated in the study. The children's deaths occurred between 1 to 2.5 years prior to contact for study recruitment. The ages of children ranged from a few days old up to elementary school aged; four children were under one year old at the time of death. All participants except for the mother and father of one child had previous experience with hospitalization of their child in the PICU. The length of stay preceding the child's death ranged from hours to months. Four children died following the withholding or withdrawal of life sustaining treatment and two children died following unsuccessful cardiopulmonary resuscitation. All but one child died in the PICU (one child died after being transferred from the PICU to the SDU).

Procedures for data collection.

Once ethical approval was obtained from both the study site and the University of Ottawa (Appendices A and B), eligible parents were identified and were mailed a recruitment package that contained a personalized invitation letter that was modeled from previous bereavement

studies (A. Butler, personal communication, June 6th, 2017; Butler, Hall, & Copnell, 2017) (Appendix C), information about the study (Appendix D), a consent form (Appendix E), information about some of the common feelings and reactions associated with grief and bereavement (Appendix F, adapted from Morris, n. d.), and a 'consent to contact' card (Appendix G) with included return postage to facilitate parents' abilities to express their interest to participate in the study. The methods underlying participant recruitment were informed by a previous study of bereaved parents (Butler, Copnell, & Hall, 2017b; Butler et al., 2017). If parents were interested in obtaining more information about the study, they could either contact me directly by email or return the consent to contact card to be contacted at a later date. After three weeks, parents who did not respond were sent a reminder card about the study (Appendix H). Two parents returned the consent to contact card and the remainder of parents who participated in the study sent emails to obtain more information about the study. I subsequently had conversations over the phone with all potential participants who demonstrated interest to answer their questions about what study participation would entail. Because of these recruitment methods, I do not know parents' reasons for non-participation.

Data was collected through face-to-face semistructured interviews that were audio-recorded to enable transcription accuracy (Polit & Beck, 2012). Parents participated in one interview that occurred at a time and place that was most convenient to them. Three sets of parents chose to be interviewed in their homes, two sets of parents were interviewed in a private conference room at the hospital site, and one parent was interviewed in a private office setting. Interviews were conducted in French (n=3) or English (n=3) according to parents' preferences. The decision to be interviewed alone or with one's partner was left to parents' discretion. Ten parents chose to participate in joint interviews (Polak & Green, 2016), and one mother (whose

partner did not participate) was interviewed alone. The use of joint interviews elicited shared experiences, and some parents also simultaneously identified aspects of their experiences that differed from their partner. During the interviews, I initially asked general questions about the experience of a child's death, and I eventually used specific probing questions to try and determine if there were differences between the experiences of each parent.

During joint interviews, there were moments where participants interacted with each other to construct their stories by prompting and reminding each other of various aspects of their experiences while each sharing complementary information (D.L. Morgan, Ataie, Carder, & Hoffman, 2013; Polak & Green, 2016). There were often instances where I offered minimal prompting, and parents constructed accounts of their stories and asked probing questions of each other to clarify and remind each other of particular details of their child's death. While these aspects of joint interviews were beneficial, there are also limitations to this interview format (Polak & Green, 2016). In two interviews, one interviewee (the mother in both cases) dominated the conversation and the fathers in each interview participated minimally. It was evident that these mothers did not intend to monopolize the conversation, as they also attempted to explicitly prompt their partners for their perspectives about their experiences, but their efforts (in addition to my own) were mostly unsuccessful.

Interviews took place between February and May 2018 and lasted between eighty minutes up to four hours and twenty minutes. Parents were asked open-ended questions to allow them to tell their stories in their own words (Polit & Beck, 2012). Participants were initially asked to tell the story of their child's death in the PICU, and were subsequently asked about their priorities during this time and how their child's nurse influenced their experiences (see Appendix I for the interview guide). With participant permission, I took notes during the interviews

regarding key points to return to at a later time in the interview while ensuring that my primary focus remained on participants' unfolding narratives of their experiences (Thorne, 2016). As we progressed through the interview, I summarized key ideas that I was hearing to determine if these topics were what the participant(s) wanted and intended to share (Thorne, 2016). Field notes were written within twenty-four hours following the interview to document my initial thoughts, impressions, and analytic ideas (Polit & Beck, 2012).

Prior to entering the research field, I considered how my professional role as a nurse might influence and constrain my ability to effectively conduct a research interview (Thorne, 2016; Thorne 2013). Rather than adopting the role of an expert clinician, I considered myself a "curious learner" by acknowledging and valuing the centrality of the narratives that participants would be sharing with me in the interview (Thorne, 2016, p. 140). I also allowed participants to lead the conversation and shape the direction that it would take (Thorne, 2016). I avoided the use of "value-laden prompts" such as stating 'that's good' or 'I understand' to prevent participants from thinking that I agreed with or preferred some of the information they were offering (Thorne, 2016, p. 125). Although I attempted to reduce the influence that my professional role may have had on the research interview, I did explicitly identify myself as a nurse to participants in the recruitment package and prior to starting the interview. This disclosure likely influenced the manner through which participants shared information, since some participants viewed me as a representative of the group of clinicians they were talking about, and they occasionally addressed me directly as a nurse during the interview.

Data analysis.

In interpretive description, data analysis is done inductively, and "requires that we learn to see beyond the obvious, rigorously deconstructing what we think we see, testing hunches as to

how it might fit together in new ways, and taking some ownership over the potential meaning and impact of the outcomes that we will eventually render as findings" (Thorne 2016, p. 156). Data analysis occurs concurrently with data collection (Thorne, 2016; Thorne et al., 2004) and preliminary analysis therefore began after the first interview was conducted. During data analysis, I had a preliminary data analysis meeting with my supervisors and I also presented my evolving results to university colleagues at a Nursing Palliative Care Research and Education Unit meeting.

I transcribed all of the interview audio recordings in the days that followed each interview; while transcribing, I included notes about what was happening during the interview (e.g., if a child entered the room and briefly interrupted the interview), about participants' emotional states (e.g., if they were raising their voice in anger, or if they were crying or laughing during a particular moment of the interview), and I wrote every word that was said by participants (including 'um', or 'like', for example). Transcripts were written in the original language of the interview; the quotes that were eventually selected to illustrate the study's results were translated into English at the outset of data analysis. This preparation of the data for analysis and the subsequent verification that occurred to assure the accuracy of each transcription was a "rudimentary" beginning to analysis as I highlighted phrases and passages that struck me as important, and began jotting down my thoughts about the text in the transcript margins (Sandelowski, 1995, p. 373).

Formal preliminary analysis started after the transcription of each interview was completed and began with my attempts to gain an understanding of each interview individually prior to attempting to draw comparisons among different interviews (Sandelowski, 1995). To "get a sense" of each interview, I repeatedly read each transcript to grasp its central features

without feeling forced to make analytic progress (Sandelowski 1995, p. 373), and I also re-listened to audio recordings while reviewing transcripts to fully engage with each interview (Thorne, 2016). I eventually created summaries for each interview describing the features that I deemed were central to each narrative (Sandelowski, 1995).

After I felt I obtained an overall understanding of an individual interview, I continued preliminary analysis by returning to the original transcript to highlight passages that I felt might be important (Thorne, 2016), and subsequently read each transcript repeatedly with a different question in mind to focus my thinking with each reading (Sandelowski, 1995). These repeated readings were done so that I could highlight transcripts with different colors when I felt that there might be similarities among different portions of the data, and to eventually gather similar portions of data together in files separate from the interview transcript to compare them to other groupings with (potentially) different properties (Thorne, 2016). Throughout data analysis, I took notes about my findings and evolving conceptualizations to record and keep track of my ideas about potential patterns in the data without committing to specific conceptualizations too early (Knafl & Webster, 1988; Thorne, 2016).

To keep my analysis focused, I repeatedly referred back to the original study aim and research question, not so that "no new insights about the phenomenon [were] possible, but rather to return to [the research question]… as a kind of beacon to guide the directional choices" that I faced as I proceeded through data analysis (Thorne, 2016, p. 165). I eventually applied descriptive titles to categories of data that appeared similar; these titles derived from in-vivo excerpts in order to honor participants' voices by employing the actual language that was used in the interviews (Saldaña, 2009) before I began applying more interpretive category titles. I

explicitly assigned titles to different categories of data in this way so that I prevented myself from inscribing meaning on a data grouping before moving forward analytically (Thorne, 2016).

The questions that I asked myself as I proceeded through each reading were increasingly complex. I initially asked more superficial, descriptive questions as I read the data, and moved towards more interpretive questions where I was attempting to ascertain the meaning underlying participant statements (Thorne, 2013). I considered interpretive analytic questions in an attempt to reveal morally significant aspects of parents' experiences of nursing care, such as

> What conceptions of right/wrong, good/bad, just/unjust underlie this assertion?
> What does this mean?
> What deeper meaning(s) underlies this assertion?
> What is the source of this deeper meaning?
> Which conceptions of right/wrong, good/bad, just/unjust are concealed?
> Which meaning(s) are concealed? (Carnevale, 2013, p. 172)

At this point in data analysis, I began developing conceptions about relationships among different data groupings in relation to the overall research question. During this stage, frequent meetings were held with one of my thesis supervisors to discuss our evolving analysis and to consider other ways that we might understand the data (Thorne, 2016). Following each meeting, the relationships between individual portions of data and the interview set as a whole became increasingly refined and developed. During data analysis, I tried different formulations to consider how individual components of the data might fit together, which took several attempts, and involved re-grouping the data according to my evolving conceptualizations. The overall analytic process and study results were the product of a collaborative effort incorporating my perspectives and those of one of my thesis supervisors.

Dimensions that were considered to enhance the quality of this study.

I considered dimensions that have been proposed by Tracy (2010) to enhance study quality in qualitative research. I have attempted to orient my thesis in a deliberate and thoughtful

way around these quality criteria. In the following section, I will elaborate on these concepts and how I attempted to establish rigor as a result of strategies that were implemented both during the inquiry itself and at the outset of the study (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Tracy, 2010).

Worthy topic.

For Tracy (2010), quality qualitative research has to explore an important topic. I considered the 'worthy topic' dimension when the study was initially conceived. As has previously been described in this thesis, the study's topic initially arose from my clinical practice as a bedside nurse, and was later modified and refined as I gained a more thorough understanding of the literature, and as a result of the guidance from my thesis supervisors. A "worthy topic" may emerge from one's clinical practice, and must be significant and interesting in that it contributes a novel perspective to a current phenomenon (Tracy, 2010, p. 840). Through my clinical practice, I know that nursing care matters in the PICU, and I felt it was therefore worthwhile to explore *how* it matters to parents at the end-of-life.

Rich rigor.

Following the identification of the study topic, 'rich rigor' was promoted throughout the design and conduct of the study. I attempted to conduct a rigorous study by engaging with theoretical scaffolding throughout the study, and by trying to obtain rich data in my interviews with parents. While "there is no magic amount of time in the field", the most significant issue pertaining to the adequacy of one's data relates to whether or not the data is able to support meaningful and substantive claims that are made in the findings (Tracy, 2010, p. 841). I explicitly account for the limitations to both the study methods and sample, and I will clearly indicate how these might affect my overall interpretations of the data.

In studies that use interviews for data collection, rigor is also assessed and demonstrated through the number and duration of interviews, the characteristics of participants and the sample size, the questions asked during the interviews, by how detailed transcription was, and by the practices that were used to promote accurate transcription (Tracy, 2010). I have included information in the methods section of this thesis about each of these aforementioned elements. Following data collection, rigorous data analysis is characterized by transparency about the manner through which data is selected and organized (Tracy, 2010). Thus, I provided readers with an explanation as to how raw transcripts were examined, and how data was ultimately chosen and organized into the study findings.

Sincerity.

I will now explain some of the quality markers that were considered as an end goal of this qualitative study. The first indicator is sincerity, which is accomplished through "self-reflexivity, vulnerability, honesty, transparency, and data auditing" (Tracy, 2010, p. 841). Overall, sincerity requires the researcher to be honest and transparent about one's biases, goals and weaknesses and how these played a role in the research process (Tracy, 2010). Throughout my thesis, I have endeavored to be transparent about the potential biases that I may have brought into this study as a PICU nurse, and as a novice researcher, and I will describe some of the limitations associated with my position as an 'insider researcher' in Chapter 5. Although I am a novice researcher, I was closely supervised throughout this study by my thesis supervisory committee members who have expertise in qualitative research, critical care, pediatrics, palliative care, anthropology, clinical nursing, and nursing ethics, and they offered support and guidance throughout the research process. According to Tracy (2010), sincerity is also accomplished by conducting transparent research, which entails the consideration of the manner through which a researcher

gains entry to the study context, and by the level of detail involved in transcription (this has also been explained in the methods section of this thesis).

Credibility.

In addition to sincerity, credibility refers to the trustworthiness of the study findings, and is realized in part through the use of triangulation (Tracy, 2010). To promote the study's credibility, I employed the use of investigator triangulation during data collection and analysis (Tracy, 2010). In this study, this was accomplished during all phases of data collection and analysis. For example, one of my thesis supervisors provided feedback about the way I conducted the first study interview, and offered constructive criticism so that I would obtain more in-depth information specific to our research aims and question in subsequent interviews. Moreover, halfway through data collection, a formal meeting was held to discuss preliminary analytic findings with both thesis supervisors before I proceeded to the latter half of the interviews. As was previously mentioned, I worked closely with one of my thesis supervisors during data analysis and the drafting of the study's findings; our diverse viewpoints about the data reduced the risk of biased analytic interpretations, and promoted our ability to explore different facets of the phenomenon of interest (Polit & Beck, 2012).

Meaningful coherence.

Meaningfully coherent studies employ methods that align with the study's theoretical frameworks and underlying paradigm, and connect the literature to the research aim, methodology and findings (Tracy, 2010). The study's conception, design, and findings must be coherently connected to one another (Tracy, 2010), so researchers must demonstrate consistency between the study's research question, underlying epistemological standpoint, and interpretive approaches that arise from the study foci (Thorne, 2016). To promote meaningful coherence, I

have attempted to present a logical line of reasoning throughout this thesis from the research question that I asked at the outset of this study, to the epistemological assumptions that I hold that are aligned with the constructivist underpinnings of interpretive description, through to the way that I have analyzed, interpreted, and presented study results.

Ethical considerations.

Prior to applying for ethical approval, administrative approval from the head nurse of the PICU (who is also a part of the thesis supervisory committee) was obtained. Ethics approval was obtained from the hospital's research ethics board (Appendix A) and from the University of Ottawa Research Ethics Board prior to study commencement (Appendix B). Eligible parents were mailed a recruitment package; bereaved parents have indicated that a letter was the least intrusive method of contact, and allowed them time to consider the request to participate in a study before being directly approached by the research team (Butler et al., 2017b).

Risks.

There were risks inherent with the informed consent process because we were conducting research about a sensitive topic with vulnerable participants. The grief that parents experience will last forever but takes on different manifestations over time (Barrera et al., 2009), and may affect parents' abilities to understand information and make informed decisions at different moments (Parkes, 1995). While grief is very subjective, there are indications in the literature that parents begin to redefine their identities and meaningfully reconnect with the world around six months after the death of a child, and although grief often remains present in parents' lives, its acute manifestations become increasingly episodic as time elapses following the child's death (Barrera et al., 2009). With these considerations in mind, parents were only eligible for study inclusion if their child died at least six months prior to recruitment (Butler et al., 2017b). The

informed consent documents were written in plain language and were included with the recruitment package to allow parents adequate time to review these documents and consult with others as needed.

To further promote participants' informed consent, written consent was obtained from each parent individually prior to the interview so that any questions could be answered. Additionally, during the interview, I verbally reaffirmed consent with participants by inquiring if it was okay to ask particularly sensitive questions (Butler et al., 2017b) to assure that participants were only sharing what they were comfortable with (Thorne, 2016). Prior to commencement of the interviews, participants were reminded that they could withdraw from the study at any time and choose not to participate. During the interviews, participants were reminded that breaks could be taken if needed, and that the interview could be stopped completely if parents felt that they did not want to continue (Butler et al., 2017b; Thorne, 2016).

Interviews occurred at a convenient time and place to minimize the burden of participation. Given that I knew there was a strong likelihood that parents would feel strong emotions during the interview (including but not limited to sadness, anger and distress), if parents felt that they required psychological support following the completion of the interview, the contact information for the PICU Spiritual Care Professional was provided. Although the majority of parents did experience such emotions, they all declined the need for support after the interview was finished. Parents were also provided with information about the common feelings that they might experience as a result of revisiting their experiences to allow them to prepare for the possible emotional reactions that they may have (Butler et al., 2017b).

To maintain confidentiality, parents, their children and any other individuals mentioned by parents (e.g., health care providers) were assigned pseudonyms that were linked to their study

data. The interview transcripts were immediately de-identified upon transcription (Thorne, 2016), and were stored in password-protected files and on secure servers that were only accessible to the research team. Any other identifying information, including paper copies of transcripts without identifying information, the audio-recorded interviews, and completed consent forms were kept in a locked office at the study site, and these documents were only accessible to the research team. Nine of eleven participants consented to the possibility that their data may be used in future secondary analyses; the audio recordings of these five interviews were conserved following transcription (one audio recording was deleted after transcription at the remaining two parents' request). Since electronic data needed to be accessible from multiple geographic locations, transcript files were encrypted and kept on a cloud storage system (a secure server through the university affiliated to the hospital) that was password-protected, and was only accessible to the research team. According to the local Research Ethics Board, study data must be kept securely for seven years following study publication (which also satisfied the University of Ottawa's data conservation timeframe).

Benefits.

Despite the potential emotional distress that participants may experience, previous participants in sensitive research have indicated that there are also positive aspects of study participation. Participants have frequently reported being appreciative of opportunities to recount their stories, and they may experience an increased sense of self-awareness and healing, empowerment, and emotional release (Elmir, Schmied, Jackson, & Wilkes, 2011; Kavanaugh & Ayres, 1998; Opsal et al., 2016; Sque, 2000); in my study, it is possible that the duration of the interviews indicated that participants wanted to talk and were appreciative of their opportunities to share their experiences. More generally, information generated from this study will contribute

to knowledge advancement of nursing care provision of children and their families at the end-of-life in the PICU.

Summary

In this chapter, I explored the study's methodology, constructivist underpinnings, and theoretical scaffolding, as well as the study methods that were employed, the dimensions that were considered to promote a quality qualitative inquiry, and the ethical risks and benefits of conducting this research study. I now turn to the results of my interviews.

Chapter 4: Results

Introduction

Recall that the research question guiding this study was: How do parents interpret and describe the influence of nurses on their moral experiences of their child's death in the PICU? Thus, I sought to identify morally significant moments of parental experiences at the end-of-life in the PICU, including aspects of their experiences that made parents feel a sense of right-wrong, good-bad, or just-unjust. I also identified moments where nurses shaped the experiences of parents at the end-of-life by considering the relational ethics framework and its constructs of environment, mutual respect, embodiment, and engagement.

Participants

Eleven parents (six mothers and five fathers) of six children who died in the PICU participated in this study. Participants included parents of children who had complex congenital cardiac malformations (n=3), genetic or metabolic conditions (n=2) and neurological disorders (n=1). Four children died following the withholding or withdrawal of life sustaining treatment. The interval between treatment withholding or withdrawal and death ranged from minutes up to days. Two children died following unsuccessful cardiopulmonary resuscitation, and three of these four parents were not present at the time of death. One child died in the SDU after being transferred from the PICU, and the rest died in the PICU. The length of stay in the hospital preceding the child's death ranged from hours to months. The ages of children ranged from days old up to eight years old, and four children were infants at the time of death. Three children had already been admitted to the PICU before the hospitalization during which they died; therefore, their parents had formed previous relationships with, and opinions or expectations of the nurses already. Two sets of parents had children who were born in hospital and lived in the PICU until

their deaths; these parents also formed relationships with their children's nurses prior to the end-of-life. One child was admitted post operatively and died unexpectedly hours later following unsuccessful resuscitation; this child's parents had no previous experience with the nurses on this unit.

End-of-Life and Postmortem Nursing Practices in the PICU and SDU

Before discussing study results, I will provide context about the end-of-life and postmortem nursing practices in this PICU and SDU. While there is no formal orientation or training for the provision of end-of-life care that is offered to nurses in this setting, there are common practices that occur. For example, either prior to or after the child's death, parents are offered a memory box to collect items and memorabilia of their child's hospital stay; formal items that are in this memory box include a card with a small zip lock bag for parents who want to collect a lock of hair, and cardstock for hand and foot prints (memory box items are provided by the hospital). In addition, nurses have access to handmade quilts and clothing for infant baptism made by volunteers, and knitted hats, mittens and socks that can also be offered to the parents of infants. Additionally, parents are encouraged to take home any personal items that they want from the child's room (e.g., the child's hospital bracelet or blankets).

After the child's death and once the parents have returned home, the PICU/SDU social worker and spiritual care professional coordinate bereavement follow up. One of the components of this follow up includes leaving a card on the unit for nurses and other health care providers to sign to express their condolences and offer messages of support to families. These cards are sent to parents between four to six weeks after the child's death. There are additional aspects of this bereavement follow up that are exclusive to the social worker or spiritual care professional, that are outside of the scope of what nurses typically participate in.

