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Maintaining Integrity: How nurses navigate boundaries in pediatric palliative care

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Maintaining integrity: How nurses navigate boundaries in pediatric palliative care

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ABSTRACT

The purpose of this grounded theory study was to explore how nurses in acute care units and an end-of-life facility manage professional and personal boundaries while delivering palliative care to children and families. Pediatric palliative care principles emphasize providing emotional support to children with life-limiting illness and thier family members. Families desire this support during such a vulnerable and intimate experience. Nurses derive satisfaction and see their work as meaningful when they are able to engage and connect with patients and families, but patients' deaths also provoke feelings of grief and a sense of loss. This study asked, "What process(es) do nurses who work in pediatric palliative care use to negotiate boundaries?" It additionally explored how work settings and emotions affect this process.

A purposive sample of 18 registered nurses participated and they were recruited from two sites: a children's hospital and a free-standing end-of-life facility. Within the children's hospital, nurses were recruited from the hematology/oncology/ bone marrow transplant unit, the Pediatric Intensive Care Unit, and the Intensive Care Nursery. Participants were interviewed using a semi-structured interview guide and observed in their work setting. Data was analyzed using grounded theory and situational analysis methodologies.

Major findings centered on how nurses constructed, perceived, and negotiated boundaries. Findings indicated that the nature of participants' practice required them to actively navigate personal and professional boundaries in order to deliver competent and compassionate care. Although there were identified differences among settings, all participants shared a similar process, *maintaining integrity*, in navigating boundaries.

Nurses worked within an external and internal context which influenced this process and subsequently shaped their nursing practice. Participants described a range of emotions and coping strategies which enabled them to continue practicing in a field which required a level of emotional engagement.

The findings contribute to better understanding of how to provide optimal palliative care to children and families. Nurses perceived boundaries as flexible, rather than rigid and they emanated from within nurses, rather than being externally imposed on them. Important practice implications suggest the need to strengthen professional support for nurses in pediatric palliative care through training, education, and ongoing emotional assessments.

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CHAPTER ONE: INTRODUCTION

Pediatric palliative care (PPC) is a philosophy of care which emphasizes holistic care of children and their families (Himelstein, Hilden, Boldt, & Weissman, 2004). It is designed to be integrated with curative treatments and occurs across settings in hospitals, families' homes, and end-of-life facilities. It optimally begins at the diagnosis of a life-limiting illness, in which a child is not expected to live until adulthood (American Academy of Pediatrics [AAP], 2000; Institute of Medicine [IOM], 2003). Life-limiting illnesses, such as cancer, heart anomalies, or cystic fibrosis, place a child at risk for premature death (Himelstein et al.). In the United States, an estimated 500,000 children cope with a life-limiting illness (Children's Project on Palliative/Hospice Services [ChiPPS], 2001). PPC services aim to provide support to these children throughout their illness trajectory, as well as provide grief and bereavement support to families. The goal of PPC is to preserve and maintain children and families' quality of life as they define it.

An interdisciplinary team is integral to the PPC philosophy and includes nurses, physicians, chaplains, social workers, psychologists, pharmacists, and child life specialists. Nurses, however, typically work closest with children and families in health-care settings, such as in hospitals where nursing care is provided around the clock. They often develop close relationships with patients and families. PPC philosophy advocates tending to patients' and families' emotional and psycho-social needs and nurses are often in a position to do so. Evidence suggests that families desire and appreciate emotional support from health-care providers, especially during the terminal phase of illness (Contro, Larson, Scofield, Sourkes, & Cohen, 2002; Davies, Collins, Steele, Pipke, &

Cook, 2003; Heller & Solomon, 2005; James & Johnson, 1997; Meyer, Ritholz, Burns, & Truog, 2006). Often due to their emotional involvement with families at a child's end of life, nurses experienced grief and feelings of loss from their patients' deaths and from bearing witness to families' suffering (Davis et al., 1996; Papadatou, Bellali, Papazoglou, & Petraki, 2002; Papadatou, Martinson, & Chung, 2001; Rushton et al., 2006; Yam, Rossiter, & Cheung, 2001). Despite contributing to their grief, nurses in these studies viewed emotional support to families as an essential aspect of their practice and constitutive to their work being rewarding and meaningful (Davies et al.; Engler et al., 2001; Olson et al., 1998; Papdatou, Bellali, et al.; Papadatou, Martinson, et al.; Rashotte, Fothergill-Bourbannais, & Chamberlain, 1997). These nurses experienced personal costs from the intensity of their work, such as feeling distress, forming close attachments, and grieving the loss of a child. It is unknown how nurses manage personal and professional boundaries working in PPC which requires a level of emotional engagement. Therefore, the goal of this dissertation study was to explore the process nurses use to navigate boundaries.

In Chapter One, I will introduce the background and significance of the research problem. This chapter will also include a description of the concept of pediatric palliative care, how it evolved out of the hospice philosophy, and existing conflicts among its definitions.

Background and Significance

Approximately 50,000 children ages 0-19 die annually in the United States (Hamilton, et al., 2007). The majority of patients' deaths are from traumatic injury and occur in children's hospitals (IOM, 2003), most frequently on critical care units

(Brandon, Docherty, & Thorpe, 2007). Although mortality rates have declined (Wise, 2004), approximately 400,000 children cope daily with life-threatening, chronic illnesses (ChiPPS, 2001; IOM, 2003). A growing body of literature identifies unmet needs of these children and their families, especially at the end of life (AAP, 2000; Contro et al., 2002; IOM; Wolfe et al., 2000). Potential barriers to services have been explored, including hospice eligibility, accessibility, or health-care provider inexperience (AAP; Boldt, Yusuf, & Himelstein, 2006; Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Fowler et al., 2006; Himelstein et al., 2004; IOM). Pediatric palliative care is both a philosophy and program of care which strives to meet the physical, psychosocial, and spiritual needs of children with life-limiting conditions and their families (Himelstein et al., 2004).

Palliative care for children differs from an adult model of care. Pediatric illnesses are often more rare and difficult to prognosticate; some children may live many years with a terminal illness (IOM, 2003; Himelstein et al., 2004). Children's deaths frequently involve complex ethical and legal issues, such as adolescent decision making and with-holding or withdrawing support (IOM; Himelstein et al.; Himelstein, 2006; Rushton, 2004). For example, the ethical principle of autonomy is challenged when parents are legally bound to make treatment and end-of-life decisions for their children (Himelstein, 2006).

Conflicting definitions for pediatric palliative care (PPC), hospice care, and end-of-life (EOL) care are evident in the literature and organizational statements. A lack of consistent definitions and their application frequently confuses practitioners, researchers, patients, and their families (Boldt et al., 2006; Docherty, Miles, & Brandon, 2007; Lamers, 2002). Further, distinctions between adult and pediatric palliative care, as well as significant differences between adult and pediatric illnesses, contribute to misunderstandings and misuses (Himelstein, 2006; Rushton, 2004). The following section will clarify these similar, yet conceptually distinct, terms. It will trace how palliative care evolved out of a hospice philosophy and discuss how this historical lineage contributes to the confusion. Current definitions from leading organizations will be reviewed and critiqued.

A search of the literature revealed that PPC is an evolving concept. Before discussing current definitions of PPC, a review of the history of death, dying, and hospice is necessary since palliative care grew out of the hospice philosophy. After World War II, the care of terminally ill people shifted from occurring in the home by family members to occurring in hospitals by health-care professionals. In 1967, the first hospice facility, St. Christopher's Hospice, was founded in the United Kingdom by Dame Cicely Saunders (Martinson, 1993; Meghani, 2004). Florence Wald, the nursing dean at Yale University, founded the first hospice in the U.S. after hearing Saunders present her work (Krisman-Scott, 2004; Lentz, 2004). In 1974, Connecticut Hospice opened and spurred the "hospice movement" across the U.S. The modern hospice facility emerged partly as a response to an increasing number of deaths occurring in hospitals. Out of families' homes, death and dying became more depersonalized, partly due to increased technological interventions in the hospitals and to health-care providers' avoidance of dying patients (Krisman-Scott). Wald was inspired to create a place which brought dignity to dying after observing terminally ill patients dying in these sub-optimal conditions (Friedrich, 1999; Lentz). Wald explained that, "one of the main problems at the time was that the patient had no choice in terms of the care that was given. Doctors essentially did not recognize that patients should participate in the decision making about care" (Friedrich, p. 1683).

Hospices continued to open across the United Kingdom (UK), US, and other countries, with the early 1980s experiencing a considerable increase of facilities in the US (Meghani, 2004). These hospices primarily cared for adults, but a few home-based pediatric hospice programs were scattered across the US (Martinson, 1993). Helen House, the world's first free-standing pediatric hospice, opened in England in 1982 (Dominica, 1985; Martinson). Mother Frances Dominica founded the facility after helping a family care for their terminally-ill daughter. She observed a lack of respite support which would have temporarily relieved parents of their around-the-clock care-giving. Mother Dominica (1985) stated the goal of Helen House was "to be alongside parents and families facing the tragedy of incurable and life-threatening illness in their child" (p. 17). As of 2001, 22 children's hospices were opened in the UK, with 16 more planned to open (The Association for Children's Palliative Care, 2001). Since the opening of Helen House, other pediatric hospice facilities have opened across the world, for example Canuck Place in Canada, and Very Special Kids in Australia. George Mark Children's House, the first free-standing end-of-life and respite facility in the US opened in 2004.

In the US, Medicare's reimbursement regulations significantly shaped the concept of hospice, and subsequently palliative care (Meghani, 2004). Its impact is due to its hospital eligibility criteria, which requires patients to end curative treatments and have a physician assess they have less than six months to live (US Department of Health and Human Services, 2005). The criteria are the same for both adults and children, which presents challenges for children receiving hospice care. First, parents are much less likely to decide to end their child's curative treatments. This is akin to giving up on the child's possible survival (Dabbs, Butterworth & Hall, 2007). Second, pediatric illnesses are difficult to prognosticate and few physicians can accurately predict a child has less than six months of life left (AAP, 2000; IOM, 2003; Mack & Wolfe, 2006). Moreover, some conditions, such as neurodegenerative illnesses, follow progressive declines over many years, where families could benefit from hospice services over time (Steele, 2005). Under Medicare's guidelines, hospice care is not reimbursed if given concurrently with curative treatment. This separation, rather than an integrated model of care, may explain why few children receive or are referred to hospice care in the US. For example, less than one percent of hospice recipients are children (Children's Hospice International [CHI], 2007), and one study found a low hospice referral rate (2.5%) by pediatric oncologists (Fowler et al., 2006).

Pediatric palliative care, which includes curative treatments, evolved from hospice's inability to fulfill patients' needs coping with a life-limiting illness. According to Meghani (2004), "the concept of palliative care in the US has evolved to address the needs of a wide range of patient populations who may not be termed 'dying' but for whom alleviation of suffering and improvement of quality of life may be relevant goals" (p. 153). Hospice historically and currently refers to both a place and a philosophy of care. As a philosophy, it seeks to improve quality of life, relieve distressing symptoms, provide holistic care (i.e. tend to physical, psychosocial, emotional, and spiritual needs), and give patients greater choice in their end of life preferences (Krisman-Scott, 2004; Martinson, 1993). Cecily Saunders' oft-cited statement reflects hospice philosophy's core values: “You matter because you are you and you matter to the last moments of your life. We will do all we can do to help you, not only to die peacefully but to live until you die” (as cited in Lentz, 2004, p. 10).

Palliative care is similarly regarded as a philosophy of care; however an important difference exists between hospice and palliative care. Palliative care focuses on quality of life across the illness trajectory, whether it ends in cure or death. In contrast, hospice care historically focused on the dying process at the end of life, partly due to its founders, Saunders and Wald, creating hospice facilities to care for people actively dying from a terminal illness. The next section will review the current definitions of PPC, while accounting for these historical roots within the philosophy of hospice care.

Definition of Pediatric Palliative Care

It is important to review and understand leading definitions of pediatric palliative care, since the concept is relevant to studying nurses working in palliative care settings. A review of the pediatric literature indicated a shift of terminology from hospice care to palliative care. For example, studies in the 1980s found on the PubMed database referred to palliative care as an intervention to reduce symptoms, such as surgical procedures for Tetrology of Fallot, a fatal heart anomaly. During this period of time, hospice care was the larger, umbrella concept, and referred to the holistic care of dying children and their families (Martinson, 1993). From the mid to the end of the 1990s, studies emerged which referred to palliative care as a philosophy of care for children with life-limiting illnesses. It retained many attributes of hospice care, such as improving quality of life and relieving pain, but shifted from end-of-life care of a terminal illness to integrated care throughout the trajectory of a life-limiting illness.

Three major organizations defined pediatric palliative care and are frequently cited across the literature. These include: 1) The American Academy of Pediatrics [AAP], 2) The World Health Organization [WHO], and 3) The Institute of Medicine [IOM]. Similarities and differences among these organizational definitions of palliative, hospice, and end-of-life care will be reviewed and then compared to other cited PPC definitions.

The AAP (2000) seminal statement, *Palliative Care on Children,* presented PPC principles, ethical considerations, and barriers to care. It promoted an integrated model of palliative and curative treatment beginning at the diagnosis of a life-limiting illness. They defined PPC as “the control of pain and other symptoms and [it] addresses the psychological, social, or spiritual problems of children (and their families) living with life-threatening or terminal conditions” (p. 351). Hospice care was defined as “a package of palliative care services (including, for example, durable medical equipment, and both diagnostic and therapeutic interventions), generally provided at a limited per diem rate by a multidisciplinary group” (p. 351). Thus, in these two definitions, palliative care is considered to encompass hospice care.

Similar to AAP statement, the WHO (Sepulveda, Marlin, Yoshida, & Ullrich, 2002) defined PPC as “active, total care of the child’s body, mind and spirit, and also involves giving support to the family” (p. 95). The authors supported palliative care beginning at a child’s diagnosis of a life-limiting illness. Additionally, the WHO noted that “it can be provided in tertiary care facilities, in community health centers and even in children’s homes” (p. 95). The WHO did not define hospice care in their discussion of palliative care.

The IOM (2003) released a landmark report about PPC entitled, *When children die: Improving palliative and end of life care for children and their families*. In this report, the authors posited that palliative care is provided concurrently with curative care. They further noted that:

> In addition to the meticulous management of pain and other physical symptoms, palliative care emphasizes the emotional, spiritual, and practical needs of patients and those close to them – from the time of diagnosis through death and bereavement. Helping people live well in the presence of life-threatening medical conditions (and their treatments) requires both compassion and sophisticated strategies and tools for measuring, preventing, and reducing the physical, psychological, and other burdens often associated with such conditions and their treatments (p. 34).

They defined hospice as "an organization or program that provides, arranges, coordinates, and advises on a wide range of medical and supportive services for dying patients and those close to them" (p. 34). It is important to note in the IOM's definition that hospice care was associated with dying patients, whereas palliative care was associated with life-limiting illnesses, which may or may not result in death. Lastly, the authors noted that end-of-life care "has no precise meaning" (p. 35); it is used to refer to the practical care in an anticipated death or managing a condition's end stage.

The organizations share similar definitions. The IOM and AAP defined hospice care in relation to PPC, but did not acknowledge how palliative care evolved out of the hospice philosophy. Their descriptions also reflect the pervasive effects of Medicare's reimbursement guidelines in defining hospice care. The original hospice philosophy is not mentioned. Lastly, only the IOM described end-of-life care. From their description, it appears end-of-life care refers to the moments in time when children are actively dying. It refers to the practical care of patients, such as administering pain medication or determining resuscitation status.

Across all three organizations' definitions, PPC is understood to begin at the diagnosis of a life-limiting illness and to continue through the child's illness trajectory. PPC can also occur in diverse practice settings. The organizations also described PPC as a philosophy of care which aims to improve the quality of life for children and families as they live with illness. It seeks to relieve distressing physical symptoms, such as pain and dyspnea, as well as spiritual or psychological distress. These characteristics are similar to the ones found in concept analyses of palliative care (Foster, 2007; Meghani, 2004). Foster presented six "critical attributes" of PPC: 1) total, active, and individualized pediatric patient care, 2) family support, 3) interdisciplinary team approach, 4) effective communication, 5) initiation with life-threatening illness diagnosis, and 6) focus on improving quality of life.