Results

In the following section, results will be presented about parents' moral experiences of end-of-life nursing care in the PICU. Although certain features of parents' experiences are common across the sample, there are differences in the ways that parents felt supported by nurses, both across different cases and between parents of the same child, and within individual parent's stories. What is evident across interviews is that the ways that nurses were most helpful to parents changed as parents' needs changed. During particularly crucial moments of the end-of-life experience, parents often did not know what they wanted and depended on nurses to adopt a directive role and make suggestions for them. From parents' perspectives, nurses consistently offered guidance throughout the end-of-life, but this guidance was manifested more subtly when the most intense moments of parents' experiences occurred (e.g. treatment withdrawal or after death). Nurses fostered positive moral experiences for parents when they simultaneously offered support while promoting parents' privacy at the end-of-life; whether parents were aware of it at the time or not, all participants later realized that they benefited from nurses' discretion during these moments. Nurses also fostered parents' positive moral experiences when they conveyed that they cared about the child, their death, and the parents themselves. The ways that nurses conveyed the significance of these relationships made parents feel that they and their child would not be forgotten. At the end of this chapter, I will present a divergent case that, in combination with my study results, highlights the individualized nature of parents' moral experiences.

In the rest of this chapter, I will provide a detailed examination of the study results and the supporting data from participants.

Participation in care

Parents often wanted to be involved as caregivers to their children while they were hospitalized in the PICU. The activities that they hoped to enact differed depending on their circumstances. Some parents wanted their perspective to be acknowledged by their child's nurses and other health care providers about the types of care that should be provided at the end-of-life, others wanted to provide 'normal' care that they would have otherwise provided to their children at home, and some parents wanted to help provide care that might stabilize their child's condition. Opportunities to provide all types of care were dependent on their children's nurses.

Nurses who included parents in caregiving activities by explicitly inquiring as to parents' desired level of involvement were found to be helpful. Catherine is the mother of an infant with a complex chronic condition, who had been hospitalized several times in the PICU, and who died following the withholding of life sustaining treatment. Catherine described how nurses asked her about the types of care she would like to provide during the hospitalization that preceded her daughter's death:

> …they would ask us, like that week we decided, you know what, it's hurting her, let's not even do dressing changes, 'cus technically like, it doesn't really make a difference anymore. Like they would ask *everything* we wanted to do, 'do you want to give her a bath?'... I remember once I just said, 'you know what? Let's just wash her hair, because her body, I don't wanna hurt her too much'.

These conversations made Catherine feel that "our opinion mattered to them [nurses] so much, in terms of what [the nurses] would do with her, what we, what we felt was comfortable", thereby making Catherine feel regarded as the expert in her daughter's care.

In times where interventions were centered on the child's survival, parents did not want to detract from this focus because they felt that life-saving care was the priority. While parents did not want to interfere with medical care, they still wanted to implicate themselves in their

child's care but described feeling hesitant to communicate this desire. Parents found that nurses were not always receptive to or inclusive of their participation in caregiving activities. This is illustrated by Liana, the mother of an infant who was hospitalized at birth and lived for months in the PICU until her death. Liana and her husband Ian both described that they experienced difficulties feeling that they were parents in this context because they often felt unable to participate in caregiving activities. In the following example, Liana discussed her perception of the nurse's role and her own role as a mother, and how she felt she had to justify her desire to be implicated in her daughter's care:

> To say, I am able to work with you, and you can work with me…I will leave you your place, you are the priority to provide care, and I know that your work is more important, but you know, to be able to say like, I am still her mother, and I am involved.

Liana felt that until the moment where she and her husband became more involved in their daughter's care that they "weren't parents". Liana's statements underline the close relationship she perceived between her ability to be involved in caregiving and her identity as a mother. This quote also suggests that at some point in her daughter's hospitalization, Liana had somehow come to feel that the significance of her role as a mother was inferior to the medical and nursing care that was being provided to her child (i.e., "I know that your work is more important").

Liana was not the only parent who experienced hesitancy in implicating themselves in their child's care. Zachary, the father of an infant who died unexpectedly hours after being admitted to the PICU, also emphasized medical and nursing care as the priority, stating that "all I care about is that they do something good for my daughter..." Nonetheless, Zachary would have felt "more comfortable to interact with my daughter, in what limited ways that I could" had nurses engaged with him and elicited his perspective about what he wanted during the time his daughter was in the PICU.

Parents' hesitancy to express this desire to be implicated in their child's care, in combination with nurses either not attempting to understand parents' perspectives or identifying this desire, led to parents feeling like "spectators" during their child's hospitalization. Zachary felt "out of place, in the sense that, people were doing all these things and I was just there, and…I didn't know what I was or wasn't allowed to do and stuff." Both Ian and Liana felt similarly during most of their daughter's hospitalization. As Ian explained:

> We're in the hospital, it's health, the care is the priority, so it's the nurses and physicians who are touching your child, who are speaking to your child, and who are taking care of your child. You're more of a spectator. There is nothing you can do…

Being present at the bedside and watching nurses provide care to their children made some parents experience feelings of powerlessness in relation to their ability to help and support their child during their illness.

In other instances, parents had to ask if they could participate in their child's care, and depending on the circumstances, this request was either met with inclusion or reluctance on the part of the bedside nurse. For example, during his daughter's hospitalization that lasted for months, Ian always knew he wanted to be more implicated in his daughter's care; some of the caregiving activities that Ian wanted to participate in included changing his daughter's diaper, giving her a bath, and dressing her in her own clothing. Ian initially felt uncertain about how he could accomplish all of this, but eventually he and his wife explicitly asked the PICU team to be implicated in their daughter's care, and although "there was not any reluctance [from the healthcare team], it [caregiving] wasn't offered to us either." Audrey, the mother of a child who was admitted for a few days before she died, also had to ask to be included in her daughter's care. In her case, she expressed this desire to the bedside nurse after her daughter Francine

experienced cardiac arrest, and the nurse subsequently made Audrey feel like they had entered a "working relationship":

> …well Francine was starting to have fever…so ok, let's get some ice, let's get her temperature down, I will put [icepacks] at different places, ok you [nurse] do this, uh you do all the monitoring, what can I do to help? And I wanna help, so what can I do? I felt, I needed to help, and uh (tearing up), yeah, [the nurse], she was really good about letting me help, you know, and, doing something for the, the situation (continues crying)…

A collaborative relationship was fostered as a result of this teamwork. Audrey's ability to assist in her daughter's care made her feel that "[she] was doing something for the situation, you know, doing something for Francine…it was just super powerful…" Audrey's ability to contribute to her daughter's care and to work with the nurse was important because it made her feel that she was helping her daughter and doing something in a situation that was otherwise out of her control. Had this nurse not engaged in this collaborative relationship with Audrey, this mother might have felt powerless in this stage of her daughter's hospitalization. The nurse's inclusion of Audrey in her daughter's care made this mother feel that she and the nurse had complementary roles, in contrast to Ian, Liana, and Zachary who felt at times that their role was not as important as the medical care and nursing care that their children received.

There were other moments where some parents felt that nurses were unwilling to include them in their child's care, and this engendered negative consequences. For example, Liana described that being implicated in Bella's care "was somewhat a battle at the beginning" because "it wasn't everyone who was comfortable letting us [be involved]." Liana's ability to provide care was initially dependent on the nurse who was assigned to her child:

> So, doing a diaper change because there was a PICC line. So they [the nurse] was there, [I would say] yeah but we're usually doing it. You know, there were multiple times where I arrived with the nurses, and …I know it's a PICC line, that I have to be careful.

> I'm doing it [changing the diaper] normally…You know there were some nurses who told us, 'no I prefer that you don't touch it and that I do it.' But if I don't change that diaper, well I'm not doing anything else. I'm sitting in the room and I'm waiting.

From Liana's perspective, although proximity to her daughter was important, it wasn't sufficient to be present in her daughter's room; she felt that she needed to actively contribute to her daughter's care in whatever ways that she could.

Those parents who were hesitant or had to ask to participate in care often felt a sense of helplessness during their child's critical illness. In some cases, parents gained a sense of control when they felt they were making unique, complementary contributions to their child's care. Ian highlighted that nurses could have fostered more of a positive, empowering moral experience had they encouraged him to be involved in his daughter's care sooner:

> …to not just be, ok we're sitting in the corner of the room, we're watching what's happening, we're not talking much. You know to be told 'implicate yourselves, participate in care,' things like that. Because you never know how long the admission will last. The faster we implicate ourselves, first it passes the time, and it helps mentally and physically. You know, you have the feeling that you're helping your child even more so.

Ian's words suggest that what is at stake for him is feeling as though he is helping his child. Indeed, involvement in caregiving activities supported parents' abilities to either fulfill their role as parents, or for parents of newborn infants, to experience this role for the first time. Liana explained that the first time she truly felt like her daughter Bella's mother was when "we did all of the things that normal parents do like sleeping with [Bella], giving her a bath, this really helped us say that we didn't spend [her whole life] in a hospital waiting room…we were parents and we did the things that parents do, and Bella is our baby."

For most parents, feeling implicated in caregiving was central to living their child's hospitalization positively, but this participation was not universally valued in all circumstances.

Similar to Ian and Liana, Jacqueline and Nathan's daughter was hospitalized for an extended period of time in the PICU; however, their daughter died unexpectedly following failed cardiopulmonary resuscitation. Jacqueline and Nathan did not describe any barriers towards being able to participate in their daughter's care during her hospitalization. After their daughter's death though, they were not interested in participating in postmortem care, as Jacqueline describes:

> It was better that it was the staff, a professional who did it, because we weren't able to. In fact, I wasn't able to, I couldn't, even if the nurse had asked if I wanted to participate, I would have said no. Because, in my head already, I didn't see that my daughter had died, I saw that she was still alive, I knew that she was sleeping. So… to tell me, we're going to give her a bath, for uh, for the morgue and everything, no, I couldn't do it.

While in most cases participating in care was helpful or even integral to participants' positive memories of being parents in the PICU, Jacqueline and Nathan did not want to participate in postmortem care because such participation would have forced them to engage with a reality that they were not yet ready to acknowledge.

I previously mentioned that Catherine appreciated being regarded as the expert in her daughter's care. However, she also did not always want to be providing care at the end-of-life, and therefore valued the quality of care that nurses provided to her daughter:

> … that last week, I didn't have to do that [worry about the quality of care] at all, was so much [of a] relief, because I already had so much on my head, and such a burden on me, already, my child is dying, how do I – how, how is it going to happen? What's going to happen after?

During these moments, this mother's priority was to focus on her personal experience of her daughter's death, and her confidence in the nursing care that was being provided allowed Catherine to focus on being with her daughter. These examples show how there is variation both

across and within cases regarding the extent to which participation is valued and influences the experiences of parents.

The need for guidance and accompaniment: "What do we do now?"

Parents also valued nurses who adopted a directive role at the end-of-life and who helped them navigate this period. As Ian put it, he felt:

> …someone was taking us by the hand, and ok, this is where we are going….the goal isn't pleasant, we don't want to go there, but you know, having a hand to guide us, having someone who's bringing us there, that's nice for that reason also.

Guidance involved more than just managing the child's medical care to sustain their life; parents described wanting to feel accompanied by nurses during these difficult moments. Accompaniment meant that nurses offered parents emotional support in addition to managing the child's care at the end-of-life. For Audrey, once she realized that her daughter would not survive, guidance meant that her daughter's nurses were "directing things [prior to her daughter's death]" because she felt "…a bit clueless, it's [the death of a child] not something you've ever done in your life, nor would you ever think of doing." Many parents felt that a significant component of the guidance offered by nurses consisted of providing helpful suggestions about how things could proceed as the child approached death, as most parents did not know what options were available to them. Audrey found it helpful when her nurse asked if she wanted to hold her daughter, while Ian and Liana found it helpful that their nurse inquired with them as to what items they would like to collect for the memory box, and what clothing they would like to dress their daughter in prior to her death. Thus, in some instances, nursing guidance facilitated parental participation.

For Denise – a mother whose daughter died in the SDU hours following treatment withdrawal – one aspect of such guidance was a nurse's suggestion to remove vital sign monitoring as her daughter neared death:

> Because then there was really too much variation [in her vitals], and it [the monitor] wasn't making noise but it was flashing. And we were getting so overwhelmed, we were really stressed from it. And at a certain point in time, she [the nurse] became aware of this, and she told us 'if you want, I can take it off, but [only] if you're ready for that.' You know she really asked us about it, she took the time to do that… because, you know it was another sign that we were getting closer to the end. So, I remember that she really took the time to ask, 'are you ready for me to take it [the monitoring] off?'

What was especially important to Denise was that this nurse sensed the distress she and her husband were experiencing, and subsequently assessed how she might help these parents focus on their daughter. From this mother's perspective, this nurse engaged with these parents and identified that they might be ready to proceed with a step that suggested their daughter was "getting closer to the end", and positively influenced the way that this mother experienced an important transition at the end of her daughter's life.

In Ian's case, his family had been assigned primary nurses because of their long stay in the PICU. These nurses would always be assigned to his child when they were scheduled to work, and as a result, he and his wife Liana developed important relationships with these nurses. One primary nurse in particular was present on the day of his daughter Bella's death, and Ian found her suggestions in preparation for this moment extremely important:

> There are so many things that if Liz [nurse] had not brought these ideas, we definitely would not have thought of them. [Bella] would have been dressed you know, yes she would have been dressed, but she wouldn't be, maybe not in the clothing that we wanted her to be wearing, we wouldn't have a lock of hair. We took photos…yes they are photos from when she died but we look at them anyway…so, it was important, I think it was

> maybe even more important than the moment itself [when she died], how we experienced that.

This father felt supported by this nurse since he felt that she was considering and bringing forward all options that he and his wife were not aware of. As a result, he was able to have more mementos of his daughter's life and death. In this instance, the nurse's directive role fostered attention to this child's personhood even after she died.

Parents described not knowing how to proceed when they learned that their child was going to die. Most parents described benefitting from nurses' abilities to recognize the ambiguity of these situations for them and to subsequently provide helpful suggestions to live through their experiences. That being said, explicit attempts to determine what might be most useful for parents at the end-of-life were not always welcomed. This was the case for Denise, who felt it was inappropriate when the palliative care team (comprised of a physician and a nurse) approached her and asked her outright what she wanted:

> They sent us the palliative care team. Who arrived with questions, 'what do you need?' But how am I supposed to know what I need? I don't need this, I mean, [the death of a child] has never happened to me, it's the first time. How am I supposed to know what I need during these moments? … Rather, I need you tell me, you know, what I should, what I need to do, and what you suggest [I should do].

In this situation, Denise did not yet know that her daughter was going to die, and she did not find it helpful when the palliative care team tried to elicit her priorities by asking her what she needed. Whereas during the previously described interaction with her daughter's nurse, Denise knew her daughter was going to die and was appreciative of the directive suggestion that the nurse offered regarding her daughter's vital sign monitoring. While it appears as though Denise found it more helpful when suggestions were provided to her versus being asked what she might

need, it is also evident that the helpfulness of these interactions and discussions are situational and dependent on the timing during which they occur.

The directive role of nurses was also important for Jacqueline and Nathan, whose daughter died suddenly and unexpectedly. In their situation, they needed their daughter's nurse to step in even more than those parents who had time to prepare for and anticipate their child's death. Both Jacqueline and Nathan felt it was difficult making decisions about what they might want or need after their daughter died; Nathan describes the types of decisions he was unable to make, and how the PICU team (including nurses) guided him and his wife during postmortem care:

> …there were other things that I was unable to decide. Like, do we leave, go to another room, do we stay here with her, do we give her a bath? Do we – there were many, many, many things, and that's exactly why, the team who was with us, like the nurses, the doctors, and the woman from spiritual care, that's why they were important. Because, what we didn't see, what we weren't thinking about, well they were capable of saying, 'is it worth doing this?'

Nathan emphasizes that he needed others to make decisions for him because "…it was difficult to think, it was difficult to make the right decisions, because we didn't even know what the right decision was." This perceived inability to make decisions about the types of postmortem care to participate in, or whether he should step out of the room momentarily, led Nathan to require nurses and other health care providers to make choices for him.

During these moments, Nathan was so focused on his daughter's death, and felt that "nothing else mattered" besides having his daughter back. Yet the clinicians caring for his daughter identified ways he could have positive memories of this traumatic experience:

> Because most of the time she was wearing a hospital gown. So, we said to ourselves, if we're going to dress her up, we will take off the hospital gown and we will put on her

> pretty dress, and we said, yes…the nurse took her things and, I would have never thought to dress her in that clothing. You know, I needed it, but I couldn't think of it because, mentally I wasn't prepared to take the right decisions at the right moments. Since I didn't even know what the right decisions were.

Nathan wanted his daughter to be dressed in her own clothing, but was unable to recognize this desire. By making this suggestion, his daughter's nurse played an instrumental role in supporting Nathan as he was processing and coming to terms with his daughter's death.

Zachary and Judith's daughter also died suddenly. However, they did not find the same comfort in the guidance that other parents found helpful, because they knew exactly what they wanted in the moments following their daughter's death. Both parents were at home when their daughter experienced cardiac arrest; Zachary arrived to the hospital before his wife, and described:

> …in terms of the thing that was most helpful – and I think this is really particular – like that, that's what I needed, I needed everybody to leave me alone, and for me to be with my daughter, and to bring my wife when she came…

Zachary was certain that he wanted to be left alone and found that the provision of different options such as music or pictures was unhelpful.

When parents sought guidance at the end-of-life, nurses' abilities to guide them and identify what they might want was essential:

> There are so many things you have to go through, to think about…and, to be reminded, a tap on the back, 'don't forget this, don't forget that'. That's what makes the difference between positively living through this experience or not. Because you don't have a second chance to redo it (Ian).

The preparation and guidance that nurses offered to parents also influenced their bereavement when they returned home after their child's death. Liana emphasizes how her nurse's guidance affected her long after her daughter's death:

> If you are well prepared before, and you've done everything you wanted to do, you've expressed or you've spoken, or you've, you know, you've really gone through everything, then, the hour where she died, it's almost just…physical…Then after that, after that hour, then it's…bereavement. So, I need to be ready for that. I don't have regrets... I, I have my things, I have all my mementos [for the memory box], so I'm sad but I can look at my mementos. You know that helps a lot.

Parents who did not know the options that were available to them or how to prepare for the end-of-life felt supported and accompanied by the nurses who identified what was most important to them, and who led them through these challenging, ambiguous moments.

There were moments for some parents where they felt that nurses lacked the ability to guide them through the child's end-of-life. In the hours leading up to her child's death, Denise recalled the general nervousness of a nurse who was caring for her daughter; Denise found this nurse "super pleasant, super nice, [they were] very gentle with us" but while the nurse was well intentioned, they were "*extremely* uncomfortable" (emphasized by participant). Denise wondered if this was this nurse's first time caring for a dying child. A specific moment that Denise felt was representative of this nurse's discomfort occurred when they brought a memory box to her daughter's room to collect mementos:

> It was maybe [that they were] awkward, you know. There is this box with uh, uhm, for the final moments, where we can put a lock of hair…[They] didn't really know, you know how to use the box. We could see that [they] had a lot, a lot of hesitation.

Denise felt that this nurse lacked confidence; if a nice attitude is not accompanied by confident nursing actions, then the risk is that parents will feel unsupported and unaccompanied during a time where they require guidance from their child's nurse.

Discretion and privacy: "Being present at the same moment that she was absent"

Parents' desires for guidance shifted during the most intense moments that they experienced; many parents wanted nurses to be discreet during their child's final moments and

immediately after death. From parents' perspectives, a nurse's discretion meant remaining present and engaged but providing care that was 'invisible'. Promoting parents' privacy through discretion allowed them to focus on their child during these intimate moments. For Zachary – who wanted to be alone with his wife and daughter after her death – the nurse's ability to provide such invisible care was such that he had difficulty recalling she was even present. Zachary questioned "was she [the nurse] even there, or am I just imagining [that she was]?" This father doubted that there was a nurse present until his wife reminded him during our interview. Both Zachary and his wife Judith felt that this nurse was discreet and "that she didn't impose [herself]", which was what they needed during this time. From this father's perspective, the nurse's decision to provide care discreetly and give them space following their request for privacy was most helpful following his daughter's death:

> I think that nurse was very good, very good in the sense that she was just there, like, almost like not there. Like, I forgot that. But like, that was good, right? Like, so she didn't interrupt anything, she just tried to be as helpful as she could.

Judith similarly emphasized the benefits of this nurse's discretion following her daughter's death:

> Well, I think it was, it was nice, it gave, it gave me time to be with her, to be with my daughter, without um, with like minor interruptions… for me that was, it was, I think it was better that way that it was more in and out, and, just give, just gave us the time to, you know, just be with her.

Zachary felt that although the nurse would occasionally inquire with him and his wife to see if they wanted any additional support, this nurse was most helpful because of the distance she established and the "intimate setting" that was created as a consequence. Ian also similarly recalled the way that the bedside nurse discreetly provided care in the moments surrounding his daughter's death. For Ian, discretion meant that this nurse was "…being present at the same

moment that she was absent, you know, as much as they were there to accompany, to be helpful, to do what they had to do, you know we were able to be Liana and myself with Bella and live that as if it was just the three of us."