Conflicting Definitions of Pediatric Palliative Care

Although leading organizations define PPC as beginning at diagnosis (AAP, 2000; ChiPPS, 2001; IOM, 2003; Sepulveda et al., 2002), articles and a major textbook have described palliative care as a transition from curative to comfort care (Brandon et al., 2007; Docherty et al., 2007; Harris, 2004; Stevens, 2003). For example, in the *Oxford Textbook of Palliative Medicine (3rd ed),* Stevens stated that, "If the disease progresses despite further therapy, a decision will become necessary to cease curative therapy and alter the emphasis of therapy from cure to palliation" (p. 806). Curative and palliative care are mutually exclusive in this statement, rather than integrated together and initiated at diagnosis. The Children's Hospice International defined palliative care as, "intervention that focuses primarily on reduction or abatement of the physical and psychological symptoms of terminal illness" (para. 18). CHI defined hospice as "a philosophy of care which addresses the physical, social, emotional, and spiritual needs of children and adolescents with life-threatening conditions and their families" (para. 12). Unlike the other organizations, CHI regards hospice care, not palliative care, as the broader and more encompassing concept.

In addition to organizational statements, health-care professionals providing direct care also regarded palliative care as a transition from aggressive, curative treatment to relieving patients' symptoms at the end-of-life. For example, Docherty and colleagues (2007) sampled 17 providers (nurses, physicians, social workers, and a respiratory therapist) who worked in pediatric acute units. Only one provider defined palliative care as ongoing and starting at the diagnosis of a life-threatening condition. The remaining providers viewed palliative care as a "critical point in the illness trajectory in which it became obvious that aggressive care was not going to be effective and the care-giving team and family needed to make a decision to transition to this different focus" (p. 337). Acknowledging this point in time was complicated, due in part to a reluctance of care-givers and families to "give up", which equated to choosing palliative care. Palliative and hospice care are frequently regarded as synonymous with dying and a withdrawal of curative treatments. When viewed from this perspective, families, and even some providers, were hesitant to shift from aggressive therapy, even in the last hours of a child's life (Docherty et al., 2007; Fowler et al., 2006; Mack & Wolfe, 2006; McCallum, Byrne, & Bruera, 2000; Tan, Totapally, Torbati, & Wolfsdorf, 2006).

This discussion of the concept of PPC demonstrated that it is an evolving concept, and defined in different ways by researchers, organizations, and providers. A universal definition was not found. Additionally, as Docherty and colleagues (2007) found, the theoretical definition of palliative care was not easily applied to practice. Although leading organizations defined PPC as beginning at diagnosis, providers reported a stark transition from curative care to palliative care. This review of the concept of PPC, hospice care, and end-of-life care, and discourses in the field, framed this study of nurses. It was important to pay attention to how participants defined the terms and how their definitions affected their care. Participants' choices in language communicated embedded meanings, which were drawn in part from their settings' implicit and explicit meanings.

Nurses Caring For Dying Children

Since nurses have ongoing contact with children and families, they can experience patients' deaths from a close and personal perspective. Nurses internationally have expressed grief and stress associated with caring for infants and children at the end of life (Davies et al., 1996; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). Families report a higher quality of care when they are given emotional support and individualized attention from health care providers caring for their child at the end of life (Heller & Solomon, 2005; Macdonald et al., 2005). Studies found that nurses derived meaning from their work through their emotional involvement with families (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). Nurses view their emotional support as integral to their role caring for children at the end-of-life and their families (Davies et al.; Engler et al., 2001; Olson et al.; Papdatou et al., 2001; Papadatou et al., 2002; Rashotte et al.). However, little is known about how nurses manage to give emotional support to families during such sensitive times and simultaneously maintain boundaries between their personal and professional selves.

I entered into this dissertation study primarily from my experience as pediatric nurse. My work with children and families touched me in deeply personal ways, and I was especially affected when patients struggled at the end of terminal illness. The effects of my work did not end when my shift ended, but carried over into my personal life. For example, I dreamed of patients, remembered dates they died, and often wondered how families were coping. Even years later, I still remember particular patients and families, and sometimes just a movie or song will spark a memory. The lines between nurse and person, or role and self, are diffuse. I could not clearly separate between the two, especially in a field of nursing which required a level of emotional engagement. I was fortunate to work with an amazing group of colleagues, who connected with children and families in profound ways and taught me *how* to care from the heart. They inspired me to find out how nurses are able to remain professional, yet invest personally into their work. I wanted to learn what other pediatric nurses' experiences are like, since little is written or talked about this issue.

During the pilot study, I interviewed six nurses who worked at a pediatric facility which provided respite, end-of-life, and transitional care to children with life-limiting illnesses and their families. I aimed to explore the nursing perspective in this newer model of care and to provide a foundation for a dissertation study comparing and contrasting nurses and nursing care at the end-of-life facility and at a children's hospital. An interesting and unexpected finding from the pilot study was that all participants spontaneously talked about personal and professional boundaries in their work. They described how they were able to maintain professionalism, but also connect closely with patients and families. They also described how they coped with emotional responses from the intensity and gravity of their work.

When I searched the literature for what was known about boundaries, I found that little is known about how nurses manage or maintain boundaries. A few studies described professional boundaries in pediatric practice (Ford & Turner, 2001; Hawes, 2005; Totka, 1996). However, no study to date explored specifically how nurses in PPC settings navigate personal and professional boundaries. Since an integral dimension of PPC is providing emotional support to children and families, I became interested in knowing how nurses do so and cope personally with this difficult work. This study aimed to tell nurses' stories and describe their experiences, in order to contribute to knowledge pertaining to pediatric palliative care.

This study's goal was to construct a theoretical or conceptual framework to explain the processes nurses use to balance their professional role and personal self while working in an emotionally demanding practice area. The framework specifies how particular factors, such as emotions or work setting, may constrain or enhance nursing practice. It also has the potential to inform empirically-based guidelines about professional boundaries for nurses working in pediatric palliative care. Additionally, nurses may use the findings to better understand how to negotiate their personal self and professional role in order to provide care to children and their families, while maintaining their emotional health.

This dissertation is then organized into five following chapters. In Chapter Two, I will present a critical review of the literature focusing on two areas: the family experience as it pertains to health-care providers and nurses' experiences caring for dying children.

Chapter Two will additionally present the theoretical framework used to guide this study which was drawn from three key theories: 1) Herbert Blumer's (1969) Symbolic Interactionism (SI), 2) Arlie R. Hochschild's (1979, 1983) Theory of Emotion Work, and 3) Suzie Kim's (2000) nature of theoretical thinking in nursing.

In Chapter Three, I will describe constructivist grounded theory and situational analysis, which were this study's methods. An overview of grounded theory will be discussed and include identifying the distinctions between underlying assumptions of classic and constructivist grounded theory. In the second half of Chapter Three, I will describe the study design which includes the study's purpose and aims.

I will discuss findings in Chapter Four and Chapter Five. In Chapter Four, I will present relevant contextual factors that influenced the process of nurses navigating boundaries. Participants were found working within an external context, which includes physical and social environments, and an internal context, which refers to nurses' unique perspectives on palliative care, death, dying, and their own personal experiences. The purpose of this chapter is to provide a foundation for understanding the identified process nurses use to navigate boundaries, which is called, *maintaining integrity*. In Chapter Five, I will describe this process and how nurses faced challenges when integrity was threatened or compromised.

Lastly, in Chapter Six, I will discuss the findings in relationship to the relevant body of literature and the theoretical framework. It describes the study's practice implications and future research directions. Additionally, the study's strengths and limitations in regards to methodology and sample will be discussed.

CHAPTER TWO: THEORETICAL FRAMEWORK AND REVIEW OF LITERATURE

This chapter will critically review the body of knowledge relevant to the study's questions and aims and discuss its theoretical framework. The review of literature will address the current state of pediatric palliative care from the family and the nurse's perspective. Gaps in the literature are identified. The theoretical background for the study was informed by three theories: 1) Blumer's (1969) Symbolic Interactionism (SI), 2) Hochschild's (1979, 1983) Theory of Emotion Work, and 3) Kim's (2000) nature of theoretical thinking in nursing. These theories create a broad analytic framework and provide structure to the study. Each theory, its premises, and central concepts will be discussed. Each provides possibilities for identifying relevant concepts and theoretical relationships germane to the phenomenon of nursing practice in PPC.

Review of Literature

Pediatric palliative care (PPC) encompasses many different meanings. It can refer to a philosophy of care, interventions, or care services. It is delivered by a multi-disciplinary team of both professionals (e.g. physicians or nurses) and non-professionals (e.g. family members or volunteers). Nurses play a vital role on the PPC team, as they often work closest with children and families through the course of their illness and, at times, death. PPC is an emerging field of research indicated by the proliferation of studies in the last decade. Children's hospitals have created PPC services to meet the identified needs of children and families (Contro et al., 2002) and newer models of care, such as respite facilities, are opening across the world.

Search Procedures

I used the PubMed and CINAHL databases as the primary search engines to locate relevant articles. Other databases used were Scholar.google, PyschINFO, and SocAbstracts. The main search terms entered in a database were “nurse”, “nursing”, “hospice”, end-of-life”, “pediatric palliative care”, “children”, “pediatric”, “families”, and “boundaries.” These terms were used in various forms, such as “nurse AND pediatric palliative care”, or “children AND hospice”. New articles were generated despite using synonymous terms. For example, the search term “*children* AND end of life” generated 252 articles, yet “*pediatric* AND end of life” generated 141 articles. Therefore, every term was used in various combinations with another to generate a wide range of possible articles. Additionally, studies about emotion labor were searched on the SocAbstracts and CINAHL databases. A combination of the terms “emotion labor”, “Hochschild”, “emotion work”, and “nursing” were entered. Studies were also hand search from reference lists.

In the PubMed database, the search term “pediatric palliative care” yielded 469 articles ranging from July 1973 to August 2007. The field is expanding as evidenced by more than 85% of the generated articles were published after 1994 and 63 new articles were published between August 2006 and August 2007. In the PubMed database, the search term “nurse AND pediatric palliative care” yielded 33 articles. Using the exact search term, the CINAHL database yielded 76 articles. Lastly, hand searches were done using references from selected studies and PPC review articles. Articles were reviewed and retained if they focused on nurses’ perspectives of their care for seriously ill children, families’ interactions with heath care providers, families’ needs, or pediatric palliative care principles. Editorials, anecdotal, and review articles were excluded from review, but read to provide context for the field of study.

The Family Experience

A family often faces many challenges caring for a child with life-limiting illness, both in the hospital and at home. A child's daily care-giving needs and frequent hospitalizations associated with life-limiting illnesses can elicit a variety of responses from families. A meta-synthesis reported that parents express unrelenting worry over their child's health and feel burdened in caring for children with chronic illnesses (Coffey, 2006). In caring for a chronically ill child, parents experience not only emotional responses but can undergo physical changes as well. One study showed that the constant stress associated with care of a chronically ill child can result in detrimental physiologic changes in mothers on a cellular level (Epel et al, 2004). Parents can face ongoing challenges throughout a child's illness trajectory, but especially during the end-of-life period (Gravelle, 1997; Steele, 2005). Families also report sub-optimal health care support and researchers have expressed the critical imperative to meet families' needs at such a vulnerable time (Bartell & Kissane, 2005).

Parents often endure life-long grief after a child's untimely death. The key factors which may alleviate or exacerbate parental grief are not known. Researchers have explored possible factors, such as location of death or parental coping skills, and their relationship to parental grief. This study focused on nurses' experiences caring for children and their families. Therefore, articles regarding family's perspectives were chosen for their relevance to health-care providers and family interactions. The review of literature regarding families' experiences revealed three themes important to health-care provider interactions: 1) the quality of the provider-parent relationship, 2) receiving emotional support, and 3) the significance of the moment of death.

The Quality of the Provider-Parent Relationship

Regardless of health-care setting, the general theme across studies was that parents appreciated and desired that care providers demonstrate genuine caring, strong communication skills, and give emotional support (Contro et al., 2002; Davies et al., 2003; Heller & Solomon, 2005; James & Johnson, 1997; Meyer et al., 2006). The relationship developed between staff and parents is often central to families' evaluation of their experience. Davies and colleagues reported that families whose child died in a pediatric hospice expressed a connection with health-care providers (most frequently nurses), who were compassionate, interested, and empathetic. These qualities contributed to parents' perceived ability to develop a trusting relationship with health care providers. Families expressed that nurses were vital to the quality of their experience in the hospice, since they had the majority of contact and ongoing interactions with nurses. In preparing a PPC hospital program, Contro and colleagues interviewed 68 family members of 44 deceased children about their experience receiving care at an academic children's hospital. The researchers noted that, "The quality of the relationship between staff and families was crucial to the families' appraisal of their experience" (p. 17). Contro et al. collected data through survey questions; therefore, factors which contributed to a positive appraisal are not known or identified.

The quality of the relationship between families and providers can be regarded as positive or negative, and can have long-lasting consequences. Positive relationships helped families feel secure and trusting of the care their child received (Heller &

Solomon, 2005). Parents have also reported a positive relationship eased the pain of hearing bad news about their child's health (Heller & Solomon). Moreover, parents' long term grief was positively affected by a caring attitude of health-care providers. For example, Meert, Thurston, & Thomas (2001), in a study of 57 parents, examined parental early and long-term grief, parents' coping resources, and caring attitudes of PICU staff. The authors stated, "We speculate that the emotional attitudes displayed by staff reflect the quality of the relationships between staff and families and that it is the nature of these relationships that ultimately affect parental bereavement" (p. 327). A major critique of this study concerns how researchers measured the emotional attitudes of PICU staff. Researchers asked parents to decide the presence or absence of eight attitudes demonstrated from staff: sympathetic, kind, nervous, evasive, guilty, frustrated, uncaring, and too busy to be bothered. The researchers did not discuss how they chose this group of attitude descriptors. It is also unclear whether parents described one staff member or staff as a collective group, nor did they differentiate among staff members' positions. Thus, parents may have assessed the attitudes of a full range of staff members, such as nurses, physicians, housekeepers, dietary aides, social workers, or respiratory therapists.

After a child dies, continued connection or follow-up contact with health-care providers is also beneficial to families (Contro et al., 2002; Davies et al, 2003; Heller & Solomon, 2005; Macdonald et al., 2005; James & Johnson, 1997). Lack of follow-up after a child died compounded parents' bereavement because they were coping with both their child's death and a loss of meaningful connections with health care providers (Contro et al.; Heller & Solomon). Parents noticed and expressed gratefulness when staff attended their child’s funeral or memorial service and disappointment when they did not (Macdonald et al.).

Negative interactions with staff were shown to have a significant impact on a family’s hospital experience as well as impact the family’s grief. Contro and colleagues (2002) found parents remembered even a single negative encounter with a health-care provider. Parents in this study expressed profound emotional distress from these incidents. A frequent rotation of new health-care providers hindered parents’ ability to develop positive relationships, which parents reported affected their hospital experience and bereavement as well (Heller & Solomon, 2005). In addition, a lack of access to staff, and consequent feelings of isolation, during their child’s hospitalization contributed to parents feeling more guilt associated with their child’s death (Surken et al., 2006).

Receiving Emotional Support

Families’ need for emotional support was a frequent finding across studies, regardless of research method, health-care setting, or hospital unit. Families frequently expressed a need to connect with providers. They also expressed feeling isolated and abandoned without this connection (Contro et al., 2002; Farnsworth & Allen, 1996; Heller & Solomon, 2005; James & Johnson, 1997; Meyer et al., 2006). Families cope with a myriad of emotions surrounding their child’s illness and subsequent death. In preparing for a child’s impending death, parents often spoke with health-care providers about emotional issues (Davies, Steele, Collins, Cook, & Smith, 2004). Emotional support from health care providers helped parents feel less alone in their experience and more confident in the care their child received. Parents whose child died in the PICU expressed wanting providers to be “real people” (Meyer et al.). In a sample of 56 parents whose children died in the PICU, Meyer and colleagues collected data through open-ended questions on anonymous, self-administered questionnaires. As they coped with their child's end of life, parents reported that they desired human-to-human connections with providers. It is unknown how an absence of these connections contributed to their long-term bereavement. However, it is important to note that parents identified providers' emotional expression as a priority for improving end of life care in the PICU.