Audrey also found it helpful when nurses removed themselves from the bedside as her daughter was taking her last breaths, and described that "…that moment, just her and I, was, very, appreciated, and they [the nurses] didn't come for quite a while. And it was good, we, we had a chat, I told her stories…so then it really felt like she was falling asleep."

Catherine also described that her daughter's nurse would periodically check in to see if she needed anything, but was otherwise not present in the room following her decision to withhold treatment. While Catherine found it was respectful that nurses were not constantly in the room, she felt that their presence was not bothersome because "even during the times the nurses are there, it's not like, they're, disturbing you, or intruding in anything, they're doing their work, you know?" Catherine perceived that nurses' presence did not impede on her experience of her daughter's death, because they were "[coming] to do their job, or just doing their thing and going" rather than trying to initiate conversations with her that were not relevant to her daughter's immediate care needs. Thus, while it appears that Catherine was not disturbed by the nurse's occasional presence, there was the potential for the nurse to be intrusive on this mother's experience had she tried to hold conversations with her besides those that were essential to her daughter's care.

From parents' perspectives, nurses' discretion and the subsequent privacy that was created often "happened naturally" without discussion. However, parents' recollections suggest that nurses might have actually been recognizing parents' needs for privacy during these moments, and purposely adjusting their presence at the bedside accordingly. It appears that

nurses simultaneously continued taking a directive role while providing care discreetly. This simultaneity is most evident in Nathan and Jacqueline's case; these parents did not know they wanted intimacy after their daughter had died until the bedside nurse suggested it:

> … like I said before, in a situation such as this one, you don't know what you need. It's hard to say, I want privacy. If she hadn't suggested this, 'do you need for us to leave you alone?' I would have never asked, yet I needed to be alone with my family. So, I see a role that we weren't able to perform at that moment, in that situation. So, the fact that someone, well I wouldn't say an outsider, but someone with another perspective, says, 'ok it's possible that this family might need some privacy, ok I am going to ask them. Ok, would you like it if I left you for two seconds?' Yes. But I would have never done that, to say, listen, you can leave us for a few seconds, and I am going to stay with my family. And no, no, I wasn't able to, I didn't even know that I would need that, but I needed it. So, you know, she thought of things, that we needed, but were unable to ask for.

In contrast to the other nurses who physically left the room, this nurse fostered these parents' privacy by staying "with [them] in the background":

> …She was right in the room, you know she was, she had closed the curtain, when we had asked for a bit of privacy, she had closed the curtain, but she was like, behind the curtain. So she was constantly with us, constantly, constantly, constantly, she didn't leave us, not for one second, no she was there the entire time, and she was just behind the curtain.

In Nathan's account we see further evidence of "being present [while] absent". In other words, discretion from nurses does not equate to disengagement or being withdrawn from the bedside. The nurse's identification of this need for privacy, and the way she remained present for these parents made Nathan's wife Jacqueline feel "important, it made us understand that we were important, and that, [the nurse] really wanted us to feel better and at ease."

Unfortunately, nurses did not always perform the discrete, invisible care that was needed to foster moments of intimacy for parents at the end-of-life. Liana recalls how her experience of

her daughter's final moments was negatively affected when the nurse did not think to clean her daughter's face following extubation:

> …one of the things that I remembered for a long time… when she was extubated…she was all sticky [from the endotracheal tube adhesive] – and all that, you know they had applied a product to remove the adhesive. And you know, it stayed a long time in my memories that when I went to kiss her, or like, I was rocking her, and it smelled so strongly. So, I was saying to myself, how difficult would it have been to just clean [her face] a little bit?

Had the nurse cleaned this child's face, Liana would have been able to kiss her daughter and possibly held onto the memory of this last kiss. She likely would not have attributed her ability to share this moment with her daughter as having been facilitated by the nurse; cleaning the child's face would likely have been an 'invisible' act that would have gone unnoticed but would have nevertheless influenced her experience. This highlights that nurses' discreet work during these moments can have impactful consequences.

Manifestations of 'Caring About'

Most parents in this study had previously established relationships with and perspectives about the quality of nursing care in the PICU. Prior to knowing that their child would die, parents benefitted from and felt supported by nurses whom they perceived were personally invested in their child's survival; this investment made parents feel that their children were important to the nurses caring for them. The relationships that parents had formed with nurses became extremely important at the end-of-life; parents talked of needing to feel that they, their child (and their death) mattered to the nurses, and this was demonstrated by nurses in the following ways:

Perceiving that nurses believe in the child's chances of recovery.

Before parents knew that their child was going to die, it was important to them that nurses believed in their child's ability to recover from their critical illness, and shared in a desire

for the child to get better. Parents felt that nurses cared about children's outcomes through the meticulous care that they provided, through explicit verbal statements asserting their beliefs about the child's ability to recuperate and through sharing in parents' grief after a child's death.

Before she knew her daughter would not recover from her illness, Audrey perceived that her child's nurse was doing everything she possibly could to promote her daughter's chances for survival:

> … she brought all her stuff from the outside inside, she, um, brought all her papers to be able to, you know how you guys monitor all the different, stuff…she set up shop inside… for me, it was like, ok, we're on a mission here, and, and, we actually told each other, ok, we're on a mission, we, we need to make this work, so let's do everything we can, and uh, and we're a team. And uh yeah, and I just thought that was great, I think she was probably exhausted when she left, cus she, there was so much to do, to try and get her to survive…

For Audrey, the nurse's decision to remain physically present in the room conveyed her commitment and hard work, and demonstrated that this nurse was doing everything she could to try and help improve her daughter's condition. In Liana's case, she felt that nurses genuinely believed that her daughter would survive; these statements were important when Liana learned that her daughter was going to die:

> With the primary [nurses] we had talked … they always said like, 'well we also believed [she would make it to the surgery]' you know. You know to be told that they also believed and that it wasn't just us who hadn't like, hadn't understood.

This assertion by these nurses revealed that they had shared the same hope for this child's recovery and also expressed their vulnerability, which made this mother feel less isolated in her perceived inability to understand how her daughter would not make it to surgery.

For Nathan, nurses expressed that they had hoped his daughter would recover from her illness through the card that was signed by his nurses and sent to him after her death:

> …And after that, when we had received, like a few weeks after her death, a card…signed by the nurses…[it made us feel that the nurses] wanted her to get better, and that we wanted her to come back, like, she would, she'd be discharged from the hospital, and that she would come back healthy, running through the hallways. It was, it was really that, for the nurses in fact. They really kept that, and that's something that was really, really, really important.

Although Nathan did not elaborate during the interview, it appears that he had a vision of his daughter as healthy, living outside the hospital, as illustrated by the imagery of her 'running through the hallways'. This idea seems to hold meaning for him, and we can wonder if Nathan bonded with his daughter's nurses during the hospitalization through this hopeful idea that he felt was meaningful to the nurses as well. For this father, the supportive thoughts and messages from nurses meant that they not only cared about his daughter when she was hospitalized for months on the unit, but that she was also remembered and cherished by these nurses months after she had died.

When parents felt that nurses had worked hard to promote their child's survival, they felt that they established significant relationships with nurses. Liana highlights the importance of the efforts that one of her daughter's primary nurses made throughout her hospitalization to try and help her daughter recover from her illness:

> For me that changed everything, everything, everything, that's for sure. It improved the experience so much – well you know, I didn't live it differently – but, improved the experience in the sense that, I knew she had fought with us [to help Bella get better]. Like all along, on – she experienced things that weren't easy also, you know she was there on days when [Bella] wasn't doing well, and she worked hard, and she came to meetings with us. You know, she came in on her personal time also, at a point in time – we had a big meeting, so she came to see us. And she had, she had come to the meeting.

Thus, when parents perceived that nurses genuinely wanted their child to get better, their relationships with nurses were strengthened. The confidence that Ian and Liana had in their

daughter's primary nurse was important as they journeyed through their child's end-of-life; these parents were unsure of when they would withdraw treatment, but their confidence in this nurse made them feel that they would be able to make it through her death:

> And the day of the death, because it was Liz who was there, I would say we were more, like, it was us who decided that it was going to happen today. How we were going to stop. But you know, we had seen that it was Liz who had arrived that morning and so we said, ok it's today.

From Liana's perspective, this nurse's commitment to her daughter throughout her hospitalization fostered a close relationship, and as a result, Liana felt that this nurse would be able to identify what was most important to her, and be best able to support her during her child's death.

Investment of personal time and resources.

Parents felt valued when nurses invested personal time or resources to accomplish things that they needed at the end-of-life. The former was provided when nurses would come in when they were not scheduled to work for important interdisciplinary meetings, or when they were so focused on their work that they did not leave the bedside for the duration of their shift. For Audrey, the nurse who "set up shop" in her daughter's room before this mother knew her daughter wouldn't survive, conveyed that "she could not have done anything more", not only from her physical presence in the room, but also because she refused to leave the bedside when colleagues offered to take over momentarily for her:

> …the nurses would come in and say, 'did you go eat?' And then she was like, 'no … I need to fix this, I'm waiting for this to go in', and [would] check all the cassettes and the stuff, and 'this is finished, okay', 'cus, I'm telling you, like it, there was a stack of stuff there.

At this time, this mother needed to feel that every effort was being made to increase her daughter's chances for survival, and this nurse's dedication made Audrey feel she was going "above and beyond duty" since she never left the bedside.

Besides devoting personal time to provide care or be present for parents, participants also recalled the significance of nurses who offered use of their personal items to accommodate parental priorities. Some nurses used personal items (or brought them from home) to promote parents' abilities to achieve things that they wanted to accomplish before their child's death. For example, Ian described how in preparation for a baby bath, that one of Bella's primary nurses "…had brought in her own material, she knew that she was going to be working that night, you know she had seen her schedule. We had said that we wanted to give [Bella] a bath, and she told us, 'oh I will bring some things from home'." The "non-medical" baby bath items that this nurse brought from home created a memorable experience for Ian and Liana; although the bath "was still under the nurse's supervision", as Ian described "we had the impression that we were at home..." because of the items the nurse brought for the bath.

When Denise expressed that she would like music to be played for her daughter, she found it important that a nurse "made the effort…it was the nurse from intensive care who made the effort to find something…you know she lent her phone…you know so we could have music played for Carina." The personal time and resources that nurses contributed to support parents' priorities gave parents the sense that these nurses cared about them because the nurses were going 'beyond' what parents perceived to be part of the nursing role.

Establishing a "human" tone of care.

Some parents felt that nurses cared about them when they perceived that nurses were offering support that they considered to be "human" in addition to the professional clinical

competence that they demonstrated. Nurses set a tone during these interactions that made parents feel that nurses were themselves people interacting with the family. This tone mitigated barriers that parents typically expected in their professional relationships with nurses. During these interactions, parents felt that nurses cared about their children by recognizing the child's personhood, and also cared about parents' well-being. For Nathan, his daughter's nurse conveyed a caring attitude following his daughter's death through her proximity at the bedside:

> … the nurse that night specifically, she was um, closer, I would say. She wasn't cold, she wasn't distant, she wasn't being a professional, she was being human. What I mean by this is that she wasn't the nurse who was, ok, I'm providing care, I am going to prepare the patient, and all that, well she was uh, the person, with the family, and it was really different.

For this father, this nurse provided 'human' care through her patience and presence:

> She [the nurse] was patient with us. The way she was taking care of us... She took the time to speak with us, 'do you need to be alone? I will close the curtain so you have more privacy. Do you have any particular needs? What can I do for you?' You know, she spent so much time trying to find the thing or things that could try to, soothe our sadness a bit.

This nurse's presence and attempts to determine what might be most helpful after the child's death made this father feel that the nurse was genuinely concerned about his well-being, in addition to offering professional guidance and support.

For Denise, a nurse exemplified this type of 'human' care in the way he gently repositioned her daughter Carina:

> You know, it, it was the way he moved Carina for position changes. You know, they always continued speaking to her, and that was also important…I remember, he, he, he would say to her 'Hello Carina', and he, you now uh, she continued being a little girl until the very end…it [position changes] was, it was done, the pique was sliding on the mattress, it was more gentle you know, and, uh he, he spoke to us and he spoke to Carina,

> and you know I have to say, how many times did he fix her hair…and made sure her hands were properly placed, and uh, it was more appropriate, I don't know.

The time that this nurse took to speak to Denise's daughter, although she was unresponsive, and the nurse's repeated attempts to find an optimal position for her comfort, made this mother feel that the nurse sincerely cared about Carina as a person. Audrey also recalled how it was important to her that the nurses kept speaking to and interacting with her daughter as they collected items for the memory box, and how these "cute and light" conversations created a calm environment prior to treatment withdrawal:

> … you know we were, um, making her super comfortable, and putting her with her [stuffed animals], [and her blankets], and, and, you know… but um, you know they, they had a positive way about dealing with all of this… you know they're talking, 'come here my beautiful Francine, we're going to give you a nice haircut' and to take uh, you know, some snips of her hair… I don't know, it was just, positive…it was, you know, cute, and, and light, and, because that's the way I would talk to my daughter anyway you know, and we'd be joking, and I'd call her little names, and, yeah…and, you know, speaking soft, uh, and, yeah, being very uh…serene.

Similar to Denise's interaction with the nurse who provided 'human' care, Audrey found that it was important that nurses interacted with her daughter in ways that emulated her normal interactions with her child, and for her, this demonstrated a caring attitude. The resulting environment that was created also put Audrey at ease during the moments leading up to her daughter's death.

Nursing actions that acknowledged the child's personhood and established a 'human' tone of care also occurred after the death of a child. Ian describes the significance of how, after his daughter's death, the primary nurse offered to carry her body down to the morgue, rather than her body being transported on a stretcher:

> …a baby doesn't move alone, a baby is made to be in [someone's] arms, so you know to, to, to know that [Bella] was brought there [to the morgue], one, I find, you know, that it proves that a nurse like Liz loves her work, and she takes it to heart, you know, we aren't just patients, we aren't just parents, you know, it was more than that at that level there…So just that she was brought there, in someone's arms, for me was significant that she was accompanied until, you know until death and even further still, you know. There was somebody with her, and she was accompanied, and she wasn't alone in it, you know we didn't, she didn't fight alone.

For Ian, this nurse's action expressed how much she cared about his family, and made him feel that this nurse accompanied his family through death and beyond. Overall, these parents felt respected and supported when they perceived that nurses continued to remain physically and emotionally present in the moment while trying to identify what was important to parents; these parents especially appreciated nurses' efforts to reduce patient-professional barriers, and to care about these families as unique individuals.

Nurses' emotionality.

For some parents, emotional expression from nurses conveyed that nurses cared about them and their children, because such displays of nurses' emotion meant that the child and their death mattered to them. When Audrey learned her daughter was going to die, she recalled that nurses who knew her child came to express their sadness and offer condolences, even though they were not assigned to her daughter's care:

> …I was surprised, because, some of the nurses that had worked with us…all came to see us…some of them heard, and…came through and said, 'hey, I wanna come and say I'm, I'm sad, you know, and come give you a hug,' and, and yeah, I thought that, the, the, the nurses really were very authentic and, you know, felt compassion toward the parents… yeah, they, they all came around, and, yeah, so you, you felt a great deal of support and that they were really sad for us, you know.

Liana also described the importance that she attributed to her nurse's emotionality regarding her daughter's death:

> It was, it wasn't just Bella's care. Everyone can unplug [withdraw treatment], and give medication. It's more like, it's psychological accompaniment, you know to say that like I look at her [the nurse] and I know that she understands me. That she has as much pain as I do, you know. Well, not as much, but you know, she has pain because she knew Bella.

For both Liana and Audrey, the sadness that nurses conveyed meant that their children's deaths were significant events that affected them, and that their children would be missed. For Liana's husband Ian however, the emotions that were frequently displayed by his daughter's primary nurses served as a constant reminder that his daughter was going to die and "sometimes [made for] a very emotional day":

> And the primary nurses were just as sad and disappointed as we were, so, they weren't negative experiences, it was just… yeah on one side it's negative, because it always brings you back [to the fact that] yeah she is going to die…but at the same time you can't prevent people from living their emotions.

Given that the days leading up to Bella's death were often very sad, Ian appreciated when a specific nurse who happened to be a man was assigned to care for his child because he enjoyed the different dynamic that existed between them:

> It was more a conversation, you know between two friends. Between two, two, guys, you know, some things we didn't need to say, some things were understood, or to get out of the, the, the, get a bit out of the, it's nothing against the [primary] nurses but, you know there were a lot of emotions. Sometimes, we [Ian and the male nurse] were a little less in it [the emotions], it did a bit of good…You know, it was like a pause in the pain, in the sadness, you know, I took a break from being sad.

What Ian found most helpful was that this friendly conversation distracted him momentarily from the constant reminders that his daughter was going to die. Emotionality from nurses, as a

contributor to parents' positive moral experiences, therefore did not necessarily have to solely convey sadness for the child's death, but could take different forms depending on the situation.

Being remembered after death.

Another manifestation of 'caring about' was conveyed by nurses who remembered parents or maintained contact with them after their child had died. Audrey recalled instances where she "crossed paths with a few of the nurses" and they recognized her. Audrey questioned, "if they [the nurses] remember everybody like this, or [if] we've created some really special links, the time that we were there with these people". Audrey felt that her daughter had made an impact on these nurses because they still remembered her.

For Jacqueline and Nathan, in addition to feeling that nurses had wanted their child to recover from her illness, the cards that were sent to these parents after their daughter's death made them feel that nurses remembered their daughter through the messages they wrote to let them know they were still thinking about them:

> And even after, after the funerals and everything, they even, they sent letters, of, of condolences, and everyone signed, and, they like wrote little messages, and everything, to encourage us, and all that. And I found that was really wonderful, because, in, that just made us understand once again that it wasn't just like, just at the hospital where you do your work and, when you leave there it's finished…But, they took the time to actually write us messages, and sent it to our family, that was really, I found that was really wonderful, really. It proves that, they really took it to heart what they were doing, that, we weren't just like, simple patients, that it really was in fact like, really something that, they took to heart…

Part of the reason these parents felt they were remembered and appreciated by these nurses was that they had established relationships with nurses as a result of their child's repeated or extended hospitalizations in the PICU. However, Judith did not have the same type of contact with nurses because her daughter was hospitalized in the PICU for hours before she died. Judith

"[remembered] them [the PICU team], so, vividly kind of, but you know, who knows if they remember you, or they remember your case or your daughter…" Nothing occurred that made Judith perceive that the PICU team would not remember her daughter, but her statement suggests that the idea of being remembered matters to parents. Unlike these other parents who feel that nurses remember their children, perhaps Judith felt that her daughter did not have the same impact. There are positive outcomes when parents perceive that nurses remember their children. For Nathan, he felt that the support offered by nurses who wrote messages to his family after they had left the hospital conveyed their love for his daughter Tessa:

> …This year, at Tessa's birthday like, well at the anniversary of her death, we received a second card…So, one year later, it, it remained, do you understand? It's not nothing, it's, it's still something that's quite important to us. It proves like my wife said that it wasn't just, for the nurses it wasn't just, ok one more patient and one more death. It was really a patient, that we took care of with love…

Exceptional case: The moral significance of time for two participants.

I am going to end my results with a focus on the parents of one child. In addition to the results that I have presented throughout this chapter, this exceptional case emphasizes the individuality of moral experiences. The other parents that I interviewed felt unrushed following their child's death, but specifically did not describe time as particularly morally significant. For Ian and Liana however, time was *incredibly* important and really mattered in the moments following their daughter's death.

These parents eloquently summarized the moral significance of time after their child's death, highlighting the impact that time had on their sense of control after their daughter's death. Here, Liana talks about how she felt she was allowed the time she wanted with her daughter following her death:

> …I held her after [the doctor pronounced her death]…and uh, when we were ready, we gave her kisses, and after that we put her back in bed. Like we let her go, I think that was really important also, it made like, a lot of sense, to take her with us, to touch her, and hold her, and after that, to let her go. It was like something that we weren't able to do, during her entire hospitalization…for her entire life it was like, it was always imposing, imposing, imposing everything, imposing a rhythm of care, a rhythm of, of news, uh, sad or not sad, you know. It was always like things that were happening to us. Whereas then, it was like something that we were deciding, and we, we let her go, in our own time…you know, time was important.

Liana highlights how she felt it was right that she and her husband made the decision to 'let their daughter go' when they were ready. Later on in the interview, I asked Liana and Ian how having this time after their daughter's death affected their experience, to which both parents replied:

> Liana: I find that it helped afterwards [in bereavement]... Because, I didn't have the impression that, there was someone who took her away from me, you know I had the impression that I was the one who let her go. During my bereavement, that was really something…if someone took her from me, if someone did that without you being in agreement…you will just live anger…Whereas then it was like, no, I took my five minutes, you know, I feel good with that…it's for the parents who stay afterward, with the memory of, there was someone who took her away from me or I am the one who handed her back.
>
> Ian: Yes, I agree with that… it was really a lot of respect…it's for afterwards, because in that moment, five minutes won't seem like much for the team. But for the parents, it's five minutes that will count for [all of our remaining] years that we have left to live.

Conclusion

Parents described the various helpful and hindering actions that nurses enacted at different points in a child's end-of-life in the PICU. All of the participants' narratives indicated the importance that parents attributed to perceiving that their child's life and death mattered to the nurses caring for them. As parents navigated towards their child's death and beyond, they

perceived that nurses adapted the ways they interacted and provided care to their children and themselves to foster positive moral experiences and provide accompaniment at the end-of-life. The interventions that were most helpful were those that fostered parents' abilities to be present with and focus on their child. Achieving this involved either stepping in or stepping back from the bedside, depending on the unique circumstances of the situation.

Parents needed nurses to identify how to best support them as they proceeded through their child's death. From parents' viewpoints, the ways that nurses promoted positive moral experiences differed depending on both temporal and contextual aspects of their experiences. Depending on the timing in the child's end-of-life, parents wanted nurses to both recognize and provide encouragement so that parents could assert themselves as autonomous in their caregiving capacities, whereas during other moments, they needed nurses to step in and guide them and identify what they might need. Besides recognizing when parents might need more guidance, they also required nurses to ascertain when to provide care discreetly to foster parents' privacy.

For some parents, the manifestations of emotionality from nurses that promoted positive moral experiences were enacted in different ways; some parents found that nurses' displays of sadness meant that their child and their death mattered, while others benefitted from friendly encounters that served as a temporary distraction from their child's impending death. Although each parent's moral experience was unique and parents described various, sometimes opposing nursing interventions that they required at different moments, nurses' abilities to engage with parents and identify what mattered most to them was evident across their accounts. All parents wanted some level of engagement; even when parents wanted privacy, they were not asking for absence. The different, occasionally opposing ways that parents felt most supported at the end-

of-life highlights the subjective and contingent nature of nurses' relational practice in this context.

Chapter 5: Discussion

Introduction

In the following chapter, after recapping the previous chapters, I will explore how the study's results relate to pertinent literature. I will then consider practical implications relevant to end-of-life care delivery in the PICU, identify the limitations of this research project, and will offer a reflection about conducting this research. I will conclude this thesis by suggesting future directions for research.

Summary of Previous Chapters

The purpose of this study was to explore parents' descriptions and interpretations of the relational influence of nurses on parents' moral experiences of a child's death in the PICU, to generate results that might offer nurses insight as to how they affect parents during these moments. Recall in Chapter 1 that I described how the parent-child relationship is frequently a core aspect of a parent's personhood (Gillis & Rennick, 2006; Meert et al., 2009) and parents may experience threats to their identity as a result of disruptions to their parental role in the PICU (Dahav & Sjöström-Strand, 2018; Gillis & Rennick, 2006; Latour et al., 2011). I also suggested that the nurse's proximity at the bedside affords the nurse unique opportunities to connect with patients and families (in comparison to the rest of the health care team) (Hess, 2003; Wright & Brajtman, 2011) when nurses engage with individuals in their care to understand what is most important to them (Austin, 2008). In Chapter 2, I explored parents' conceptions of what it means to be a 'good' parent to a seriously ill child in various hospital contexts in relation to decision-making about their child's care (Hinds et al., 2009; October et al., 2014; Rushton, 1994), and I examined how parents have defined the parental role in the PICU (Ames et al., 2011). Further, I highlighted literature pertaining to the ways that parents have described the

influence of nurses on their experiences of their child's death in the PICU.

In Chapter 3, I proposed the moral experience (Hunt & Carnevale, 2011) and relational ethics (Bergum & Dossetor, 2005) frameworks (and the care for—care about continuum as a manifestation of engagement), as lenses to illuminate how nurses' relational engagement and caring attitudes influence parental values that are at stake at the end-of-life. Moreover, I identified that these frameworks can help uncover the moral significance of "everyday" experiences that have not typically been the focus of previous bioethics research (Hunt & Carnevale, 2011, p. 660). While the PICU context and a child's death are by no means common or everyday experiences for parents, what I hoped to highlight is the ethical significance underlying *all* interactions between nurses and parents in this context, even if they may seem mundane or appear to be insignificant.

In Chapter 4, I presented my interpretation of participant narratives, and highlighted that positive experiences were fostered through nurses' engagement when nurses identified what mattered most to parents at the end-of-life. Parents valued nurses who were able to anticipate their needs, including their desire to participate in their child's care, who recognized when parents benefitted from the nurse's physical presence at the bedside, and when it was time to let parents be with their children in as intimate an environment as possible. The results suggested that parents' needs and desires in this context are complex and sometimes contradictory, and parents therefore required nurses to tailor their care accordingly. The results also suggest that genuine caring and concern on the part of the nurse (as perceived by parents) carries moral significance; parents often highlighted the meaningfulness they attributed to the caring attitude that they felt nurses portrayed during interactions with the child and parents.

Discussion of Results

This study explores parents' experiences of nursing care at the end-of-life in the PICU. In my results, moral aspects of parental experiences are discernible. In this discussion, I will integrate my results more explicitly with my theoretical lenses to clearly identify the moral aspects of parental experiences of nursing care. To do so, I will explore how the concept of a parent's personhood is an integral dimension of parent's moral experiences of nursing care in this setting. I will examine how, from parents' perspectives, nursing care that promotes the personhood of parents at the end-of-life in the PICU consists of the nurse's skilled assessment of what is ethically at stake in the immediate clinical encounter, and anticipation of what might possibly be at stake in the future (i.e., as the child's death approaches).

I will also explore how nurses' relational practice in this setting relates to the Supportive Care Model (SCM), including the 'doing for', 'empowering', 'doing with', and 'connecting' dimensions (Davies & Oberle, 1990; Widger, Steele, Oberle, & Davies, 2009). More specifically, I will examine how PICU nurses promoted the personhood of parents at the end-of-life by identifying instances where parents may benefit from the nurse's ability to step in to perform interventions for parent, by stepping back to different degrees from the bedside to create intimate moments for parents with their child, and by supporting parents' abilities to remain caregivers to their children when this was desired. I will highlight how nurses' skilled assessments and supportive interventions can promote the personhood of parents at the end-of-life, and I will concomitantly examine the moral consequences of nurses' inaccurate assumptions about, or dismissal of, parental priorities, and how the personhood of parents may be constrained as a result.

In all situations, parents in this study valued interactions with nurses where they felt that

professional boundaries (that they had perceived as inherent to nurse-parent relationships) were reduced or eliminated. I will discuss how nurses foster positive moral experiences when they provide 'human' care and establish personal connections with parents, which aligns with the SCM dimension 'connecting' (Davies & Oberle, 1990). In this study, many parents perceived that the establishment of such personal connections entailed nurses going beyond what they perceived to be part of their professional roles. I will instead argue that 'human' nursing care should be integral to, and underlie all nursing practice. Overall, in discussing my results, I will highlight how interactions between nurses and parents in the PICU at the end-of-life are invariably morally significant.

The personhood of parents at the end-of-life.

Personhood is a core concept in the nursing profession because people are at the center of nursing care and the nursing encounter. The concept of personhood has frequently been used to designate the ways that people conceptualize others or themselves as unique individuals, and constitutes the essence of "what it means to be a person" (Sofronas, Wright, & Carnevale, 2018, p. 3). Sofronas and colleagues (2018) conducted a concept analysis of personhood and found that this complex concept has evolved over time in the nursing literature. Personhood is, in part, a "morally significant, relational process that is realized through nursing care" and may therefore be enacted and conserved through interactions between patients, families and nurses (Sofronas et al., 2018, p. 4). Indeed, in a qualitative study of individuals with dementia and their family caregivers in acute care, every nurse-patient encounter had the potential to promote or constrain the patient's personhood (Clissett, Porock, Harwood, & Gladman, 2013).

The recognition of an individual's personhood is morally significant since affirmation of one's personhood can promote agency and feelings of empowerment; conversely, suffering, or

feeling “depersonalized” may ensue when nurses fail to consider the importance of personhood in the clinical encounter (Sofronas et al., 2018, p. 5). Personhood is promoted when nurses individualize and tailor their care according to specific patient (and family) needs, desires and priorities (Barker, 2001; Chochinov et al., 2015), rather than applying standardized interventions across clinical situations that are assumed to be similar. When nurses focus solely on illness management and care that prioritizes the accomplishment of nursing tasks rather than engagement with the individual, personhood is lost or neglected (Sofronas et al., 2018).

In Chapter 2, I highlighted that many bereaved parents have emphasized the importance they attribute to the nurse’s recognition of the child’s personhood in the PICU. In my study, parents similarly valued nurses who acknowledged and promoted the child’s personhood. While it is evident that it is important for nurses to recognize the personhood of the child at the end-of-life, parents in my study valued nurses who, in addition to recognizing the child’s personhood, promoted the personhood of parents themselves. For study participants, one of the core aspects of their moral experiences of nursing care at the end-of-life centered on their abilities to contribute to their child’s care, in ways that they felt were meaningful. Nursing actions that facilitated parental participation in care in the PICU served to recognize and promote the personhood of parents. For study participants, nursing actions that promoted the personhood of parents included the nurse’s acknowledgment of parental expertise regarding the types of care that should be provided at the end-of-life, and the inclusion or accommodation of parents in caregiving activities when parents identified this desire. In a long-term care context, individuals with dementia, and their families, similarly described that personhood was promoted when circumstances were created where patients felt useful and valued, and when patients could participate in activities that were meaningful to them (Milte et al., 2016; Sofronas et al., 2018).

In my study, nurses also promoted the personhood of parents through the guidance that they offered at the end-of-life and during the postmortem period; for many participants, the preparation offered by nurses prior to the withdrawal of life sustaining treatment promoted the personhood of parents both during these moments, and after the child's death. For example, suggestions offered by nurses to collect mementos for the child's memory box were "maybe even more important than the moment [when the child died]" for some participants (Ian, p. 79), as these mementos allowed parents to maintain a connection to their child during bereavement. Stevenson and colleagues (2016) interviewed bereaved parents in the year following the death of a child to understand how parents cope with their grief during this time, and found that many parents went through a process of reorganizing their identity from "being a parent to a living child to being a [parent] of a deceased child" (p. 6); during this reorganization period, parents strove to maintain bonds with their child by sustaining their memory, which was accomplished in part by keeping mementos of their child's life (Stevenson et al., 2016). Nurses have an integral role in helping parents collect such mementos; as one participant said, nurses can "[make] the difference between positively living through [the child's death] or not" (Ian, p. 81) through thoughtful interventions that promote the personhood of parents beyond the immediate clinical encounter. Such interventions can support parents' evolving conceptualizations of what it means to be a parent even when their child is no longer living.

While there were many instances in my study where PICU nurses promoted the personhood of parents, there were also moments where nurses did not always acknowledge and recognize parents' personhood during the child's hospitalization. In these cases, some parents made statements that suggested that their personhood as parents was lost or neglected. Some parents felt "out of place" (Zachary, p. 73), that "the care is the priority" (Ian, p. 73), while some

felt like ‘spectators’, or detached observers of their child, rather than parents. These feelings were often a direct result of the nurse’s inattention to, exclusion of, or disregard for, parents’ desires to participate in their child’s care. The relation between a parent’s personhood and their (in)ability to participate in their child’s care – or in other words, to parent their child – was perhaps most evident for Ian and Liana, who felt that besides being the decision-makers for their daughter’s medical care, that they “weren’t parents” (p. 72) before they were able to *provide* care to their daughter.

In a study exploring the experiences of parents of extremely preterm infants at the end-of-life in a neonatal intensive care unit (NICU), participants described differences between being “assigned” parents and “embodied” parents (Abraham & Hendriks, 2017, p. 2104). The former entailed being acknowledged by health care providers as a parent following the infant’s birth, while the latter meant truly feeling like parents as a result of caregiving activities (e.g., holding the infant) that parents felt helped them bond with their child at the end-of-life (Abraham & Hendriks, 2017). Liana similarly described feeling like an ‘embodied’ parent as a result of the “normal” caregiving activities that she and her husband were able to participate in (p. 75).

The importance that parents attributed to their abilities to participate in their child’s care at the end-of-life highlights the moral significance of nursing care during this time. Nursing interventions that promoted parents’ abilities to participate in their child’s care, or that helped parents collect and create mementos of the child’s life, promoted participants’ personhood-as-parents at the end-of-life in this context, and were highly valued by many participants. Participants’ personhood-as-parents at the end-of-life in the PICU was constrained, promoted or sometimes disregarded by nurses depending on nurses’ willingness and abilities to anticipate and engage with parents to identify what they desired.

Ethical sensitivity.

From the perspectives of parents in this study, nurses engaged with them to identity what was at stake by being open to hearing what parents wanted. What was also evident in participants' accounts is that nursing engagement involved constant, skilled assessments by nurses during moments that nurses felt could be particularly important for parents. Such skilled assessments and frequently checking in with parents allowed nurses to obtain the "big picture", which includes both a sense of the immediate clinical situation, as well as grasping a sense of possible future trajectories (Benner, Tanner, & Chesla, 2009, p. 151) that might occur for parents. Many parents highlighted that individualized supportive nursing actions resulted because nurses appeared to anticipate what parents desired, during moments where parents did not necessarily know what might be most helpful.

Thus, participant narratives indicated that nurses were engaging in ethically sensitive practice. According to Lützén, Blom, Ewalds-Kvist and Winch (2010), ethical sensitivity occurs when nurses identify moments where people might be particularly vulnerable. Moreover, other researchers have suggested that ethical sensitivity entails nurses recognizing when moral issues are at stake, and responding accordingly in an ethical, compassionate manner (Milliken, 2018; Weaver, 2007). From parents' perspectives in my study, nurses often appeared to identify especially vulnerable moments for parents, and responded by tailoring their care to parents' unique circumstances. For example, recall when Nathan spoke of how his nurse thought to dress his daughter in her "pretty" clothing following her unexpected death (p. 80-1), and how this created a positive memory for him during incredibly difficult circumstances. In addition to recognizing instances where people are vulnerable, Weaver, Morse, and Mitcham (2008) have proposed that ethical sensitivity, in part, requires drawing on disciplinary knowledge and past

clinical experiences. Although it is hard to explicitly discern that nurses were drawing on clinical expertise to engage in ethically sensitive practice in my study, it is evident that when this expertise was absent, that some parents lacked confidence in the nurse's ability to support them at the end-of-life (e.g., the "uncomfortable" nurse; Denise, p. 82).

The central moral issue that was at stake for parents in this study was the promotion of their personhood-as-parents; the simultaneous guidance and privacy that many nurses offered to parents by providing "invisible" care promoted parents' personhood by supporting parents' abilities to be with, and focus on their children in an intimate setting with minimal distractions. According to Bebeau, Rest, and Narvaez (1999), ethical sensitivity entails an awareness of the ways that a person's actions might affect other people. In my study, nurses intervened during certain moments in ways that made parents feel that they were "present at the same moment that [they were] absent" (Ian, p. 83-4), suggesting that nurses were aware that their presence had the potential to be intrusive on parents' moral experiences of their child's death.

Some participants described moments when they felt supported by nurses who "became aware of", or attuned to, the distress they were living as their child neared death (Denise, p. 78). By skillfully checking in with parents to determine if they were ready for certain steps to occur (e.g., by turning off the vital sign monitoring), nurses confidently assisted parents to mentally prepare for their child's death, and simultaneously helped parents focus on their child, thus promoting their personhood-as-parents. Some researchers have suggested that enacting interventions such as this and offering them at appropriate times requires both the ability to recognize the ethical issue at stake (Milliken, 2018), and the "courage to act" on the part of nurses amid occasionally uncertain circumstances (Weaver et al., 2008, p. 610). In my study, these attributes of ethical sensitivity appear to underlie parents' reports of nurses who identified

helpful interventions and "thought of things, that [parents] needed, but were unable to ask for" (Nathan, p. 85), amid circumstances where many parents were experiencing uncertainty. Nurses' abilities to confidently, thoughtfully and gently check in with parents and offer these supportive interventions were meaningful to parents.

The Supportive Care Model.

In addition to engaging in ethically sensitive nursing practice, many other nursing actions and behaviors shaped participants' personhood-as-parents at the end-of-life, and have implications for how we think theoretically about the relational ethics of pediatric palliative care. In the following sections, I will explore how the SCM (Davies & Oberle, 1990) applies to the study results in relation to nursing care that influenced participants' moral experiences at the end-of-life.

The SCM was conceptualized by two nursing scholars, one of whom is a pediatric palliative care nurse, and originated from the analysis of a single nurse's practice in an adult pain and symptom control clinic (Davies & Oberle, 1990). In that study, data was derived from the nurse's retrospective descriptions of the care given to ten patients and families (Davies & Oberle, 1990). Davies and Oberle's (1990) analysis identified six interrelated dimensions that encompass excellent clinical nursing in palliative care.

The six interconnected constructs that characterize the SCM include valuing, finding meaning, preserving integrity, doing for, empowering, and connecting (Davies & Oberle, 1990). 'Valuing' in this model relates to the nurse's beliefs regarding the inherent worth of all people and the value that they attribute to patients and families once they get to know them as individuals. 'Finding meaning' is meant to guide nurses to help families make sense of what is occurring to them at the end-of-life. 'Preserving integrity' was initially intended to conceptualize

the integrity of the nurse providing care, and subsequently evolved to also encompass the goal of nursing care (Oberle & Davies, 1993). 'Doing for' focuses on the dimensions of care that patients and families feel they are unable to accomplish themselves, such as physical care or advocating for unmet needs. 'Empowering' refers to care that builds on the strengths of patients and families, appreciates their limitations, supports their decisions and family relationships, and includes care that enables patients and families to attain their goals. 'Connecting' entails nurses forming, sustaining and subsequently ending connections with patients and families through their abilities to develop trust, remain available and give of themselves in the clinical encounter (Davies & Oberle 1990; Widger et al., 2009).

Since the SCM was published, this model has influenced the ways in which palliative care nursing practice and education have developed internationally (e.g., Baldwin, 2011; Becker, 2009; McWilliam, Burdock, & Wamsley, 1993; Newton & McVicar, 2014; Parola, Coelho, Sandgren, Fernandes, & Apostolo, 2018). The SCM has also been linked to the support offered by nurses to patients at the end-of-life in other settings, such as the community (Lawton, Cantrell, & Harris, 2000; Walshe & Luker, 2010), acute care (Thompson, McClement, & Daeninck, 2006), intensive care (Vandall-Walker, Jensen, & Oberle, 2007), and in pediatric contexts (Widger et al., 2009). In 2001, the SCM dimensions were foundational to the development of the Canadian Standards of Hospice Palliative Care Nursing (CPCA Nursing Standards Committee). The SCM has also been adapted to explore the practice of other clinicians in palliative settings (e.g., social workers) (Sheldon, 2000). In empirical studies, the SCM has mostly been applied to describe nursing practice from the perspective of nurses (e.g., McWilliam et al., 1993; Parola et al., 2018), and in some studies, patients and family members have also

been interviewed in relation to the applicability of the SCM in a hospice setting (Newton & McVicar, 2014).

Of particular relevance for my purposes, Widger and colleagues (2009) explored the applicability of the SCM with existing empirical literature exploring parental perspectives in pediatric palliative care settings. Widger et al. (2009) included forty-nine articles in their review, they identified instances across studies where parents spoke of the care provided by clinicians at the end-of-life, and subsequently grouped similar findings according to the SCM dimensions; they found that although the SCM was originally based on nursing care in an adult palliative care setting, that the interrelated SCM constructs aligned with parental reports of care preferences across studies. There were some important distinctions noted about the importance that parents attributed to certain SCM dimensions in comparison to those in the original model. Widger et al. (2009) noted a fine line between care where nurses were 'doing for' or 'empowering', and determined that while parents desired support, they did not want to be treated in a "paternalistic manner" (p. 214). Thus, these authors added the term 'doing with' to the SCM to identify instances where nurses may need to "do *with*" parents to optimally meet parental desires (Widger et al., 2009, emphasis in original, p. 214). Another difference that was identified was the significance that parents attributed to 'connecting' with their nurses. Many parents reported perceiving that their relationships with nurses ended too soon following their child's death, and it was unclear when it might be optimal for these relationships to end (Widger et al., 2009).

The SCM dimensions 'doing for', 'empowering', and 'doing with' closely describe nurses' relational practice in my study. In the following sections, I will expand on the ways that nurses, from the perspectives of parents, engaged to learn how to best support, enhance and recognize participants' personhood-as-parents in the PICU, and how instances of such nursing

guidance support or challenge some assumptions present in related literature. I will speak to the usefulness of the SCM as a way of framing helpful PICU end-of-life nursing practice, from parents' perspectives.

Nurses' relational engagement.

Similar to parents interviewed in my study, Widger and colleagues (2009) found that parents within and across studies had occasionally contrasting perspectives regarding the interventions that were most helpful at the end-of-life, and thus concluded that no particular intervention will necessarily offer optimal support to each child and family. Therefore, nurses must attempt to strike a balance between 'doing for', 'empowering', and 'doing with' by engaging to identify what is most important to parents and tailoring their care accordingly. In my study, in addition to nursing care that supported and empowered parents, parents felt that nurses fostered positive moral experiences when they recognized moments where they should 'step in' or 'step back' from the bedside.