Families appreciated "acts of kindness" from health-care providers; actions that go "above and beyond" professional requirements (Davies et al., 2003; Heller & Solomon, 2005; Macdonald et al., 2005). Macdonald and colleagues interviewed 14 families whose child died in the PICU. They noted that acts of kindness reflected providers' humanity through communicating genuine caring and acknowledging the families' situation, which resulted from providers spending time and paying attention to families' unique traits or needs. Examples of these acts of kindness included attending funerals, sending bereavement cards, checking in with families after a shift ends, or advocating for families' needs. Families reported significantly benefiting from these seemingly small acts (Davies et al.; Heller & Solomon; Macdonald et al.). Families at a pediatric hospice identified nurses as the most helpful in providing this type of care (Davies et al., 2005).

The simple act of listening also was a frequent theme across studies (Davies et al., 2003: Farnsworth & Allen, 1996; Meyer et al., 2006). Listening reflects the quality of communication between parents and providers and was a frequently identified parental need across all locations of care (Bellali & Papadatou, 2006; Davies et al., 2003; Heller & Solomon, 2006; James & Johnson, 1997; Macdonald et al., 2005; Meyer et al.;

Seecharen, Andresen, Norris, & Toce, 2004; Surkan, et al., 2006; Vickers & Carlisle, 2000; Ward, 2001). Active listening required a degree of emotional engagement on behalf of the health-care provider. Bereaved mothers expressed appreciation in nurses who respectfully sat and listened to their concerns (Farnsworth & Allen, 1996). The authors suggested that listening was therapeutic to the mothers' grief process and helped to reduce their feelings of marginalization and isolation.

The Significance of the Moment at Death

A third important theme across studies was the significance of the moment of death to families. A child's death carries life-long memories for a family. The memories surrounding the moment of death can have a profound impact on families' grief and bereavement. During this time, families require perhaps the greatest amount of positive health-care support. Bellali and Papadatou (2006) stated that, "It became apparent that the memory of events, experiences, and interactions surrounding the child's death had a profound positive or negative effect upon the grieving process of parents for several years after the loss" (p. 891). Frequently, families reported great comfort in staff just "being there" while their child died (Heller & Solomon, 2005). Failing to acknowledge the family's emotional needs immediately following a child's death proved profoundly distressing for some families (Heller & Solomon).

Studies identified absent health-care providers and poor pain control as the primary issues associated with this sensitive period of time (Bellali & Papadatou, 2006; Hays et al., 2006; Heller & Solomon, 2005; Kreicbergs et al., 2005). Kreicbergs and colleagues, studied 449 parents whose child died of cancer to examine how care-related stressors (e.g. negligent care or a child's unrelieved pain) affected parents' distress 4-9 years after the death. They found that parents were more likely to report a difficult moment at death if staff were absent. Moreover, if parents reported a difficult moment of death, a slightly more than half the sample continued to experience distress four to nine years after their child died.

Summary

Pediatric palliative care precepts suggest that providers attend to families' emotional needs during the course of their child's life-limiting illness and death. The selected studies support the notion that families expect emotional support from caregivers, most often identifying their interactions with nurses and physicians. Further, this emotional support can be critically therapeutic and helpful to parents' grief and bereavement. Data suggest that failing to provide emotional support across the illness trajectory may cause ongoing distress for families, especially during the critical period of time surrounding a child's death. Parents across studies and across health-care settings expressed needing providers to demonstrate their humanity through active listening, sharing emotions, and being present. Nurses have the most contact with families regardless of location of care. Thus, in order to provide optimal family-centered care congruent with the PPC philosophy, health-care providers must connect with families on a personal level, yet also within professional boundaries.

Nurses' Experience

Nurses frequently care for patients under vulnerable and intimate circumstances. Caring for a dying child and a bereaved family is challenging work. Although pediatric palliative care is multi-disciplinary, nurses are often the health-care provider working most closely with a patient and family, and are frequently present during the child's death

(Olson et al., 2001; Papadatou et al., 2002). For example, nurses are primarily responsible for cleansing and caring for the child's body post-mortem and they usually transport the body to the hospital morgue (Rashotte et al., 1997). Moreover, due to their frequent and ongoing contact with families, nurses are the primary health-care provider giving emotional support to families (Davies et al., 2005). Nurses reported feeling grief over these intimate experiences and close relationships related to a child's death. Despite grief associated with their profession, nurses also derived meaningful rewards through their relationship with patients and their families. The following section will discuss what is known about how nurses managed emotions associated with their care of dying children. In addition, selected studies will be critiqued and research gaps will be identified. The critical review revealed four themes across the studies: 1) nurses' grief processes, 2) professional expectations, 3) meaningful work, and 4) personal and professional boundaries.

Nurses' Grief Processes

Six studies specifically examined pediatric nurses' grief (Davis et al., 1996; Papadatou, et al., 2002; Papadatou et al., 2001; Rushton et al., 2006; Yam et al., 2001). These studies represented nurses from the NICU, PICU, and pediatric oncology units. Nurses comprised the sample in four of the six samples. In each study, nurses expressed a sense of grief associated with their work with dying children. With the exception of Rushton and colleagues' study, the others were qualitative studies that explored and richly described the complex nature of nurses' grief. According to Papadatou and colleagues (2002), nurses' described their grief "as a continuous, ongoing fluctuation process between focusing on the loss and pain, and avoiding or repressing it." (p. 407).

Grieving was a complex process in which nurses engaged in a combination of coping strategies. However, avoidance, or a conscious suppression of sad feelings, was a major theme across five studies (Davis et al., 1996; Papadatou et al.; Papadatou et al., 2001; Rashotte et al., 1997; Yam et al., 2001). Nurses reported avoiding these feelings to protect their emotional selves (Yam et al.). Powerlessness and helplessness associated with caring for a dying child were common themes across studies (Davies et al.; Papadatou et al., 2002; Papadatou et al.; 2001, Rashotte et al.; Olson et al.; 1998; Yam et al.). Grief perhaps intensified these feelings of medical futility for nurses and they used avoidance strategies to promote a sense of control (Rashotte et al.). Thus, nurses avoided feeling undesirable emotions (e.g. grief or anger) to retain a sense of control of an uncontrollable situation.

Papadatou and colleagues (2002) reported 75% of their Chinese participants used avoidance techniques to control their feelings, which was significantly more than their Greek counterparts. These avoidance techniques included focusing on professional tasks which required little emotion. Nurses in this study also distanced themselves from patients through depersonalization strategies where nurses regarded patients as dolls, rather than children. Nurses across studies differentiated between the technical and emotional aspects of their jobs and fixated on performing technical skills to avoid acknowledging, and thus dealing with, their grief. Additionally, nurses feared that their emotions might compromise their professional competence (Davies et al., 1996). Nurses also regulated how close they got to future patients and their families, or they avoided caring for patients with life-limiting illnesses after suffering the loss of a patient (Davies et al.; Rashotte et al., 1997).

Avoidance was seen as beneficial in the short-term (nurses could “get the job done”), but ultimately nurses risked enduring long-term negative consequences. Davies et al. (1996) reported nurses who used withdrawal as a primary coping strategy, often left their practice setting to work in areas with fewer seriously-ill patients. Papadatou and colleagues (2002) studied Greek and Chinese nurses and described a cycle of avoidance and burnout which can develop with cumulative losses. The authors noted that, “A few professionals who experienced high degrees of burnout used massive avoidance strategies to protect themselves from the experience of suffering and pain caused by childhood death” (p. 2002). Greek nurses, unlike Canadian nurses in Davies and colleagues’ study, could not voluntarily transfer to a different work setting due to burnout. They were assigned to practice areas by hospital administration. For some nurses, avoidance ultimately resulted in unresolved grief and distress, which worsened with cumulative losses (Davies et al.).