Nurses' relational engagement, in part, requires that the nurse "read the situation" to 'step in' and 'step back' as the clinical encounter requires (Benner et al., 2009, p. 77). Indeed, in a qualitative study of nineteen intensive care unit nurses who "were comfortable with dying patients and their families", nurses created an intimate space for families to say goodbye to their loved ones by stepping back and letting families retain control over the timing of the withdrawal of life support, or by stepping in and recommending ways that families might meaningfully spend their final moments with the dying individual (Peden-McAlpine, Liaschenko, Traudt, & Gilmore-Szott, 2015, p. 1148). Oliveira (2013) found that comfort measures similarly entailed interventions where health care providers offered supportive care through an active, calculated process that required 'stepping in' and 'stepping back'; in this concept analysis, the former

involves entering a clinical encounter and ‘doing something’ to promote the patient and family’s comfort (e.g., encouraging the family’s presence at the bedside despite restrictive visiting hours that may be in place) while the latter entails a conscious decision ‘not to do something’ to promote comfort (i.e., withholding artificial nutrition and hydration) (Oliveira, 2013, p. 99). Interventions where nurses are ‘stepping in’ and ‘stepping back’ are not necessarily incongruous, and may be offered simultaneously according to patient and family desires (Oliveira, 2013). From the perspectives of parents in my study, nurses had to achieve the right balance between ‘stepping in’ and ‘stepping back’. For nurses to promote positive moral experiences at the end-of-life, individualized care approaches are required, and nurses consequently must draw on past clinical experiences while navigating between the occasionally competing desires of different parents.

I will now explore some of the concrete ways that nurses, from parents’ viewpoints, did for, empowered, or cared with parents by ‘stepping in’ and ‘stepping back’. In my study, the SCM construct ‘doing for’ closely relates to the theme *Parental Participation in Care*. ‘Doing for’ on the part of nurses was valued to different degrees by different parents and constituted ‘good’ nursing care in many instances, but when nurses retained control and prevented parents from participating in care, they constrained some participants’ personhood-as-parents.

Doing for.

Recall Jacqueline and Nathan’s narrative about their daughter’s sudden and unexpected death, and how Jacqueline, in reference to postmortem care, felt that “it was better that it was the staff, a professional who did it, because we weren’t able to” (p. 76). In this instance, this mother alludes to the value that she attributed to the nurse’s ability to ‘step in’ and provide care that she felt she was unable to perform during this time. Similarly, Widger et al. (2009) found that

although parents want to be partners with their child's health care providers, they do not always want to provide all of the child's care at the end-of-life. From the perspectives of parents, 'doing for' entailed nurses managing the child's pain and distress and administering treatments, offering psychosocial support, and practical assistance (e.g., food, helping with transportation) (Widger et al., 2009). Harbaugh, Tomlinson, and Kirschbaum (2004) explored parental perspectives of PICU nurses' caregiving behaviors with parents of children who had no previous PICU admissions, and whose children survived, and found "essential nurse behaviors" that parents valued and felt constituted good nursing care in the PICU (p. 175); among these behaviors, parents valued nurses who performed painful, but necessary, interventions that promoted the child's recovery, and described being "grateful" and "glad" that they did not have to perform these painful interventions themselves (Harbaugh et al., 2004, p. 174). It is evident from my study and these related examples that 'doing for' can be a positive, valued nursing intervention when it is done in relation to parental priorities.

In a qualitative study exploring the perspectives of nurses, parents, and children on parental participation in care on a medical-surgical ward, Coyne and Cowley (2007) identified instances where nurses did not always adequately assess parental priorities, but instead assumed that all parents would benefit from similar nursing interventions. Parents whose children survived felt their presence and responsibility primarily consisted of the provision of emotional support to their child, and they did not desire complete responsibility for all of their child's physical care, whereas nurses assumed that parents universally desired involvement in all of their child's care so that they could "re-establish their roles as parents" (Coyne & Cowley, 2007, p. 900). Parents in this study would have benefitted from tailored nursing care, where nurses would

recognize the need to 'step in' to perform interventions that parents did not feel comfortable providing to their child.

In a secondary analysis of interviews with thirty six bereaved family caregivers in Western Canada, Stajduhar, Nickel, Martin and Funk (2008) described how caregivers viewed their roles in hospice palliative care and also found that caregivers were sometimes "*situated* as co-workers in a system with limited financial and human resources", often feeling unprepared to provide certain types of care but feeling expected to do so (Stajduhar et al., 2008, emphasis in original, p. 1792). During other moments, family caregivers "situated *themselves* as co-workers" when they sought an active role in the health care team, but described difficulties accomplishing this role at times where clinicians viewed these family members as care recipients (Stajduhar et al., 2008, emphasis in original, p. 1794). In my study, many parents also desired an active role in their child's care, but on occasion, parents were displaced from this role by nurses who explicitly hindered parents' participation in certain activities, or by nurses who were 'doing for' parents without asking how parents wanted to participate in the child's care. These contrasting viewpoints about the optimal level of involvement in caregiving suggest that explicit conversations need to occur between nurses and parents or family caregivers to identify desired levels of involvement (Stajduhar et al., 2008).

The results found in these hospital settings (Coyne & Cowley, 2007; Stajduhar et al., 2008) and in my study demonstrate the importance and nuances of nurses' relational practice, since generalized assumptions about what may be most helpful do not necessarily offer optimal support. Determining the right balance of 'doing for' children and parents at the end-of-life requires assessments by nurses to achieve the appropriate balance, since some parents may be hesitant to express their desire to participate in care. Incorrectly assuming that a parent wants or

does not want to provide certain care, or disregarding parents' requests to perform certain caregiving activities can negatively shape parents' moral experiences by constraining their personhood-as-parents, as was evident in Chapter 4 when Liana and Ian recounted instances where nurses prevented them from providing care to their child.

Empowering.

Widger et al. (2009) found that from the perspectives of parents, 'empowering' actions reflected nursing approaches that helped parents "get what they need so they can do whatever they need to do" (p. 212). In my study, nurses' efforts to promote parental participation in care contributed to the recognition of their personhood-as-parents at the end-of-life, and may have allowed parents to feel empowered to "have as normal a life as possible" for themselves and their child in these challenging circumstances (Widger, et al., 2009, p. 213). Widger et al. (2009) found that 'empowering' nursing interventions most often entailed the provision of information, followed by support for parents' decision-making abilities, and also included interventions that helped parents cope with a child's death. Similar to my study, these authors found that parents did not always know what they wanted or what was possible at the end-of-life, and felt supported when options were offered to them that they otherwise would not have known about (Widger et al., 2009). Relatedly, Rini and Loriz (2007) interviewed parents of children admitted to the PICU, NICU, and the general floor who were hospitalized less than 24 hours, up to four weeks preceding their child's death, and found that parents frequently referred to helpful health care providers whom they described as coaches. For these parents, the term "coach" referred to a "competent" clinician who described "what the death experience was going to be like, look like, and feel like", which was valued by parents since they were unsure of what would happen to their child, and how they should prepare for their child's death (Rini & Loriz, p. 278-9). Parents

in my study also valued nurses - “someone [who] was taking us by the hand” (Ian, p. 77) - to help them navigate through the end-of-life and postmortem periods by offering options to prepare for a child’s death, by responding to parental desires and by occasionally identifying parents’ unknown desires during these moments.

In my study, a crucial aspect of relational engagement and ‘empowering’ at the end-of-life required ethical sensitivity on the part of the nurse, to identify when parents desired the nurse’s presence at the bedside, and when parents wanted intimate moments with their child, even when parents could not themselves identify this desire. Recall that in Chapter 1, I argued that the PICU nurse’s physical proximity at the bedside provides unique opportunities to form relationships with patients and families, and to identify what matters most to parents at the end-of-life. While this assertion remains evident from my study results, it is also clear that for some parents in my study, the nurse’s proximity at the bedside was not universally valued; there were moments where nurses promoted participants’ personhood-as-parents when they were physically absent from the bedside (but were still conveying a supportive emotional presence). As Zachary summarized, the nurse offered optimal support by being present, but was “almost like not there...so she [the nurse] didn’t interrupt anything, she just tried to be as helpful as she could” (p. 83), thereby allowing him to live his daughter’s death privately with his wife. In a study of parents of extremely preterm infants who died in a NICU, participants also felt that they needed both privacy and support, and reported feeling “a sense of ambivalence” at the end-of-life when health care providers were present in their child’s room at moments where they desired more intimacy (Abraham & Hendriks, 2017, p. 2107). In this setting, perhaps nurses were not aware of the ethical implications of how their presence might negatively impact parental experiences.

From the perspectives of parents in my study, nurses demonstrated expertise when determining when to 'step in' to offer guidance and empower parents to comfortably be with their children at the end-of-life, and knowing when to 'step back' to foster intimacy. Similar to the concept analysis on comfort measures described earlier, these processes were not mutually exclusive (Oliveira, 2013). Successfully 'stepping back' meant that nurses continued being supportive and intervening using what some parents described as "discretion". For parents in my study, these 'stepping in' and 'stepping back' processes promoted and recognized their personhood-as-parents during treatment withdrawal and postmortem care by recognizing the importance of the parent-child relationship and 'empowering' parents to live their child's death privately as a family, to "just be with" their child (Judith, p. 83), and to continue feeling supported during this time.

Yet, in a qualitative synthesis of nurses' experiences of end-of-life care delivery in the PICU, Grimston, Butler, and Copnell (2018) concluded that nurses perceived that being with families during the child's death was an "integral nursing role, to provide support and comfort and truly meet the needs of the family" (p. 1764). Further, in a qualitative study exploring clinicians' perceived moral obligations in delivering end-of-life care in a NICU, Epstein (2010) found that while nurses perceived it was their duty to provide privacy, privacy involved sheltering parents from the rest of the unit, and did not necessarily entail the nurse's own separation from the family. While nurses most often remained in the child's room during this time, there were also instances where nurses felt that "the obligations of being with and providing privacy were blurred" when nurses perceived that they may be intruding on the experiences of parents, and so some nurses described being 'within earshot' or 'just outside the door' (Epstein, 2010, p. 584). This is similar to how one parent in my study reported the nurse

was most supportive while remaining "just behind the curtain" (Nathan, p. 85). My study results challenge the notion that a nurse's physical presence, or 'being with' parents is universally valued and always necessary to convey support.

Privacy can be 'empowering' if it creates possibility for parents to have "non-moderated" interactions with their child (Abraham & Hendriks, p. 2111). As one participant in my study stated in reference to his daughter's death, privacy allowed this father to "live that as if it was just the three of us" (Ian, p. 84). The ability to have such interactions is morally significant, since privacy may enable parents to "regain parental agency after being observers and onlookers" (Abraham & Hendriks, 2017, p. 2111). In my study, privacy was 'empowering' to parents because they were able to regain a sense of control after experiencing feelings of powerlessness; the privacy that occurred as a result of nurses' 'discretion' was important to parents, as the majority of parents' interactions with their children in this context were controlled and monitored by nurses. Private moments as a family, with the 'invisible' support of bedside nurses "in the background" (Nathan, p. 85), promoted participants' personhood-as-parents at the end-of-life.

Doing with.

In my study, there were some instances where nurses were 'empowering' to parents when nurses cared *with* them in situations where they felt unable to provide care without the nurse's support. Widger et al. (2009) added the 'doing with' construct to the SCM in pediatric settings because of the overlap that they found in the literature between the 'doing for' and 'empowering' dimensions. Some parents in my study described appreciating nurses' assistance to provide care that they wanted to participate in. Instances where nurses were 'doing with' parents included caregiving that was done "under the nurse's supervision" (Ian, p. 90), or when parents and nurses

formed a “working relationship” (Audrey, p. 74) and complementarily managed aspects of the child’s care.

In a qualitative study of parents of children who were admitted to PICUs in Sweden, when asked to articulate the meaning of caring in a PICU, parents described that nurses “built bridges side by side *with* the parent,” which meant that nurses helped parents’ participate in the child’s care (Mattsson, Arman, Castren, & Forsner, 2014, emphasis added, p. 341). Harbaugh and colleagues (2004) also found that parents valued PICU nurses who stepped in to complement aspects of the parental role by supporting parents who were overwhelmed and distressed, and who therefore felt unable to perform certain caregiving activities alone. Overall, participants’ personhood-as-parents was promoted in situations where nurses engaged in ethically sensitive practice, and when nurses accordingly navigated between interventions that were aligned with the ‘doing for’, ‘empowering’, or ‘doing with’ constructs from the SCM by ‘stepping in’ and ‘stepping back’ (often simultaneously).

Connecting.

For parents in my study, valued nursing care was also done in a way that demonstrated a caring attitude from the nurse. Widger and colleagues (2009) also found that parents perceived ‘connecting’ with health care providers as foundational to good care; from the perspectives of parents, ‘connecting’ meant that care providers formed “human relationships” during a child’s hospitalization (Widger et al., 2009, p. 211). In my study, nursing care that was valued by parents was described as competent, was done with confidence, and was done by nurses who were technically proficient. What was especially valued by parents however was often more difficult to articulate; for example, recall Audrey, who described feeling that the nurses’ “cute and light” conversations preceding her daughter’s death created a “serene” environment before

treatment withdrawal occurred (p. 92), or Nathan, who referred to the nurse as being "closer" in comparison to other health care providers, as "human" and as "the person, with the family" rather than the professional with the patient (p. 91).

There are several examples in the literature where patients and families refer to the importance of care that is provided "humanistically" (Attree, 2001, p. 459), warmly and with compassion (Davies et al., 2004), and where nurses achieve a balance between being professional and presenting themselves as "real people" (Hale, Long, Sanderson, & Carr, 2008, p. 16), because these attributes make patients and families feel cared about (Heller & Solomon, 2005). Similarly, in my study, while it was important that nurses had the skills required to intervene effectively with children in the PICU, many of the interactions that were morally significant to parents involved moments where they felt they established personal relationships with nurses. Friendly conversation with a nurse created "a pause in the pain" for Ian (p. 94), and many parents especially valued the "psychological accompaniment" that nurses offered (Liana, p. 94). The meaningfulness that parents assigned to the personal connections formed with nurses highlights the value of "human-to-human" interactions (Davies & Connaughty, 2002, p. 6) in the often highly medicalized, impersonal environment of the PICU.

PICU nurses may also experience a blurring of their "personal and professional selves" (Grimston et al., 2018, p. 1753) while caring for – and about – a child at the end-of-life. Administrative bodies and professional codes of conduct often suggest that such personal involvement with children and their families is inappropriate, as professional boundaries can be crossed as a result (Grimston et al., 2018). Indeed, in a document titled *Therapeutic Nurse-Client Relationships*, the College of Nurses of Ontario (2006, updated in 2018) defines the boundary in nurse-patient relationships as "…the point at which the relationship changes from professional

and therapeutic to unprofessional and personal" (p. 4), and highlights practice standards that imply that ineffective, non-therapeutic relationships always result from 'boundary crossing' when personal connections are established with patients and families. By suggesting that harms will always result from nurses crossing professional boundaries, such professional codes of conduct leave no room for nurses to consider the therapeutic benefits that can result from establishing personal relationships.

Perspectives where personal involvement is seen as a transgression of the nurse's professional role may be ethically problematic, as the "concrete boundaries in therapeutic relationships can diminish both the humanness of encounter between client and practitioner and therapeutic effectiveness" (Austin, Bergum, Nuttgens, & Peternelj-Taylor, 2006, p. 84). Boundaries designate what is off limits in professional relationships, and although they are in place to protect patients who may be vulnerable in the clinical encounter, this notion does not "help us explore the ethics of engagement, nor does it reveal that *not* attempting to connect with a patient can be unethical" (Austin et al., 2006, emphasis in original, p. 85). For many parents in my study, the personal connections established with nurses were morally significant, and many meaningful moments would not have occurred for parents (and likely nurses also) had nurses strictly followed recommendations that suggest it is inappropriate to cross boundaries in the nurse-patient and family professional relationship.

Parents, and patients and families in general, notice when 'humanistic' care is absent in the clinical encounter. For example, parents have described regarding PICU nurses who did not display warmth "somewhat neutrally", and parents' expectations of nursing care "were only minimally met" assuming that nurses were safely providing care (Harbaugh et al., 2004, p. 172). Parents of children who died from hematological or oncological conditions have also expressed

feeling “doubt as to the genuineness of care which they described as task oriented”, when they felt that health care providers were not acknowledging their emotions (James & Johnson, 1997, p. 90). However, when holistic care was present in my study, some parents felt that nurses were going “above and beyond duty” (Audrey, p. 90).

Likewise, there are instances in the literature where parents have reflected on “fantastic” care by health care providers that goes ‘above and beyond’ what they expected of clinicians in their professional roles (e.g., Butler et al., 2018, p. 22; Meyer et al., 2006). It appears that parents (and the public) perceive that nurses who take the time to get to know their patients personally, and who incorporate personal or human aspects into caregiving, are providing care that lies outside the scope of what they expect of the nursing role. In the following section, I will explore how this perception may result from what Borgstrom and Walter (2015) have deemed the “commodification of care” (p. 103).

Commodification of care.

Some have referred to the commodification of care as the “intensification and routinisation of nursing work,” (Maben, Latter, & Clark, 2006, as cited in Maben 2007, p. 336), or care that results from a “‘task and time’ driven culture” (Kitson, Muntlin Athlin, & Conroy, the International Learning Collaborative, 2014, p. 332). Regardless of the term used, such care often arises from “managerial discourses of efficiency” (Maben, 2007, p. 337) that prioritize nursing actions according to discrete elements without considering or acknowledging the ways that such acts are performed (Borgstrom & Walter, 2015; Chan, Macdonald, Carnevale & Cohen, 2018; Kitson et al., 2014). When efficiency is measured according to discrete nursing interventions, the efforts made by caregivers to demonstrate compassion, for example, are

devalued since these actions are less measurable and visible (Borgstrom & Walter, 2015; Chan et al., 2018; Maben, 2007; Maben et al., 2006).

The "invisibility of much nursing work" (Maben, 2007, p. 335), or what some parents in my study referred to as nursing "discretion", may be so embedded in a nurse's practice that the nurse may not even recognize the support they are providing to patients and families (Morse, 1992; Oliveira, 2013). 'Invisible' nursing care often fostered positive moral experiences for parents in my study by promoting their personhood-as-parents. But when such nursing care was absent, parents' memories of their final moments with their child could be negatively affected. Parents in my study often attributed immense value to nurses' 'invisible' practices at the end-of-life. Yet, often only quantifiable nursing interventions are given priority by administrative bodies, and nurses' relational practice may subsequently be constrained as nurses' perceptions of what constitutes 'care' can be shaped by the environments in which they work (Chan et al., 2018; Maben, 2007). For example, in a study exploring the ways that curative care environments influence the care of patients who are dying, Chan and colleagues (2018) found that nurses felt "forced to be 'task-oriented'" to complete care that had "top priority", and therefore prioritized medication administration and intravenous line maintenance, for example, above 'basic' care (i.e., bathing patients) and emotional engagement with patients and families (p. 457). The prioritization of care in such a way is morally significant, since "the patient's experience of care will be fragmented, depersonalized, and physical acts of care will not be seen as recovery and therapeutic activities in themselves, but merely as tasks that have to be performed in an over [*sic*] busy chaotic environment" (Kitson & Soerenson, 2016, p. 1754).

In my study, a nurse's emotional engagement and supportive presence "in the background" was morally significant for two parents following their daughter's death, as it

simultaneously fostered their privacy, while making these parents "understand that we were important" (Jacqueline, p. 85). The support that this nurse offered through her presence would be extremely difficult to quantify according to a 'task based' approach to care; yet, this intervention significantly shaped the moral experiences of these parents. There is clearly a tension between invisible nursing practices, and the need to make such practices visible to individuals in positions of leadership. The importance of the 'invisible' aspects of nursing work must be recognized and not disregarded as inferior to other forms of nursing care if they are to remain a central component of the nursing role (Borgstrom & Walter, 2015; Maben, 2007).

Summary of Discussion

In the discussion of my results, I extended the concept of personhood (Sofronas et al., 2018) to include the conceptualization of personhood-as-parents, and highlighted that nurses who engage in ethically sensitive practice foster positive moral experiences for parents by supporting parents' abilities to regain control at the end-of-life in the PICU. From parents' perspectives, nurses effectively promoted their personhood-as-parents by helping parents realize complex, and occasionally contrasting needs and desires. I also considered the relevance of some of the dimensions of the SCM (Davies & Oberle, 1990; Widger et al., 2009) to frame helpful nursing interventions at the end-of-life in the PICU from the perspectives of parents, and offered further empirical validation for the work conducted by Widger and colleagues in 2009. Moreover, I highlighted the value that parents attribute to the personal connections they form with nurses in the clinical encounter, and problematized the discourse that suggests that boundary transgressions are always inappropriate in every situation. I concluded the discussion of my results by examining how the "commodification of care" (Borgstrom & Walter, 2015, p. 103) results in the devaluing of compassionate, thoughtful, and ultimately ethical nursing care.

Implications for Practice

In this section, I will discuss implications resulting from this study. These implications are relevant to bedside nurses in the PICU, advanced practice nurses (e.g., clinical nurse specialists), and individuals in administrative leadership positions within hospitals (including, but not limited to, nurse managers and assistant head nurses).