Professional Expectations

Suppressing distressing emotions, through avoidance or withdrawal, reflected in part, nurses’ aim to fulfill professional expectations. Nurses reported it was unprofessional to cry because it deleteriously affected their competence by hindering their ability to remain strong and supportive to the family (Davies et al., 1996; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). Inherent to this expectation was the assumption that nurses are able to clearly separate their professional (i.e. *un*emotional) and emotional (i.e. *un*professional) selves. As Davies and colleagues stated, “Nurses struggled between expressing their sad feelings and knowing such emotional expression contradicted the expectations for professional behavior” (p.

502). These professional standards were unwritten and unspoken, yet nurses felt obliged to follow them, affecting their ability to express or show “unprofessional” emotions. Examples of these codes of conduct were: “be cheerful at all times; do not cry while on duty; be strong for the patient and for other nurses – do not let emotions interfere with the tasks to be done; refrain from getting emotionally involved with your patients and their families” (Davies et al, p. 502). Similarly, Papadatou and colleagues (2001) reported Chinese nurses more frequently expressed a sense of duty with their positions and repressed their grief in order to carry out their professional duties.

Positive Coping Strategies

Some nurses reported that expressing their emotions (rather than suppressing them) was a positive coping mechanism (Davies et al., 1996; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1998). Papadatou and colleagues (2001) reported nurses differed from physicians in how they coped with their grief. Physicians sought relief in spending time alone, whereas nurses derived comfort from talking to colleagues about their experiences. Since colleagues often encountered similar situations, they shared an unspoken understanding and thereby an informal support system for coping with distressing feelings. Grief was not only felt on an individual level, but also collectively among the health-care providers who cared for patients and their families throughout an illness trajectory (Papadatou et al., 2002).

According to Davies and colleagues, nurses coped with their work-related distress primarily through peer support. Managing their distress through a supportive peer environment helped nurses to reinvest energy and compassion into relationships with future patients and their families. Formal support systems were beneficial as well.

Rushton and colleagues (2006) reported nearly all health-care providers found that attending bereavement debriefing meetings was helpful to their grief. Whether nurses used formal or informal support resources to express emotions, Rashotte and colleagues (1997) suggested that the important factor was for nurses to choose *when* they wanted to talk. Nurses were not forced or required to express their emotions, but rather could voluntarily access an available supportive resource.

Studies suggested nurses engaged in a complex grieving process, in which they fluctuated among different responses. For instance, sometimes they suppressed painful feelings and other times they openly shared their emotions. As previously discussed, long term avoidance strategies resulted in feelings of burnout and distress, whereas expressing these feelings comforted some nurses. From relieving distress, nurses more easily reinvested energy into patient relationships and derived fulfillment from their jobs.

Meaningful Work

When nurses were able to resolve their grief, they regarded their work as meaningful and rewarding (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). Grief resolution in these studies was determined from self report and was not a process or concept described in this body of literature. Nurses reported unresolved or suppressed grief led to feelings of burnout (Davies et al.). Davies and colleagues found that nurses left their positions to work in areas where they did not care for children at the end of life.

For some nurses, grief provided a learning experience and they applied the lesson to improving their practice (Davies et al. 1996; Rashotte et al., 1997). Rashotte and colleagues reported that nurses learned through reflection and repeated exposure to patients' deaths. Through self-reflection, they also learned effective coping strategies which helped to manage their grief. Nurses' comfort level in providing end-of-life care to children and their families also increased after repeated exposure of patients' deaths (Davies et al.; Engler et al., 2004; Olson et al., 1998).

Nurses derived satisfaction from their care practices by making a positive contribution and establishing close relationships with children and their families (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2002). According to Davies and colleagues, nurses developed close relationships with patients and families if they acknowledged or expressed their distress within their supportive peer network. Avoidance or suppression of grief inhibited their desire to form close relationships with patients and families and they withdrew both emotionally and physically. Nurses kept an emotional distance between themselves and others, as they diverted energy to maintaining a professional appearance. In contrast, through actively managing their grief, nurses were present with children and their families; they found meaning in childhood death. Similarly, Olson and colleagues reported the most frequently identified peak experiences associated with caring for pediatric oncology patients were related to nurses' emotional involvement with patients and/or their families.

Studies suggested that meaningful relationships with patients and their families were also a necessary component to nurses' work satisfaction. Meaningful relationships, however, required a level of emotional engagement. After a child died, nurses reported grief and a sense of loss resulting from their emotional involvement with patients and families. Nurses utilized a range of coping strategies, such as suppressing feelings and focusing on technical skills, or acknowledging their grief and sharing it within a supportive network. The evidence suggested that when nurses acknowledged their grief, they were able to reinvest energy into establishing new meaningful relationships. However, if nurses suppressed their grief, they maintained an emotional distance and did not develop meaningful relationships. Through suppression, nurses may have not felt grief, but due to an absence of meaningful relationships, nurses did not derive satisfaction from their work. Low satisfaction resulted in nurses leaving their positions and finding other work which did not provoke such intense emotions. Thus, emotional involvement with patients and families may result in grief, but it is a central factor for nurses finding fulfillment in their work.

Professional and Personal Selves

No study specifically discussed how nurses managed personal and professional boundaries in their work with dying children. However, researchers made reference to nurses' self-processes, such as "self-nurturance" (Rashotte et al., 1997) or "protecting self" (Yam et al., 2001), and to a nurse's personal lives (Davies et al., 1996; Papadatou et al., 2001). It is clear that nurses live with their work experiences after their shift ends. Rashotte and colleagues described the memories of patients, their families, and their deaths continued to "haunt" nurses. In Papadatou and colleagues' (2002) study, a participant stated that, "Grieving over the death of a child does not end the day after his or her death. Every day something the child did or said comes to our mind. There is a continuous relocation of the loss; there is a continuous stirring" (p. 350). In addition, Olson et al. (1998) reported nurses openly wept when recounting nadir experiences which may have occurred many years earlier.

Papadatou and colleagues (2001) reported that nurses' expressed various grief responses and their grief extended beyond grieving the death of a patient. They identified seven categories of losses. Four of these categories included losses which related to a nurses' personal life: 1) loss of one's personal assumptions and beliefs about self, life, and death, 2) past unresolved losses, 3) future anticipated losses of loved ones, and 4) loss of self through death (p. 408). A patient's death triggered nurses to consider their own or their children's mortality (Davies et al.; Papadatou et al., 2001). These feelings of real and imagined losses suggest a blurred boundary between a professional and personal self, or perhaps no boundary at all. The death of a pediatric patient could not be contained neatly within professional boundaries, for it affected nurses on a deeply personal level.

Literature Critique

Although researchers noted that caring for dying children affected nurses' personal lives, or life outside of work, it is not known how nurses perceive their sense of selves in their work. The emotional responses described across the selected studies included grief, distress, moral distress, hurting, struggling, or suffering. Nurses across hospital units and nationalities felt these emotions in response to children's deaths. The findings suggested that if nurses were able to acknowledge and work through these emotional responses, they invested more fully in future patient and family relationships. Although this was a common observation across studies, it may not capture nurses' full range of coping strategies. Nurses may cope in other ways than currently known. This narrow understanding of pediatric nurses' coping strategies may stem from the relatively small body of studies which explored this issue. Further exploration is needed into additional coping strategies to create a fuller picture of nurses' experiences.

As discussed in the family experience section, bereaved families need emotional support from health-care providers. Nurses derive meaning from their work through emotional involvement with families (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). Moreover, nurses view emotional support as integral to their role caring for children at the end-of-life and their families (Davies; Engler et al., 2001; Olson et al.; Papdatou et al., 2001; Papadatou et al., 2002; Rashotte et al.). However, a gap exists in understanding how nurses manage to give this emotional support during such sensitive times and simultaneously maintain boundaries between their personal and professional selves.

All studies researched hospital nurses' experience. No research was found about the experiences of nurses who work in pediatric end-of-life facilities. This gap is likely attributed to the small number of pediatric end-of-life facilities in the world. Subtle differences regarding grief processes were identified between critical care nurses and oncology nurses (Papadatou et al., 2002). Oncology nurses more frequently grieved the loss of a special relationship with a child and their family, whereas critical care nurses had less time to develop such bonds. Further exploration into the similarities and differences across settings and units is needed for a fuller understanding of the nurse's experience providing pediatric palliative care.

Females frequently comprised over 95% of studies' samples (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2001; Rashotte et al., 1997). The gender imbalance in the samples may reflect cultural gender differences, wherein females may be more likely to express and discuss emotions. Or it may be due to a small population of male pediatric nurses. It is not known how many males are pediatric nurses, but according to the Health and Human Services Administration’s (HRSA) 2004 National Sample Survey, males comprised 5.8% of the registered nurse population in the US. Regardless, little is known about male nurses’ experience who care for dying children and their families and whether their emotional responses are similar to or different from the current understanding of caregiver grief.

Unspoken professional expectations, which equated emotions with unprofessional practice, affected nurses’ ability to express their grief (Davies et al., 1996; Papadatou et al., 2001; Papadatou et al., 2002). These expectations may derive from the larger professional culture, the unit culture or from work place administrators. It is not known how nurses perceive their work administrators propagating or promoting this viewpoint. The literature includes little empirical work about professional boundaries and appropriate professional behavior. There is no definitive answer to “How close is too close?” Only two articles discussed therapeutic boundaries in pediatric nursing (Rushton, Armstrong, & McEnhill, 1996; Totka, 1996). Totka interviewed five pediatric nurses to understand what “unhealthy involvement” meant to them. She reported nurses often experienced interpersonal struggles in trying to balance their involvement with families with their professional boundaries. Boundaries were not clear and continually differed from patient to patient. Nurses echoed similar concerns in the selected studies (Davies et al., 1996; Rashotte et al., 1997). No work has been done specifically exploring how bedside nurses describe personal and professional boundaries in PPC. It is important to explore how nurses manage professional boundaries when their work requires emotional engagement and affects them in deeply personal ways.

Critique of methodological approaches. Two studies used quantitative research designs (Engler et al., 2004; Rushton et al., 2004), but the majority of findings were drawn from the six selected studies which used qualitative research methodologies (Davies et al., 1996; Olson et al., 1998; Papadatou et al., 2001; Papadatou et al., 2002; Rashotte et al., 1997; Yam et al., 2001). The qualitative methodologies resulted in full descriptions of nurses' experiences, including the complexities and subtleties of nurses' grief processes. Researchers presented clear descriptions of their method and design. The qualitative methods used were thematic analysis, content analysis, grounded theory, and phenomenology. The methods matched the researchers' aims. For example, Davies and colleagues utilized grounded theory methodologies to construct substantive theory about nurses' experiences caring for dying children. In each study, data were collected through semi-structured interviews with open-ended questions. Although interviews elicited rich narratives, a major critique is the absence of participant observation to collect data. Observations can provide a fuller picture of participants' lives and reveal new insights (Angrosino, 2005), as well as strengthen method triangulation (Polit & Beck, 2004). Lastly, sample sizes were adequate for the studies' chosen methodologies, ranging from 10 nurses to 64 nurses.

Summary

Nurses' work caring for dying infants and children is clearly complex. In this practice area, professional and personal boundaries intersect and overlap partly because of the emotional support nurses must provide to families. Nurses are frequently the providers bearing witness to families' profound grief during an incredible heartbreaking time. As discussed in the literature, nurses do not easily leave these experiences behind when they leave work. Further exploration is necessary to understand the processes nurses use to navigate professional boundaries within this nursing specialty.

Theoretical Framework

Three theories created a theoretical framework to explore how nurses navigate personal and professional boundaries in a PPC practice areas: 1) Blumer’s (1969) Symbolic Interactionism (SI), 2) Hochschild’s (1979, 1983) Theory of Emotion Work, and 3) Kim’s (2000) nature of theoretical thinking in nursing. These complementary theories enhanced one another and created a broad analytic framework to structure this study. Although each theory has a different focus, they are all rooted in the assumption that meanings emanate from actions and interactions between people. Emotion work and SI were drawn from the sociology literature, since nursing is primarily a social occupation and nursing practice occurs within a social culture of the health-care system. A sociological lens permits discovery of taken-for-granted ideas, assumptions, practices, and actions within nursing, as well as facilitates examination of interactions. Although nurses have debated the relevancy of sociology to nursing (Allen, 2001; Pinikahana, 2003), this perspective was a lens, which illuminated social influences, relationships, and meaning that were relevant to central phenomenon of this dissertation. Kim’s theoretical framework, culled from the nursing literature, provided an organized structure for conceptualizing nursing practice and enhanced the selected sociological theories by foregrounding meanings significant to nursing. The following section includes a brief overview of each theory, in addition to a discussion of their relevant concepts.

Symbolic Interactionism

Symbolic Interactionism (SI) is a theory that considers human behavior in social interactions. George Herbert Mead, a noted pragmatist, established SI's foundational roots (White & Klein, 2002). Blumer, a student of Mead, elaborated upon Mead's work and introduced SI in his classic book, *Symbolic interactionism: Perspective and Method.* Mead's work spurred other SI variants; however, this study used the premises and concepts from Blumer's perspective. Blumer asserted that interactions directly shape human behavior. From an SI perspective, most human behaviors are seen as *conscious* acts, and not reflexive responses to external stimuli. Thus, an underlying assumption is that humans possess the agency and capacity to make choices, rather than act as passive responders. Its three premises are; 1) human beings act toward things on the basis of the meanings that the things have for them; 2) meanings of such things, is derived from, or arises out of, the social interaction that one has with one's fellows; and 3) meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters (Blumer, p. 2).

These premises emphasize the central concepts of human interaction, meanings, and the process of interpretation. A symbolic interactionist perspective is rooted in the assumption that society is built on ongoing and unfolding meanings, which are conditional and continuously emerging. The creation of meanings depends upon social interactions. Blumer (1969) defined meanings as social products. Objects do not have inherent meanings; meanings are derived from how people act toward objects. Meanings develop from interpretation of self and others' actions. Blumer succinctly noted that, "The meaning sets the way in which he sees the object, the way in which he is prepared to act toward it, and the way in which he is ready to talk about it" (p. 11).

Central Concepts

Blumer (1969) discussed and detailed SI's major concepts, which were human society, social interaction, objects, the human being as an acting organism, human action, and interlinkage of actions, or joint actions. Two concepts chosen for their relevancy to the study are social interaction and objects. Interactions directly shape human behavior and serve as a necessary medium to communicate, modify, confront, or support meanings. People learn how to act in their world based on interactions through interpretation of their own and other's actions. Meanings are communicated through this process. For example, studies have demonstrated that when nurses avoided talking about or acknowledging death with children dying of cancer, children learned to stay quiet on the subject (Bluebond-Langner, 1980). These children formed negative meanings about death, and saw it as mysterious and scary.

Objects are "anything that can be indicated, anything that is pointed to or referred to" (p. 10). SI's foundational assumption is that objects' meanings are variable and continually evolving; thus, universal meanings do not exist. Blumer (1969) classified objects into three categories: 1) physical objects, such as toys, medical charts, or stethoscopes, 2) social objects, which are usually people, such as parents, nurses, or medical directors, and 3) abstract objects, such as death, hope, or ethical principles. Objects themselves do not have inherent or intrinsic meaning; they are derived from how people act toward objects. People's actions reveal what meanings they hold. Objects can have different meanings by different people, as well as people can have different meanings for the same object. People are also objects to their self and interpret their own actions. Role-taking is a means of viewing one's self as an object. According to Blumer, individuals must partake in mutual role-taking for effective symbolic interaction. That is, they view themselves in another's role as a strategy to understand the other person's gestures, intentions, and actions. Meanings arise out of this self-reflection, which subsequently guide their behavior.