Bedside nurses should consider the family as the unit of care (Rallison & Moules, 2004). One way that nurses can begin incorporating the child's family into their practice is by reflecting on their beliefs and values related to working with parents in the PICU (Butler, Copnell, & Willetts, 2013), and on their willingness to collaborate with parents and involve them in their child's care (Fegran, Sølvi, & Slettebø, 2006). The reflective process is necessary for nurses to be able to think through past encounters with parents, and to subsequently draw on the successes and challenges of these interactions to support the nurse's practice in the future (Tomlinson, Thomlinson, Peden-McAlpine, & Kirschbaum, 2002). Although a nurse's previous experience with parents can be helpful to draw on, nurses must also simultaneously recognize that parents may not follow "the usual trajectories" that are anticipated based on past clinical experience (Benner et al., 2009, p 412), so nurses cannot rely exclusively on these prior experiences when engaging with parents.

Engaging in reflective practice and being self-aware about one's beliefs and values are integral to effective communication and relationship building with parents at the end-of-life (Browning, 2005). Nurses' abilities to effectively communicate can promote and recognize parents' personhood-as-parents, and can help nurses provide holistic nursing care. Nurses must recognize that communication occurs in a social and cultural context, which can be accomplished by adopting an "ethnographic approach" to conversations with parents at the end-of-life

(Browning, 2005, p. 25). Adopting an "ethnographic approach" means being cognizant of the ways that cultures (like the biomedical culture of the PICU) have distinct rules, traditions, and customs that can shape thoughts, feelings, and experiences (Browning, 2005). In their encounters with parents, nurses are often much more fluent in the language that exists in the PICU, and are more comfortable with its customs in comparison to parents. From an ethnographic perspective, meaningful relationships are established when effective communication is accomplished by nurses who strive to become "bicultural" by partly entering into each parent's culture (Browning, 2005, p. 25), while simultaneously acknowledging the PICU culture's influences on their interactions with parents.

To effectively communicate with parents, nurses must also recognize the inherent power differentials that exist in their relationships with parents (Browning, 2005). In my study and in several other studies of parental experiences in hospital, parents have described feeling displaced from their roles as primary caregivers, and have experienced feelings of powerlessness as a result. In my study, parents' perceived inabilities to participate in their child's care, and the ways that nurses occasionally excluded parents when they expressed this desire, highlights the power that nurses have regarding the extent to which parental involvement might occur (or not) during hospitalization (Fegran et al., 2006; O'Haire & Blackford, 2005). To increase parents' feelings of inclusion and reduce these power imbalances, nurses must be prepared to engage in conversations with parents to identify how they envision their parental role in the PICU, and how they define meaningful involvement in their child's care. Nurses must work with parents to "*jointly* determine" the nurse's and parents' respective roles in the clinical encounter (Mackean, Thurston, & Scott, 2005, emphasis added, p. 83), so that parents do not feel like they are being situated as 'spectators' during their child's hospitalization. Nurses must also recognize that

nursing support and interventions that promote the personhood of parents at the end-of-life will likely evolve throughout the child's hospitalization, especially at moments of increased vulnerability (e.g., during treatment withdrawal and after the child's death). Nurses must therefore revisit these conversations with parents throughout the child's stay in the PICU.

In my study, some participants identified that nurses promoted their personhood-as-parents when nurses prepared them for their child's death. An important area of conversation to achieve this aim involves what Rallison and Moules (2004) have labeled as "speaking the unspeakable" (p. 298); such conversations include informing parents about what physical changes might look like as the child is dying, what parents might expect when death occurs, and how parents can be with their child during these moments. Although difficult to discuss, this information can help parents anticipate what can happen to their child and some of the reactions they might experience themselves (Rallison & Moules, 2004).

Parents in my study described appreciating the professionalism and expertise that nurses demonstrated in preparing them for their child's death. However, the "stance of expert" can be counterproductive when parents desire engagement on a human-to-human level (Browning, 2005, p. 25). To accommodate all of the needs and desires of parents at the end-of-life, nurses should be able to effectively shift between their stance as an expert and as a learner by striving to be "curious and respectful human beings" (Browning, 2005, p. 25). Accordingly, nurses must listen to, acknowledge, and value parents' narratives of their experiences at the end-of-life.

Efforts to provide holistic care can also extend beyond the child's death, as was evident by parents in my study who fondly remembered the cards they received once they had returned home after their child had died. A related intervention that could sustain these important relationships during parents' bereavement is therapeutic letter writing (Moules, 2002; Rallison &

Moules, 2004). Letters, as a clinical nursing intervention, can be used to acknowledge the suffering that parents have experienced, allow the chance to offer commendations based on the nurse's experience with the parents about parents' strength, courage, and the care they provided to their child, without minimizing the challenges and suffering that they have experienced (Moules, 2002; Rallison & Moules, 2004). Therapeutic letters also offer nurses the chance to comment on the relationships that they have formed with parents, and the ways that these relationships might have influenced the nurse's practice (Rallison & Moules, 2004).

The nursing interventions described above can be fostered by educational initiatives from advanced practice nurses and individuals in administrative leadership positions; a helpful educational approach to consider that can help sensitize nurses to the moral issues at stake for parents at the end-of-life is "relational learning" (Browning & Solomon, 2006, p. 797). The relational learning approach emphasizes that educational initiatives must be led by pedagogy that is "grounded in the charged existential space of relationships among children, families, and practitioners, because the learning that matters most occurs within these relationships" (Browning & Solomon, 2006, p. 797). Education and learning using this approach must be linked in practical and meaningful ways to the concrete experiences of children, parents, and nurses who engage in important conversations during this time, and although knowledge of basic 'communication skills' such as maintaining eye contact or validating emotions is helpful knowledge for nurses to acquire, it is evident from my study and from related research, that it is insufficient to solely teach such skills without consciously considering the depth of emotions and complex moral issues that underlie the encounters between health care providers and parents at the end-of-life (Browning, 2005; Browning & Solomon, 2006).

Indeed, Browning (2005) has highlighted that more is at stake for parents at the end-of-life than can be solely addressed by "the addition of behavioral skills to the practitioner's repertoire":

> There are times when children and family members need to sense that their professional caregivers acknowledge and, at times, share their suffering. At other times, they need their practitioners to step out of a narrowly defined professional role to reveal a more 'human' side. (p. 23)

I would also argue that 'human' or holistic nursing care should be integrated into *all* nursing practice, and not just at the end-of-life. Parents in my study and in related literature have described holistic nursing care as going 'above and beyond' the professional nursing role; this framing likely results from the task-based, efficiency discourses that are prioritized in many hospital settings. From an administrative perspective, nurse-patient staffing ratios must be appropriately supported so that nurses have adequate time to provide holistic, individualized care (O'Haire & Blackford, 2005; Roscigno, 2016) to further promote nurses' abilities to foster parents' positive moral experiences at the end-of-life.

My thesis has focused on the experiences of parents, but it is also important to note that the nurse's experience is relevant to providing 'human' nursing care at the end-of-life (Browning, 2005). Nurses who choose to engage in parents' suffering and who establish personal connections with parents may suffer themselves, and this can have significant consequences in settings that emphasize expertise and objectivity, rather than engagement (Browning, 2005). Thus, professional and organizational structures must not only create educational initiatives to promote nurses' abilities to engage with parents, but must also acknowledge and respond to the suffering that nurses might experience while delivering end-of-life care (Browning, 2005; Browning & Solomon, 2005; D. Morgan, 2009).

The relational learning approach is relevant to my study, because it challenges nurses (and other clinicians) to consider that the professional expertise required to competently support parents during these moments is highly contextual, and requires the accrual and assimilation of a wide range of relational experiences with children, parents, and other colleagues (Browning & Solomon, 2006) to develop expertise working with parents at the end-of-life. Nursing management and advanced practice nurses can create cultures that support opportunities for relational learning. For example, advanced practice nurses can foster a culture of relational learning by creating a multidisciplinary team of leaders who are interested and passionate about adapting practices to improve end-of-life care (Browning & Solomon, 2006). This multidisciplinary group could also include parents who have specific, related experience, and who are similarly interested in promoting change to improve practices (Browning & Solomon, 2006). The scope and purpose of such groups may range from study groups, where literature is reviewed and discussed, while other groups may ascertain and record gaps in the quality of end-of-life care and create educational or quality improvement solutions to address these gaps (Browning & Solomon, 2006).

Besides forming interdisciplinary groups, nurse managers and advanced practice nurses should identify formal learning activities to promote a context where relational learning can occur (Browning & Solomon, 2006). PICU nurses will inevitably encounter children who will die in their practice, and they will have to support both children and parents during these moments (D. Morgan, 2009). Working with parents in crisis is complex as it requires skills that nurses may not necessarily acquire without additional training, education and continued support (Tomlinson, et al., 2002). Thus, while there is certainly a priority to develop technical skill acquisition to safely provide care to children in the PICU, nurse administrators and advanced

practice nurses should equally prioritize the development of nurses' relational competencies with parents in this setting (Baird, Davies, Hinds, Baggott, & Rehm, 2015).

Advanced practice nurses can facilitate and organize in-services for bedside nurses during which relevant research is discussed, and where expert guest speakers from nursing and other disciplines are invited to share their perspectives about end-of-life care (D. Morgan, 2009). Additionally, other educational strategies such as small inter- or uni-disclipinary group seminars, and role-play activities can be helpful to promote relational learning (Browning & Solomon, 2005, 2006). Small seminars can be used as a forum where individuals share morally salient stories of instances where they felt challenged when identifying what might be 'the right thing to do', and participants can generate alternative strategies to better handle similar situations in future clinical encounters (Browning & Solomon, 2006).

Role-play activities, or simulation of end-of-life case scenarios, provide a venue where participants interact with patient and family actors in a setting that mimics the clinical context (Campbell & Daley, 2013). Simulation scenarios that are relevant to relational learning, and are grounded in the conversations that can occur at the end-of-life, could include communicating bad news, or bearing witness to anger and sadness (Browning & Solomon, 2006). Simulations are a useful educational tool because participants are assured that their interactions will not be harmful since they are working with professional actors; moreover, when a debriefing period is incorporated into simulation sessions, participants and observers alike have opportunities to reflect on their thought processes and actions, which may facilitate knowledge transfer to practice (Campbell & Daley, 2013).

In addition to these educational strategies, advanced practice nurses can develop family-oriented policies that may serve as reference tools or guides to assist practicing nurses at the end-

of-life (Aldridge, 2005; D. Morgan, 2009), and they can also explicitly incorporate such policies into nursing orientations to PICUs. While such policies are a helpful starting point to support practicing nurses, they must not be viewed as practice mandates since the realities of practice will consistently be more complex and nuanced than what can be captured by formal guidelines (Barker, 2001; Benner et al., 2009). By creating an environment where relational learning can occur, advanced practice nurses and nursing leadership foster conditions and provide tools for nurses so they can learn to respond to parents in a nuanced manner, rather than adopting standardized approaches with all parents in their care.

Study Limitations

The aim of this study was to better understand parents' moral experiences of end-of-life nursing care in the PICU. As I previously alluded to in Chapter 3 when discussing the study sample, moral experiences are personal and subjective, and may therefore differ significantly among parents. Therefore, empirical studies exploring moral experiences will always have a limitation related to sampling; researchers can only ever access "fragmentary and incomplete" aspects of people's moral experiences (Hunt & Carnevale, 2011, p. 661). Despite this inherent limitation, I provided an in-depth description of the participants and research setting, so readers can evaluate how this study's results might be relevant to nursing practice in other PICUs.

There are also limitations associated with my position as an 'insider' researcher. I am considering myself an insider researcher because I conducted this study with parents whose children died on the unit where I work. Although I excluded parents whom I had directly worked with at the end-of-life from recruitment, some parents did recognize me from their time spent on the unit. I also disclosed myself as a nurse on this unit in the recruitment package and in person prior to starting the interview, and several parents grouped me as a part of the PICU team during

our interviews (e.g. “you know how *you guys* monitor all the different, stuff…”). A limitation associated with conducting research as an ‘insider’ is the assumed understanding that can occur during data collection (Asselin, 2003; Blythe, Wikles, Jackson, & Halcomb, 2013). During interviews, parents frequently looked to me when they were having difficulty recalling medical terminology to describe certain parts of their experience, and sometimes made statements to suggest I should know what they were talking about (e.g., ‘you know what I mean’). Statements such as this often signify that something is being left unsaid during an interview (Blythe et al., 2013). Such ‘taken for granted’ assumptions can restrict the researcher’s ability to explore the deeper meaning underlying participants’ statements (Asselin, 2003, p. 100). When parents implied I knew what they were talking about, I conscientiously made efforts to ask probing questions so that parents could elaborate and clarify what they were communicating (Asselin, 2003; Blythe et al., 2013). As I described in Chapter 3, I also let parents tell their stories in their own words rather than ‘taking over’ and interjecting with what I thought they were trying to communicate.

A second limitation associated with conducting research as an ‘insider’ occurs during data analysis when researchers can potentially produce biased interpretations of study data (Asselin, 2003; Blythe et al., 2013). As previously described in Chapter 3, I addressed this limitation throughout the design and conduct of my study by identifying my preconceptions and assumptions on entering the study, and I revisited these assumptions as I conducted interviews, analyzed data, and wrote up the results. Moreover, data analysis and the presentation of results were a collaborative effort between my thesis supervisors and myself; such collaboration enhanced study credibility and reduced the potential biases that may not have been addressed by the aforementioned reflective strategies that I implemented (Blythe et al., 2013; Tracy 2010).

Participants can also have misconceptions and inaccurate expectations about the 'insider' researcher's role during data collection (Asselin, 2003). For example, one mother asked me to obtain the name of the nurse who cared for her daughter before she died since she could not remember it, so that she could make a donation to the hospital foundation in this nurse's name. Participants may blur the role of nurse with the role of researcher and learner during study interviews (Asselin, 2003). During recruitment and data collection, I clearly highlighted my role as a researcher and the aims of the study to address this limitation (Blythe et al., 2013).

A methodological limitation of my study was the use of joint interviews. Conflicts or arguments can occur during joint interviews (Zarhin, 2018), and while these did not occur during my study, there were occasionally divergent viewpoints from mothers and fathers during the same interview. In some instances, parents spontaneously presented differing perspectives about their experiences, and I occasionally had to explicitly ask probing questions during interviews to identify differences in experiences between each parent. The phenomenon that I chose to explore is one that is inherently subjective; thus, balancing individual subjectivity within joint interviews was a methodological challenge (and eventually became an analytic challenge). I try to account for the subjectivity of parents' moral experiences of nursing care in this context throughout my thesis in the way that I present my results, discussion, and study implications by highlighting the contextual nature of parental experiences, and by emphasizing the importance of individualized nursing approaches when caring for parents at the end-of-life.

The most significant limitation of conducting joint interviews was the unintentional silencing that occurred (D. L. Morgan, 2016; Zarhin 2018) in two interviews where fathers were physically present but did not participate much during the interview beyond agreeing with their partners' statements. During these two interviews, I obtained consent from each parent

individually, and emphasized (as I did during each interview) that each parent could stop participating in the interview at any time without consequence. It is possible however, that these two fathers' silence during data collection may have resulted from a hesitation in participating in the study (Butler et al., 2017b; Zarhin, 2018). Perhaps these fathers felt obligated to participate because their partners were participating (Butler et al., 2017b; Zarhin, 2018); indeed, one father left midway during one of these two interviews because the parking meter was running out despite knowing how long the interview could potentially last. Perhaps this was this father's way of communicating that he really did not want to participate in this study. This is an important ethical challenge to highlight, and it remains unclear how best to address situations where a participant may feel obligated to participate because their partner is participating in the study (Butler et al., 2017b; Zarhin, 2018).

The silence of these two fathers during study interviews may also be related to the chosen data collection method. The silencing that occurred during these joint interviews is possibly related to the "gendered assumptions" underlying the semi structured interview method (M. E. Macdonald, Chilibeck, Affleck, & Cadell, 2010, p. 441); study methods that rely primarily on verbal expression can dissuade men from participating during interviews since, in comparison to women, men may be more likely to experience discomfort at the thought of expressing their emotions and vulnerability in the presence of a stranger (M. E. Macdonald et al., 2010). This is problematic because of the gender imbalances that exist in the wider literature examining 'parental' perspectives of pediatric palliative care. In a systematic review of parental perspectives of pediatric palliative care, M. E. Macdonald and colleagues (2010) found that 75% of participants were mothers (in forty five studies on this topic), and only four studies identified this imbalance as a limitation; moreover, even in studies where fathers participated, it was

unclear what their participation entailed when partners were interviewed as couples (M. E. Macdonald et al., 2010).

It is important for researchers to consider that different fathers and mothers may not necessarily conform to gender roles and patterns (M. E. Macdonald et al., 2010). In the remaining three interviews in my study where fathers participated, joint interviews resulted in rich narratives from both mothers and fathers because of the interactions that occurred between partners during the interview, including occasions where participants complemented each other's narratives by adding details, omitted material, and where participants asked questions of each other to clarify incomplete thoughts (D. L. Morgan, 2016). Nonetheless, the important imbalances in the literature suggest that qualitative interviews may not be optimal for exploring emotionally sensitive topics with some men (Affleck, Glass, & Macdonald, 2013; M. E. Macdonald, et al., 2010).

Reflections on Conducting Sensitive Research as a Novice Researcher

I want to briefly reflect on my personal experiences of conducting sensitive research and 'situating myself as a researcher' during data collection.

While designing this study, I knew that this was a difficult topic to explore and attempted to mentally prepare myself prior to conducting interviews, knowing that parents would likely get quite emotional. There were moments during some interviews where the anger and sadness that parents expressed was incredibly difficult to witness, and I found myself simultaneously trying to manage the outward expression of my own emotions while continuing to 'be a researcher' and determining the next questions I should ask during the course of the interview. Some qualitative researchers value displays of emotions during a qualitative interview (Dickson-Swift, James, Kippen, & Liamputtong, 2007), while others feel that researchers should remain professional and

should not show signs of emotion to maintain the boundaries of the researcher-participant relationship (Dickson-Swift, James, Kippen, & Liamputtong, 2009). I have not yet personally aligned myself with either perspective, and while I think that emotional expression might not necessarily negatively affect data collection (unless the participant has to start comforting the researcher), there are important risks to consider for researchers who conduct sensitive qualitative inquiries (Butler et al., 2017b; Dickson-Swift et al., 2007). Qualitative researchers have identified experiencing significant emotional effects following data collection on sensitive topics, describing feelings of anger, sadness and anxiety in some cases (Dickson-Swift et al., 2009); researchers have also described feeling emotionally and physically exhausted both during and after research projects (Dickson-Swift et al., 2007). I similarly found myself feeling emotionally and physically drained after each interview, and found that I could not do any other activities related to my thesis the same day that I completed an interview.

Researchers who choose to explore sensitive topics will inevitably be repeatedly immersed in participants' distress and pain (Dickson-Swift et al., 2009). This does not end with the completion of study interviews, but extends through to transcription and analysis (Dickson-Swift et al., 2007). I found that the repeated opportunities to engage with the audio recordings as I transcribed each interview were an important part of my preliminary data analysis. However, transcription is not a purely technical task (Butler et al., 2017b; Dickson-Swift et al., 2007), and I found that some of the emotions I experienced while conducting the interviews re-surfaced at particularly charged moments as I transcribed the audio recordings.

To manage the emotions that I experienced, I left time between interviews so that I could process each interview individually before proceeding to the next one, and I relied on informal support networks (trusted family members) throughout the research process to 'debrief' with

these individuals about whatever emotions I was experiencing (while maintaining participant confidentiality). These strategies sufficed in my case, and I felt adequately supported throughout the research process. However, I was surprised at how difficult and exhausting it could be to conduct and transcribe these interviews.

Dickson-Swift and colleagues (2007) have recommended that researchers, supervisors, and ethics committees should more thoroughly consider the potential negative effects that can result on the physical and emotional health of researchers who conduct sensitive qualitative research. Efforts should be made to inform novice researchers of the issues they may encounter, and appropriate supports and strategies should be in place should the need arise for them during the research process (Dickson-Swift et al., 2007). Ethics committees could also consider requiring researchers to outline the risks to themselves (in addition to those that participants may experience) in research ethic board proposals as an additional step to help novice researchers prepare for the negative effects they might encounter during sensitive qualitative research projects.

Recommendations for Future Research

Given the gender imbalance that exists in the literature on parental experiences of pediatric palliative care (M. E. Macdonald et al., 2010), researchers exploring the moral experiences of parents at the end-of-life in the PICU and in other pediatric settings should consider study methods besides the semi structured interview (Affleck et al., 2013). Photographic and other visual methods could be considered for individuals who are more uncomfortable with emotional expression (M. E. Macdonald et al., 2010), and are also helpful for exploring the experiences of people who have difficulty with language or those who are more interested in visual forms of expression (Affleck et al., 2013; Teachman & Gibson, 2013). Study

methods such as photo-elicitation or photovoice, where participants meet researchers several weeks in advance of the study 'interview', are provided with a camera to take photos that are representative of their experiences, and are instructed to write captions about the relationship between each image and their experience, are advantageous in comparison to the traditional interview because researchers can build a rapport with participants, participants have an increased sense of control over what is discussed during the interview and participants may be able to better express complex, emotionally-charged experiences (Affleck et al., 2013; Nykiforuk, Vallianatos, & Nieuwendyk, 2011).

Moreover, photographic methods may evoke forgotten or dismissed memories, and some photos can be shown to research audiences, which can enhance knowledge translation in comparison to interviews alone (Affleck et al., 2013). Photo-based methods can also help to lessen some of the anxiety that men may face with emotional expression, and men may be more inclined to participate in a study using this method in comparison to a study using the traditional qualitative interview (Affleck et al., 2013). Photo-based methods can also be used in conjunction with traditional interviews, and can result in more rigorous research designs by offering broader insight into a study phenomenon (Affleck et al., 2013; Thorne, 2016).

Another research design that researchers could consider to explore parents' moral experiences of nursing care at the end-of-life is focused ethnography. Focused ethnography uses the data collection strategies that are used in traditional ethnography, but to differing degrees; traditional ethnography uses three complementary data collection strategies including participant observation (time spent observing participants in their 'natural' setting), formal and informal interviews, and examination of relevant documents (e.g., patients' charts, or family orientation materials to a hospital unit). In comparison to traditional ethnography, studies using focused

ethnography typically involve briefer periods spent conducting participant observation (e.g., three to twelve months) (Roper & Shapira, 2000), and often investigate "more narrowly defined cultures" (Polit & Beck, 2012, p. 492). Focused ethnographies are relevant to researchers in nursing who want to explore a distinct issue that is experienced by individuals within a specific context (like the PICU), can be used as a research design in empirical studies where researchers want to understand the meaning that members of a subgroup assign to their experiences, and can also be used to examine nursing practice as a cultural phenomenon (Cruz & Higginbottom, 2013; Roper & Shapira, 2000). Exploring my study topic using focused ethnography would provide a novel perspective to this phenomenon since my study solely explored parental experiences; the motivations and thought processes behind specific nursing interventions could be better understood through interviews with nurses, and participant observation might offer different insights into the nursing care that is provided in this context. Moreover, researchers could explore the ways that the PICU culture shapes the interactions between nurses and parents at the end-of-life.

Conclusion

In my thesis, I sought to animate a relational ethical understanding of PICU nursing practice. Nurses' engagement at the end-of-life is crucial to fostering positive moral experiences for parents. In instances where nurses did not engage with parents (or were unable to), parents felt displaced from their parental role; although it is impossible to know what nurses' perspectives were in such situations in my study, a relational ethical understanding of contrasting viewpoints in a given situation challenges nurses (and care recipients) to strive to achieve mutual respect by reflecting on the value of the other's perspective. When mutual respect was achieved between nurses and parents in my study, nurses supported parents' abilities to reconnect to *who*

they were as parents at the end-of-life, and participated in moments that would shape parents' memories of their child's death and their evolving conceptualizations of their personhood-as-parents through bereavement. In the discussion of my results, I also sought to more broadly examine the ethical significance of the environment, and how the caregiving context can shape a nurse's ability to be open and able to respond to the moral issues that are at stake for those in their care.

Through interviews with parents of children who died in a PICU, study results revealed the subjective, contingent nature of nurses' relational practice at the end-of-life. Parents revealed that nurses could promote their personhood-as-parents through holistic, individualized interventions that supported parents' abilities to provide care to their child, prepared them for their child's death, and fostered their privacy as a family during their most vulnerable moments so they could live the child's death intimately, while still feeling supported by their nurse. Overall, this study enhances our knowledge about the complex, nuanced ways in which parents live their interactions with nurses during these significant moments.

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[redacted]

2017-12-11

Professor Mary Ellen Macdonald
Faculty of Dentistry - McGill University
c/o: Stephanie Avery
email: [redacted]

RE: Final REB Approval of a New Research Project
Attending to values at stake when a child is dying: a study of pediatric intensive care nursing from the perspectives of bereaved parents
(EOL RN Care in the PICU / [redacted])

[redacted] REB Co-Chair for the [redacted] panel: Me [redacted] [redacted]

Dear Dr. Macdonald,

Thank you for submitting your responses and corrections for the research project indicated above, as requested by the [redacted] Research Ethics Board (REB).

The [redacted] REB, more precisely its [redacted] research panel ([redacted] provided conditional approval for the research project after a delegated review provided by its member(s).

On 2017-12-11, delegated review of your responses and corrections was provided by member(s) of the [redacted] REB. The research project was found to meet scientific and ethical standards for conduct at the [redacted]

The following documents were approved or acknowledged by the [redacted] REB:

- Initial Submission Form (F11NIR - 18497)
- REB Conditions & PI Responses Form(s) (F20 - 24644)
- - Research protocol
    - (Study Protocol V5.pdf) [Date: 2017-11-03, Version: 5]
  - Information & consent form
    - (Nurse consent form [redacted] V2.pdf) [Date: 2017-11-03, Version: 2]
    - (Parent Consent form [redacted] V2.docx) [Date: 2017-11-03, Version: 2]
    - (Parent consent form [redacted] french V2.docx) [Date: 2017-11-03, Version: 2]
  - Questionnaires & research material
    - (Semistructured interview guides.pdf) [Date: 2017-10-13, Version: 2]
  - Recruitment documents
    - (French RN poster.pdf) [Date: 2017-10-13, Version: 2]
    - (Consent to Contact Card V2.png) [Date: 2017-11-03, Version: 2]
    - (Reminder Card V2.png) [Date: 2017-11-03, Version: 2]
    - (Personalized invitation letter V2.docx) [Date: 2017-11-16, Version: 2]

        - (Plain language information sheet.pdf) [Date: 2017-11-03, Version: 2]
        - (English RN poster.pdf) [Date: 2017-10-13, Version: 2]
    - Information for participants
        - (Information about Grief English.pdf) [Date: 2017-10-13, Version: 2]
        - (Information about Grief French.pdf) [Date: 2017-10-13, Version: 2]
    - Approval of the Department / Division Head
        - (Stephanie Avery - research approval[1].pdf) [Date: 2017-11-16]

This will be reported to the [redacted] REB and will be entered accordingly into the minutes of the next [redacted] meeting. Please be advised that you may only initiate the study after all required reviews and decisions are received and documented.

The approval of the research project is valid until 2018-12-11.

All research involving human subjects requires review at recurring intervals. To comply with the regulation for continuing review of at least once per year, it is the responsibility of the investigator to submit an *Annual Renewal Submission Form* [redacted] to the REB prior to expiry. Please be advised that should be protocol reach its expiry before a Continuing review has been submitted, the data collected after the expiry date may not be considered valid. However, should the research conclude for any reason prior to approval expiry, you are required to submit a *Completion (End of Study) Report* [redacted] to the board once the data analysis is complete to give an account of the study findings and publication status.

Furthermore, should any revision to the project or other development occur prior to the next continuing review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to its approval by the REB.

The [redacted] REB is registered and works under the published guidelines of the *Tri-Council Policy Statement 2*, in compliance with the *Plan d'action ministériel en éthique de la recherche et en intégrité scientifique* (MSSS, 1998) and the *Food and Drugs Act* (2001.06.07), acting in conformity with standards set forth in the (US) *Code of Federal Regulations* governing human subjects research and functioning in a manner consistent with internationally accepted principles of good clinical practice.al Wide Assurance is conducted under FWA00000840.

We trust this will prove satisfactory to you. Thank you for your consideration in this matter.

Best Regards,

[redacted]

[redacted]
[redacted] REB Coordinator
for [redacted] Co-chair mentioned above

Appendix B: Study Approval from the Office of Research Ethics and Integrity at the University

04/01/2018

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

University of Ottawa
Office of Research Ethics and Integrity

CERTIFICAT D'APPROBATION ÉTHIQUE | CERTIFICATE OF ETHICS APPROVAL

Numéro du dossier / Ethics File Number	H-12-17-242
Titre du projet / Project Title	Attending to values at stake when a child is dying: A study of pediatric intensive care nursing from the perspectives of bereaved parents
Type de projet / Project Type	Thèse de maîtrise / Master's thesis
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	04/01/2018
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	03/01/2019

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Stephanie AVERY	École des sciences infirmières / School of Nursing	Chercheur Principal / Principal Investigator
David WRIGHT	École des sciences infirmières / School of Nursing	Superviseur / Supervisor

Conditions spéciales ou commentaires / Special conditions or comments

550, rue Cumberland, pièce 154
Ottawa (Ontario) K1N 6N5 Canada

550 Cumberland Street, Room 154
Ottawa, Ontario K1N 6N5 Canada

☎ 613-562-5387 • 🖷 613-562-5338 • ✉ ethique@uOttawa.ca / ethics@uOttawa.ca
www.recherche.uottawa.ca/deontologie | www.recherche.uottawa.ca/ethics

Appendix C: Personalized Recruitment Letter

Dear [name of parent A],

On behalf of the medical, nursing, and allied health teams in the pediatric intensive care unit (PICU) of the [hospital name], I would like to extend my condolences on the death of your child, (insert name of child). I am sorry to write you at such a difficult time in your life, however I would like to tell you about a research project which is currently being undertaken in this PICU by myself, Stephanie Avery. I am a nurse in the PICU, and I am conducting a research project as a part of my master's degree in nursing, under the supervision of Dr. David Wright and Dr. Mary Ellen Macdonald.

The project aims to examine the experiences of parents who have a child who died in the PICU. More specifically, we are interested in exploring how nursing care influences these experiences, so that we might be able to better support families during this difficult time.

We would like to invite you to take part in this research study, which consists of a face-to-face, confidential interview. We understand that participating in this interview might be very difficult for you. You do not have to take part in this research study if you do not want to. If you decide to take part, you will be asked to meet with me for an interview about your time in the PICU with your child and your interactions with (his/her) nurses, at a time and place that is convenient to you. By participating in this research, you will be helping us to learn how to take better care of other families who go through this experience.

If you are interested in the study and would like to be contacted further, please complete the enclosed 'Consent to contact' card, and return it as soon as possible, or contact me by the email address below. I will then contact you via phone to discuss the study and your potential participation. You will receive a reminder card in 3 weeks about this study; otherwise, if you prefer not to be contacted again, you do not need to do anything further.

We have also enclosed a copy of the consent form for you to read. It contains details about this study and what your participation would involve. Please read it carefully, as it will help you to decide if you would like to participate. You may find it helpful to discuss the form with a family member before you decide.

If you have any questions or concerns regarding this study, or would rather speak to the research team in person, you may contact me at xxxx@uottawa.ca. If you have any questions about the ethical conduct of the study, you may contact the Protocol Officer for Ethics in Research at the University of Ottawa at (xxx) xxx-xxxx or the XXXX Office of the Ombudsman at xxx-xxx-xxxx extension xxxxx.

We appreciate your consideration.

Sincerely,

Stephanie Avery [Chief Physician of the PICU]

Cher(ère) parent(s) A,

De la part des équipes médicales, infirmières, et des autres membres de l`équipe de l'unité des soins intensifs pédiatriques (USIP) de [nom de l'hopital], j'aimerais exprimer mes condoléances suite au décès de votre enfant, (insert name of child). Je suis désolée de vous écrire à un moment aussi difficile dans votre vie, mais j'aimerais vous introduire à une étude que je, Stéphanie Avery, débute dans cette unité. Je suis infirmière dans l'USIP et j'effectue cette étude dans le cadre de mon diplôme de maîtrise, sous la supervision du Dr. David Wright et Dr. Mary Ellen Macdonald.

L'étude vise à examiner les expériences des parents ayant vécu le décès d'un enfant dans l'USIP. Plus précisément, nous nous intéressons à mieux comprendre comment les soins infirmiers ont influencés ces expériences, afin que nous puissions être mieux en mesure de supporter les familles pendant ces temps difficiles.

Nous aimerions vous inviter à participer dans cette étude qui prendrait la forme d'une entrevue personnelle et confidentielle. Nous comprenons que votre participation dans cette rencontre pourrait être difficile pour vous et rien ne vous oblige à y participer si vous ne le voulez pas. Si vous décidez de participer, nous vous demanderons de me rencontrer pour une entrevue individuelle à propos de votre expérience vécue dans l'USIP avec votre enfant et vos interactions avec ses infirmiers(ères), à un moment et à un endroit qui vous conviennent. En participant à cette étude, vous nous aiderez à apprendre comment mieux prendre soins des autres familles qui vivent cette expérience difficile.

Si vous êtes intéressés par l'étude et souhaitez être contactés, veuillez s'il vous plaît remplir la carte « Consentement pour être contacté » qui est incluse ci-joint, et retournez la dès que possible, ou contactez moi par courriel (voir le courriel ci-bas). Par la suite, je vous contacterais par téléphone pour discuter de l'étude et votre participation potentielle. Vous recevrez une carte de rappel dans 3 semaines. Si vous préférez ne pas être contactés à nouveau, simplement ne pas répondre au rappel.

Nous avons inclus des informations et une copie du formulaire de consentement que vous pouvez consulter. Cela contient des détails à propos de l'étude et des implications liées à votre participation. S'il vous plaît, lisez les attentivement, car ça vous aidera à décider si vous voudriez participer. Vous pourriez trouver utile de discuter du formulaire avec un membre de votre famille avant de décider de participer à l'étude.

Si vous avez des questions ou des inquiétudes, ou si vous préférez parler avec quelqu'un directement, vous pouvez me contacter au courriel suivant xxxx@uottawa.ca. Si vous avez des questions reliées aux aspects éthiques de l'étude, vous pouvez contacter le Responsable de l'éthique en recherche de l'Université d'Ottawa au numéro de téléphone suivant (xxx) xxx-xxxx ou vous pouvez également contacter le Bureau de la commissaire aux plaintes et à la qualité du XXXX au numéro de téléphone suivant (xxx) xxx xxxx poste xxxxx.

Nous apprécions votre considération.

Sincèrement,

Stephanie Avery [Chief Physician of the PICU]

Appendix D: Study Information

General Information

Parent A,

The purpose of this study is to gain a better understanding about your experiences during your child's hospitalization and death in the pediatric intensive care unit, and to understand how your child's bedside nurse influenced this experience.

To find out about this experience, we would like for you to participate in a face-to-face interview. This interview will last approximately 1-2 hours and will be set up at a time and place that is convenient to you. This interview will be audiotaped so that we can learn about your experience in this setting. All data will be anonymous and kept confidential.

There is a strong likelihood that you will experience emotional and psychological distress from participating in this interview. We have included information about some of the common feelings associated with grief and bereavement that you may experience, should you choose to participate.

This is a study being conducted as part of a Masters in nursing degree by Stephanie Avery.

If you are interesting in participating in the study, have any questions, or would like more information, please feel free to contact Stephanie Avery at xxxx@uottawa.ca

Thank you for your consideration,

Student Researcher:

Stephanie Avery, MScN (student)
School of Nursing, Faculty of Health Sciences, University of Ottawa

Thesis Supervisors:

David K Wright, PhD, CHPCN(C)
School of Nursing, Faculty of Health Sciences, University of Ottawa
xxxx@uottawa.ca

Mary Ellen Macdonald, PhD
Division of Oral Health and Society, Faculty of Dentistry, McGill University; Program Head, Pediatric Palliative Care Research, Montreal Children's Hospital of the McGill University Health Centre
xxxx@mcgill.ca

Informations Générales

Parent A,

L'objectif de l'étude est de mieux comprendre vos expériences pendant le décès de votre enfant dans l'unité de soins intensif pédiatriques, et de mieux comprendre comment l'infirmier(ère) de votre enfant a influencé cette expérience.

Pour en savoir plus sur cette expérience, nous aimerions que vous participiez dans une entrevue en personne. Cette entrevue durera approximativement 1 à 2 heures et se déroulera à un moment et un endroit qui vous conviennent. L'entrevue sera enregistrée (audio seulement) afin que nous puissions en apprendre plus sur votre expérience dans cette unité. Toutes les données seront tenues anonymes et confidentielles.

Il est fort probable que vous rencontriez une détresse émotionnelle et psychologique au moment de votre participation dans l'entrevue. Nous avons inclus des informations à propos de quelques-unes des réactions émotionnelles et physiques associés avec le deuil qui pourraient être vécues, si vous décidez de participer.

L'étude se déroule dans le cadre de la maîtrise en sciences infirmières de Stéphanie Avery.

Si la participation à cette étude vous intéresse, si vous avez des questions, ou si vous aimeriez avoir plus d'informations, vous pouvez contacter Stéphanie Avery par courriel (xxxx@uottawa.ca)

Merci pour votre considération,

Chercheuse:
Stephanie Avery, MScN (étudiante)
École des sciences infirmières, Faculté des sciences de la santé, Université d'Ottawa

Superviseur de thèses :
David K Wright, PhD, CHPCN(C)
École des sciences infirmières, Faculté des sciences de la santé, Université d'Ottawa
Courriel: xxxx@uottawa.ca

Mary Ellen Macdonald, PhD
Division of Oral Health and Society, Faculty of Dentistry, McGill University; Program Head, Pediatric Palliative Care Research, Montreal Children's Hospital of the McGill University Health Centre
Courriel : xxxx@mcgill.ca

Appendix E: Consent Form

'Image of hospital center logo'

INFORMATION AND CONSENT FORM

Parental consent form

Research Study Title:	Attending to values at stake when a child is dying: A study of pediatric intensive care nursing from the perspectives of bereaved parents
Protocol number:	2018-3586
Researcher responsible for the research study and thesis co-supervisor:	Mary Ellen Macdonald, PhD, Division of Oral Health and Society, Faculty of Dentistry, McGill University; Program Head, Pediatric Palliative Care Research, Montreal Children's Hospital of the McGill University Health Centre Email: xxxx@mcgill.ca
Co-Investigator and student Researcher:	Stephanie Avery, MScN (student), School of Nursing, Faculty of Health Sciences, University of Ottawa Email: xxxx@uottawa.ca
Co-Investigator and thesis supervisor:	David K Wright, PhD, CHPCN(C), School of Nursing, Faculty of Health Sciences, University of Ottawa Email: xxxx@uottawa.ca

1. INTRODUCTION

We are inviting you to take part in this research study because you are the parent of a child who was hospitalized and who died in the pediatric intensive care unit at the xxxx Hospital.

However, before you accept to take part in this study and sign this information and consent form, please take the time to read, understand and carefully examine the following information. You may also want to discuss this study with your family doctor, a family member and/or a close friend.

This form may contain words that you do not understand. We invite you to speak to the researcher responsible for this study or to other members of the research team, and ask them to explain to you any word or information that is unclear to you before you sign this form.

2. OVERVIEW AND PURPOSE OF THE STUDY

The purpose of this study is to gain a better understanding about your experiences during your child's hospitalization and death in the pediatric intensive care unit, and to understand how your child's bedside nurse influenced this experience.

We hope that the study results will contribute to the advancement of knowledge to improve the ways that nurses care for dying children and their families in the pediatric intensive care unit, and to benefit families that go through this experience in the future.

This study will take place at the xxxx Hospital. We will recruit 8-12 participants who are parents of children who died in the pediatric intensive care unit.

3. STUDY PROCEDURES

Your participation will consist of participating in a face-to-face, audio-recorded interview with the student researcher that will last around 1-2 hours. During this interview you will be asked questions about your experiences in this setting. This interview will occur at a time and place (in a private conference room at the xxxx Hospital, or in your home) that is convenient to you, and will be scheduled with the researcher. This interview will eventually be transcribed, but any information that might be able to identify you will be removed from the transcript.

Responsibilities as participant

To summarise, your responsibilities as a participant of this study will be to:

- Participate in a face-to-face interview with the student researcher

4. BENEFITS ASSOCIATED WITH THE STUDY

You may or may not personally benefit from your participation in this study. Although it is very difficult to discuss these experiences, some people find it helpful to share their child and family's story.

5. RISKS ASSOCIATED WITH THE STUDY

A possible risk associated with this study is a breach of confidentiality or use of your personal information by a third party. To limit this risk, we will take the steps to protect your confidentiality described in Section 9 (Confidentiality), below.

You may find the interviews upsetting or distressing. You can refuse to respond to any of the questions and/or choose to stop participating in the study altogether at any time. You do not have to give any reason for refusing to answer a question or for stopping to participate. If you feel uncomfortable at any time, do not hesitate to tell the student researcher who will stop the interview, and refer you to a support person as needed with your consent.

Potential inconveniences linked to study procedures

Your time and money spent travelling to the xxxx hospital if you prefer that the interview occur in a private conference room (otherwise, the time taken to participate in the interview in your home).

6. VOLUNTARY PARTICIPATION AND THE RIGHT TO WITHDRAW

Your participation in this study is voluntary. Therefore, you may refuse to participate. You may also withdraw from the *ongoing* project at any time, without giving any reason, by informing a member of the study team. Your decision not to participate in the study, or to withdraw from it, will have no negative consequences. You will be informed in a timely manner if any information becomes available that may impact your willingness to continue participating in this study.

If you withdraw or are withdrawn from the study, any analyses that have already been completed using your data will be kept.

7. CONFIDENTIALITY

During your participation in this study, we will collect information from you about your experience through the face-to-face interview. All the information collected during this study will remain confidential to the extent provided by law.

For auditing purposes your study file may be examined by individuals mandated by the funder, the xxxx, or the Research Ethics Board. All these individuals adhere to policies on confidentiality.

To protect your identity and the confidentiality of your personal information, you will only be identified by a code number. The key to the code linking your name to your study file will be kept by the researcher in charge of this study. All study data will be kept for seven years, starting from January 2018.

The data may be published or shared during scientific meetings; however, precautions will be taken to ensure that it will not be possible to identify you.

It is possible that members of the research team (including the supervisors and/or their future students) may want to re-read your interview to answer a different nursing research question. This is referred to as secondary analysis of data. In the event that your data is used in a secondary analysis, all of the conditions specified here with respect to protection of your personal information will apply. You will be asked below whether you give permission to the research team to use your data in potential future secondary analyses. This permission is separate from your consent to participate in this study.

9. FUNDING OF THE STUDY

The researchers have received no funding to conduct this study.

10. CONFLICT OF INTEREST

The researchers have no conflict of interest to declare.

11. REIMBURSEMENT

You will not be reimbursed for any of the costs related to your participation in this study.

12. SHARING STUDY RESULTS

Results from this study will be presented at conferences and published in journals.

13. CONTACT INFORMATION

If you have questions or if you have a problem you think may be related to your participation in this study, or if you would like to withdraw, you may communicate with Mary Ellen Macdonald, the researcher responsible for this project at xxxx@mcgill.ca or with Stephanie Avery, the student researcher for this project, by email at xxxx@uottawa.ca.

For any question concerning your rights as a research participant taking part in this study, or if you have comments, or wish to file a complaint, you may communicate with:

> The Patient Ombudsman of the xxxx Office of the Ombudsman, xxxx, xxxx, xxxx, xx, xxx xxx at the following phone number: xxx-xxx-xxxx extension xxxxx.
>
> Or you may communicate with:
>
> The Protocol Officer for Ethics in Research, University of Ottawa, xxxx, xxx Street, xxx, Ottawa, ON xxx xxx at the following phone number: xxx-xxx-xxxx or by email at xxxx@uottawa.ca

14. REVIEW OF THE ETHICAL ASPECTS OF THE STUDY

The xxxx Research Ethics Board and the Office of Research Ethics and Integrity at the University of Ottawa reviewed this study and are responsible for monitoring the study.

Study Title: Attending to values at stake when a child is dying: A study of pediatric intensive care nursing from the perspectives of bereaved parents

SIGNATURES

Signature of the participant

1) I have reviewed the information and consent form. Both the study and the information and consent form were explained to me. My questions were answered, and I was given sufficient time to make a decision. I was given a copy of the information sheet and consent form for my personal records. After reflection, I consent to participate in this study in accordance with the conditions stated above.

2) I accept that my participation in the study be audio-recorded.

3) I give permission to the research team to use my data in future secondary analyses.

    a. **Yes** **No**

Name of participant Signature Date

Signature of the person obtaining consent

I have explained the study and the terms of this information and consent form to the study participant, and I answered all his/her questions.

Name of the person obtaining consent Signature Date

'Image of hospital center logo'

INFORMATIONS ET FORMULAIRE DE CONSENTEMENT

Formulaire de consentement pour parents

Titre de l'étude:	Prendre en considération les valeurs en jeu quand un enfant est mourant: Une étude des soins infirmiers à l'unité de soins intensifs pédiatrique des perspectives des parents en deuil
Numéro de Protocole:	2018-3586
Chercheuse responsable pour l'étude et co-superviseur de thèse :	Mary Ellen Macdonald, PhD, Division of Oral Health and Society, Faculty of Dentistry, McGill University; Program Head, Pediatric Palliative Care Research, Montreal Children's Hospital of the McGill University Health Centre Courriel: xxxx@mcgill.ca
Co-chercheuse :	Stephanie Avery, MScN (étudiante), École des sciences infirmières, Faculté des sciences de la santé, Université d'Ottawa Courriel: xxxx@uottawa.ca
Co-chercheur et superviseur de thèse:	David Kenneth Wright, PhD, CHPCN(C), École des sciences infirmières, Faculté des sciences de la santé, Université d'Ottawa Courriel: xxxx@uottawa.ca

1. INTRODUCTION

Vous avez été invités à participer à cette étude de recherche puisque vous êtes le parent d'un enfant ayant été hospitalisé et qui est décédé dans l'unité de soins intensifs pédiatriques de l'hôpital xxxx.

Avant d'accepter de prendre part à l'étude, veuillez vous assurer d'avoir bien pris le temps de lire et de comprendre l'information qui se trouve dans cette brochure. Vous êtes également invités à discuter de cette étude avec votre médecin de famille, votre famille ou un ami proche.

Dans le cas où ce pamphlet contiendrait des informations ou des mots dont vous ne saisissez pas la signification, nous vous invitons fortement à contacter la personne en charge de l'étude ou son équipe afin d'obtenir plus d'explications et vous aider à bien comprendre l'information qu'il contient.

2. SURVOL ET OBJECTIFS DE L'ÉTUDE

L'objective de cette étude est de réellement comprendre le fondement de vos expériences vécues lors

de l'hospitalisation et le décès de votre enfant à l'unité de soins intensifs pédiatriques, et de comprendre l'influence qu'ont pu avoir les infirmiers et infirmières durant cette épreuve.

Nous espérons que les résultats de l'étude aideront à faire avancer et à améliorer les pratiques des infirmiers et infirmières auprès des enfants en fin de vie et leurs familles lors de leur passage aux soins intensifs, et surtout de permettre aux familles ayant à vivre cette épreuve dans le futur de bénéficier des expériences vécues.

L'étude se déroulera à l'hôpital xxxx. Nous allons recruter 8-12 participant(e)s qui sont parents d'un enfant qui est décédé dans l'unité de soins intensifs pédiatriques

3. PROCÉDURES DE L'ÉTUDE

Votre participation prendra la forme d'une entrevue en personne variant 1-2h et sera audio-enregistrée. Durant l'entrevue, vous serez questionné sur vos expériences dans ce contexte et l'expérience se déroulera dans un lieu et à un moment (soit à l'hôpital xxxx dans un salle de conférence privé, ou à votre maison) qui vous conviendront, selon un horaire établi avec la chercheuse. Cette entrevue sera éventuellement transcrite, mais les informations qui pourront vous identifier seront enlevées de la transcription.

Responsabilités du participant

L'unique responsabilité d'un participant à cette étude est:

- Réaliser l'entrevue avec la chercheuse étudiante responsable de l'étude.

4. Bienfaits de l'étude

Vous pourriez ou non bénéficier personnellement de votre participation à cette étude. Bien qu'il soit difficile de discuter des expériences dont il est question dans ce projet de recherche, certains trouvent bénéfique de partager ces évènements.

5. RISQUES ASSOCIÉS À CETTE ÉTUDE

Un des risques associés à cette étude est la possible divulgation de certains renseignements confidentiels à une tierce partie. Afin de limiter ce risque, nous prendrons les mesures décrites à la section 9 (confidentialité) ci-dessous.

Vous pourriez trouver la participation aux entrevues perturbante ou bouleversante. À tout moment, vous êtes autorisés à refuser de répondre à certaines des questions de l'étude, ou de vous y retirer si vous en sentez le besoin. En aucun cas, vous n'aurez à donner d'explications pour refuser de participer. Si vous vous sentez inconfortables à tout moment de l'étude, n'hésitez surtout pas à en faire part à la personne responsable qui saura au besoin vous guider vers les ressources nécessaires.

Désagréments potentiels de l'étude

Le temps de transport requis pour vous rendre au Site xxxx du xxxx et le temps requis pour participer à l'étude (temps requis pour participer à l'étude seulement dans le cas où vous choisissez de réaliser l'étude à la maison).

6. PARTICIPATION VOLONTAIRE ET DROIT À L'ABANDON

Votre participation à cette étude est complètement volontaire. Vous pouvez donc refuser de participer. Vous pouvez également décider de vous retirer du projet en cours à tout moment, sans avoir à donner de raisons ou d'explications. Si tel était le cas, vous n'avez simplement qu'à aviser un(e) membre de l'équipe de recherche pour lui faire part de votre abandon. Il n'y a pas de conséquences liées a l'abandon de l'étude. Toute information jugée pertinente pour vous et/ou qui pourrait influencer votre intérêt à participer à cette étude vous sera communiquée dans les meilleurs délais possibles.

Si vous vous retirez ou êtes retiré de l'étude, les analyses qui ont déjà été faites avec vos données seront conservées.

7. CONFIDENTIALITÉ

Durant votre participation à cette étude, nous allons recueillir de l'information à propos de votre expérience sous forme d'entrevue individuelle. Toute information recueillie demeurera confidentielle dans la mesure permise par la loi.

Pour des fins de vérifications, votre dossier de recherche pourrait faire office de révisions supplémentaires par des individus mandates par le commanditaire, par le xxxx ou le Comité d'éthique de la recherche. Les individus en question adhèrent entièrement aux politiques de confidentialités.

Dans le but de protéger votre identité et la confidentialité de vos renseignements personnels, vous vous verrez attribué un numéro de code. L'encryptage permettant de faire le lien entre votre dossier et le numéro de code vous ayant été attribué sera gardé par l'individu en charge de l'étude. Les données de l'étude seront conservées pour une durée totale de sept ans, à compter de janvier 2018.

Les données de l'étude pourraient faire l'objet de publications ou de discussions scientifiques. Les mesures nécessaires seront mises en place afin qu'il soit impossible de retracer l'identité des participants à partir des informations rendues publiques.

Il est possible que les membres de l'équipe de recherche (incluant les superviseurs de la chercheuse et/ou leurs futurs étudiants) veuillent relire votre entrevue pour répondre à une autre question de recherche. Cela s'agit d'une analyse secondaire des données. Si vos données sont utilisées dans une analyse secondaire, toutes les conditions spécifiées ci-dessus sur la protection des informations personnelles s'appliqueront. Votre consentement pour l'autorisation à utiliser les données dans des analyses secondaires sera demandé ci-dessous et est séparé du consentement pour la participation dans cette étude.

9. FINANCEMENT DE L'ÉTUDE

Aucun financement n'a été attribué à cette étude.

10. CONFLITS D'INTÉRÊTS

Aucun individu en charge de l'étude n'est en conflit d'intérêts.

11. REMBOURSEMENT

Aucun remboursement ne sera attribué aux participants de cette étude.

12. PARTAGE DES RÉSULTATS

Les résultats de l'étude pourraient et seront potentiellement publiés sous forme de revues ou discussions scientifiques.

13. COORDONNÉES

Si vous avez des questions ou si vous avez un problème que vous pensez pourrait être relié à votre participation dans cette étude, ou si vous voudriez retirer du projet, vous pouvez communiquer avec Mary Ellen Macdonald, qui est responsable pour cette étude, par courriel à xxxx@mcgill.ca ou avec Stephanie Avery (la chercheuse étudiante), par courriel à xxxx@uottawa.ca.

Pour toutes questions concernant vos droits comme participant(e) dans cette étude, ou si vous avez des commentaires, ou vous désirez faire une plainte, vous pouvez communiquer avec :

> Bureau de la commissaire aux plaintes et à la qualité du xxxx, xxxx, av. xxxx, poste xxxxx, xxxx, XX, xxx xxx , téléphone: xxx-xxx-xxxx poste xxxxx.
>
> Ou vous pouvez communiquer avec:
>
> Le Bureau d'éthique et d'intégrité de la recherche, xxxx, xxx rue xxxx, xxxx, Ottawa, ON, Canada, xxx xxx, Tél. : xxx-xxx-xxxx ou par courriel à xxxx@uottawa.ca

14. RÉVISION DES ASPECTS ÉTHIQUES DE L'ÉTUDE

Le comité d'éthique du xxxx et le bureau d'éthique et d'intégrité de la recherche de l'Université d'Ottawa ont révisé cette étude, et sont responsable de la surveillance de l'étude.

Titre de l'étude: Prendre en considération les valeurs en jeu quand un enfant est mourant: Une étude des soins infirmiers à l'unité de soins

intensifs pédiatrique des perspectives des parents en deuil

SIGNATURES

Signature du ou de la participant(e)

1) J'ai révisé les informations et le formulaire de consentement. L'étude et les informations m'ont été expliquées. Mes questions ont été répondues, et j'ai eu assez de temps pour prendre une décision. J'ai reçu une copie des informations et le formulaire de consentement pour mes dossiers personnels. Après réflexion, je consente a participé dans cette étude en accord avec les conditions écrits ci-dessus.

2) J'accepte que ma participation soit audio-enregistré.

3) Je donne la permission à l'équipe de recherche d'utiliser mes données dans des analyses secondaires a l'avenir.

    b. **Oui** **Non**

Nom du/de la participant(e) Signature Date

Signature de la personne qui obtient le consentement

J'ai expliqué l'étude et les termes de ce formulaire de consentement a le/la participant(e), et j'ai répondu a toutes leur questions.

Nom de la personne qui obtient le consentement Signature Date

Appendix F: Information about Grief

Adapted from "When grief is new: A guide for parents and families"

INFORMATION ABOUT GRIEF FOR PARENTS

Grief is Unique

Grief is unique and there is no right or wrong way to grieve. How you grieve depends on many things. If you are a parent and sharing your grief with your child's other parent, you both will most likely express your grief individually and need different things at different times.

You will experience many ups and downs with grief, which may lessen in intensity over time, but you may still have bad days months or years later. It is important to remind yourself that there is no set timetable for grief. Here are some common physical and emotional reactions that you may experience.

Physical Reactions	Emotional Reactions
crying	yearning or longing
panic attacks	numbness
fear	intense sadness
heart palpitations/chest pain	despair
headache	disbelief
muscle tension/body aches	anguish
agitation	emptiness
upset stomach	confusion
sleeping problems	anger
nausea	guilt
loss of appetite	shock
difficultlty concentrating	worry
	anxiety
	relief
	peace
	helplessness
	feelings of self doubt

Realistic beliefs about grief

- Grief is unique
- Grief cannot be hurried
- Grief is not a sign of weakness, it's a normal response to loss
- There is no quick fix
- Grief is not an illness with a prescribed cure
- Yearning is a normal part of grief
- The death of a child, no matter how young or old, changes your life forever
- The process of grieving allows you the time and space to adjust to the loss of your child
- There will always be triggers to your grief – finding ways to manage these triggers is the aim

Adapté de "When grief is new: A guide for parents and families"

INFORMATIONS SUR LE DEUIL POUR LES PARENTS

Le Deuil est Propre à Chacun

Le deuil est propre à chacun et il n'y a pas de bonne ou de mauvaise façon de supporter la perte d'un être cher. Cela depend de plusieurs facteurs. Si vous êtes un parent et que vous partagez cette douloureuse experience avec l'autre parent, vous surmonterez chacun votre deuil de façon différente, à des moments différents et avec des besoins différents.

Vous vivrez des hauts et des bas qui devraient s'atténuer avec le temps. Cependant des jours difficiles pourraient ressurgir des mois voire des années plus tard. Il est important de vous rappeler qu'il n'y a pas de temps limité pour faire son deuil d'un être cher. Nous avons recensé quelques émotions ou reactions physiques que vous pourriez experimenter.

Réactions Physiques	Réactions Émotionnelles
pleurs	angoisse, désir intense
crises de panique	torpeur, perte de sensibilité
avoir peur	une tristesse intense
douleur dans la poitrine	désespoir
mal de tête	incrédulité
tension musculaire/courbatures	souffrance
agitation	se sentir vide
mal d'estomac	confusion
problèmes de sommeil	colère
la nausée	culpabilité
perte d'appétit	choc
difficulté de concentration	inquiètude
	anxiété
	soulagement
	paix
	impuissance
	sentiments de doute de soi

Croyances réalistes sur le deuil

- Le deuil est propre à chacun
- On ne peut sauter les étapes
- Le deuil n'est pas un signe de faiblesse, c'est une réponse normale à la perte d'un être cher
- Il n'y a pas de solution rapide
- Il n'y a pas de remède miracle
- Le besoin de faire quelque chose fait partie du processus de deuil
- Peut importe l'age de votre enfant, sa perte change votre vie pour toujours
- Le processus de deuil vous donne le temps et l'espace pour vous ajuster à la perte de votre enfant
- Il y aura toujours des déclencheurs de souvenirs douloureux - le but est de trouver un moyen de les surmonter

Appendix G: Consent to Contact Card

Consent to Contact Card

By returning this card to the student researcher (Stephanie Avery), I am indicating that I would like to be contacted by telephone for more information about the research study.

Any additional comments:

_____

_____

_____

Parent name
1234 Main Street
City, Province, Postal Code

Carte de consentement pour être contacter

En renvoyant cette carte, j'indique que j'aimerais être contacter par téléphone pour plus de plus amples informations sur cette étude.

Autres commentaires:

_____

_____

_____

Parent name
1234 Main Street
City, Province, Postal Code

Appendix H: Reminder Card

Reminder Card

This card is being sent as a reminder for the package that you previously received by mail about a study of your perspectives about your child's nursing care around the time of their death in the paediatric intensive care unit.

Carte de Rappel

Cette carte est un rappel pour le paquet d'informations que vous avez reçues pour l'étude de vos perspectives à propos des soins infirmiers de votre enfant lors de leur décès à l'unite de soins intensifs pédiatriques.

Appendix I: Semi-structured Interview Guide

Questions will be adapted to individual participants as required.

Before the start of the interview
Is there anything about your experience that you do not want to discuss?

Introduction
Tell me the story of your child's death in the pediatric intensive care unit.

Description/recollection of the situation

1. Talk to me about the nurses in the PICU. What was your experience with them?
2. In what ways did these nurses (or a specific nurse if the participant starts talking about one nurse) care for your child and family?
3. During this time, what was most important to you?
    a. Probes for question 3: what were you most concerned about?; what was your priority?
4. To what extent did the nurses help you to facilitate [insert parent priority(ies)]?
5. When you told your story at the start of this conversation, it sounded like you said that [involvement, interaction, physical environment, social support, etc.] was also important to you. Did I understand that correctly?
6. I'm wondering, how did the nurses in the PICU influence [insert response from question 5]?
7. What else stands out about the relationship between the nurses and your family during your time in the PICU?

Reflections (to examine what parents regarded as 'good' or 'bad' in this experience)

8. How do you feel about your child's nursing care during this time?
    a. What about your interactions with the nurse(s) made you feel this way?
9. How do you feel about your ability to accomplish (or not) [insert priority/matter of importance]?
10. If you could change things, how would you say that your child's nursing care should have been different?
11. Is there anything else you would like to tell me?
12. Are there any other questions that you think I should have asked you?

Would it be okay with you if I ask you a couple questions about what it has been like for you to participate in this research?
Research Process/Participation

13. How did you feel about being contacted to participate in this research through the use of a letter?
    a. Would you modify any aspects of the letter?
    b. Would you have preferred being contacted by another means of communication?
14. How has it been participating in this interview for you?

Before the start of the interview

Avant de débuter l'entrevue, relié à votre expérience vécue y a-t-il un sujet donc vous aimeriez ne pas discuter?

Introduction

Racontez-moi l'histoire du décès de votre enfant dans l'unité de soins intensifs pédiatrique

Description/recollection of the situation

1. Pourriez-vous me parler des infirmières de l'USIP et me décrire votre expérience avec elles?
2. De quelle manière est ce que les infirmières (ou infirmière X) se sont-elles occupées de votre enfant et de votre famille?
3. Quelle était votre ou vos plus grande(s) préoccupation(s) lors de l'hospitalisation?
    a. Probes for question 3: Qu'est ce qui vous concernait le plus? Quelles était vos priorités?
4. Est-ce que les infirmières ont été capable d'alléger votre(vos) préoccupation(s)?
5. Lorsque vous m'avez racontez l'histoire du décès de votre enfant, il me semble que vous m'avez dit que [involvement, interaction, physical environment, social support, etc.] était aussi important pour vous. Ai-je bien compris?
6. Je me demande, comment est-ce que les infirmières de l'USIP ont influencé [insert response from question 5]?
7. Y a-t-il autre chose qui est ressorti de votre relation entre les infirmières et votre famille lors de votre séjour à l'USIP?

Reflections (to examine what parents regarded as 'good' or 'bad' in this experience)

8. Comment vous sentez-vous à propos des soins offerts à votre enfant lors de l'hospitalisation?
    a. Y a-t-il des interactions avec les infirmières que vous pourriez nommer qui font en sorte que vous vous sentiez de cette façon?
9. Comment vous sentiez-vous à propos de votre capacité de réaliser (ou de ne pas) [insert priority/matter of importance]?
10. Si vous pourriez améliorer les soins reçus à votre enfant et votre famille, auriez-vous une suggestion à proposer à l'unité?
11. Y a-t-il autre chose que vous aimeriez me partager?
12. Y a-t-il d'autres questions dont j'ai omis de vous demander?

Est-ce que je peux vous demander quelques questions à propos de vos expériences en participant dans cette étude?

Research Process/Participation

13. Comment avez-vous trouvé d'avoir été contacté par une lettre pour participer à la recherche?
    a. Modifierez-vous des aspects de la lettre?
    b. Auriez-vous préféré être contacté par un autre moyen de communication?

Comment avez-vous trouvé de participer à l'entrevue?