Hochschild's Theory of Emotion Work

In Hochschild's (1979, 1983) theory of emotion work, emotions are considered social products. Hochschild perceived emotions from a sociological perspective, and influenced by social rules and norms. In her seminal book, *The Managed Heart,* Hochschild traced the development of her theory from organismic and interactional models of emotion; each had strengths and limitations. The organismic model, as described by Darwin, Freud and others, posited emotions as biologic, instinctual entities. According to Hochschild, it "reduces us to an elicitation-expression model" (1983, p. 211). In an organismic model, emotions are a prelude or signal to action. Feelings are not influenced by social rules or norms. In contrast, an interactional model accounts for the biologic qualities of emotions and that social factors primarily affect the experience and perception of emotions. Hochschild's critiqued interactional theorists, namely Goffman, for ignoring the self in the experience of emotions because he focused too closely on larger societal influences. She questioned, "Where is the self as subject to emotive experience?" (p. 217). Hochschild extended and expanded on Goffman's work, particularly in her central concepts of surface acting and gestures. She combined both the social and psychological sides of the two models and developed a social theory of emotion. She summarized this process;

> …drawing from Dewey, Gerth and Mills, and Goffman, within the interactional tradition, I explore what gets "done to" emotion and how feelings are permeable to what gets done to them. From Darwin, in the organismic tradition, I posit a sense of what is there, impermeable, to be "done to", namely, a biologically given sense related to an orientation to action. Finally, through Freud, I circle back from the organismic to the interactional tradition, tracing through an analysis of the signal function of feeling how social factors influence what we expect thus what feelings "signal (Hochschild, 1979, p. 222).

The central premise of Hochschild's theory is that individuals can actively manage their emotions. It departed from the organismic model which viewed emotions as instinctual responses to stimuli. In the theory of emotion work, individuals have capacity to suppress or induce emotions and this management is influenced by social rules and expectations.

The central theoretical concepts are feeling rules, surface acting, deep acting, emotion work, and emotion labor. Feeling rules are social expectations which dictate appropriate emotions. In order to comply with feeling rules, people engage in surface acting or deep acting to demonstrate and/or feel the socially appropriate emotion. Emotion work becomes emotion labor when emotions are used for the commoditization of a product or service.

Feeling rules reflect social norms and values, providing scripts for how to act in a social situation. They set guidelines for how one *should* feel, such as elation at a wedding or grief at a funeral. If a person does not feel the expected, appropriate emotion, then he or she consciously tries to change it to be in accordance with the feeling rule. Gestures are outward signs of emotions, such as a frown for sadness, a furrowed brow for anger, or a laugh for delight. Gestures communicate the socially appropriate emotion, regardless if a person actually feels that emotion.

People use surface and deep acting as strategies to manage emotions. Surface acting is the outward *appearance* of an appropriate emotion through gestures. A person, however, does not actually feel the emotion. For example, a person may not feel cheerful, but may communicate the feeling of happiness through a smile. Whereas surface acting is an appearance of emotion, deep acting is the actual transformation of an emotion: the “work” of emotion work. When individuals encounter tension between what they actually feel and what they should feel, they will employ different strategies to change the inappropriate feeling. Evocation and suppression are two processes for transforming emotions when confronting a gap between an actual feeling and an expected feeling. An individual either conjures an absent, but desired feeling (evocation), or diminishes an undesired feeling (suppression). Feeling rules trigger the tension and illuminate the gap between how one should feel and how he or she actually feels.

Emotion management is carried out in both private and public spheres. When emotions transfer from private worlds to commercial use, emotion *work* then becomes emotion *labor* and is tied into the commercialization and commoditization of a service or product. What is typically done privately transforms into an occupational requirement and feeling states are used to produce an expected feeling in another. For example, flight attendants act happy and cheerful to sustain a contented state of mind in airline customers. Emotional displays connect to a commercialized product, such that “the emotional style of offering the service is part of the service itself” (p. 5). An assortment of nonprofessional and professional jobs entail emotional labor, which must meet three criteria; 1) require face-to-face or voice-to-voice contact with the public, 2) require the worker to produce an emotional state in another person, and 3) allow the employer, through training and supervision, to exercise a degree of control over the emotional activities of employees (p. 147). The nursing profession meets all three criteria.

According to Hochschild, a successful transmutation from emotion work to emotion labor relies on the transformation of “the three basic elements of emotional life: emotion work, feeling rules, and social exchange” (p. 118). Emotion work becomes a public act governed by publicly sanctioned feeling rules. Organizational authorities set the rules and then supervise and direct the emotion work of subordinates. They designate what is expected and what is not allowed. Emotion labor is further defined when social exchange occurs in a public arena and is driven by a profit motive. Gestures, such as courtesy smiles, become a marketed product.

In the development of her theory, Hochschild (1983) described a portion of flight attendants who “go into robot” mode. They purposely acted phony in response to their position’s emotional demands, and consequently increased their role stress. Many flight attendants viewed their reaction as defensive. Nurses working with dying infants and children have also expressed the conscious distancing of themselves from their job (Davis et al., 1996; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997; Yam et al., 2001). They focused on their technical skills and physically avoided potentially emotional situations. Some nurses left these stressful positions due to burnout (Davies et al.). Other nurses, who cared for children with chronic illnesses, experienced burnout caused by “compassion fatigue” (Maytum, Heiman, & Garwick, 2004). Hochschild asserted that burnout is the most harmful personal cost due to emotion labor. She posited that workers cannot adequately extricate their role identity from their real self and subsequently identify too closely with their job. Workers are expected to display authentic selves to the customer, and are trained to do so through deep acting. However, a sense of self can be lost within the process of successful commercialization. Workers must redefine their sense of self, as they are confronted with multiple self definitions: a true self, an acting self, a public self, and a private self.

To combat professional burnout, Hochschild (1983) argued for a “healthy estrangement” of a person’s sense of self from their job, since organizations train workers to “fuse a sense of personal satisfaction with a sense of company well being and identity” (p. 132). She hypothesized that workers must distinguish between their self identity and their role identity. They should “depersonalize” situations, (i.e. take their real selves out of interactions). Hochschild found that employees successful at depersonalizing situations were usually older, experienced, married, and employed by companies did not enforce a fused personal and company identity. Additionally important is that these workers viewed emotions as objects which can be actively controlled. Since they could control emotions, these workers performed deep acting more successfully when confronted with a gap between what they should feel and what they actually felt. Hochschild argued that burnout and stress could be reduced through workers feeling a “sense of control over the conditions of their work lives” (p. 187) and a sense of ownership about their feelings.

Kim’s Nature of Theoretical Thinking in Nursing

Kim (2000) presented a typology for theoretical thinking to study phenomena from a nursing perspective. Although not a theory, her typology provides a conceptual framework for nursing research. It is “a device that can help us to make sense of reality in a frame of reference that is nursing" (p. 31). Kim's typology has an underlying assumption that nursing work is not a collection of technical skills or quantifiable actions. Studying nursing practice may appear like ordinary actions devoid of professional meanings, but nursing actions are embedded with covert and overt meanings. Kim noted that "the essential objective for the science of nursing is to strive for a system of knowledge that will increase the proportion of rational and explained acts" (p. 143). She divides research phenomena into four domains: 1) the client, 2) the client-nurse, 3) the practice of nursing, and 4) the environment. The domains of nursing practice and environment are reviewed here because they were most relevant to the research problem.

The Practice Domain of Nursing

According to Kim, nursing practice, "includes the cognitive, behavioral, social, and ethical aspects of professional actions and activities performed hand/or experienced by nurses in relation to patient care" (p. 127). She premised it is the balance of two philosophies; 1) the philosophy of therapy, which tends to patients' problems, and 2) the philosophy of care, which holistically tends to a patient as a person. Two dimensions, deliberation and enactment, are organized below the philosophies. First, the *deliberation* dimension describes how nurses develop their plans for actions through the process of gathering pertinent information, formulating problems, and deciding on ways to address identified issues. Nurses act to achieve an intended result. At times, nursing work is instinctual or automatic, and nurses are unaware that they are engaging in the process of deliberation. Deliberation is influenced by five factors: 1) the client, 2) nurse-agent relationship, 3) nursing goals, 4) nursing means, and 5) the context of the nurse-agent relationship. These factors affect how nurses make decisions and formulate actions plans.

For example, client qualities, such as a negative attitude, or nurse qualities, such as years of job experience, exert influence on the deliberation process and subsequently on how nurses formulate and solve problems. Secondly, the enactment dimension is the actual performance of nursing work, such as administering medication, giving a bath, or feeding an infant. Like deliberation, enactment is influenced by certain factors, which are: 1) aspects of nurse-agents, 2) aspects of the client, and 3) the context of nursing action. Although Kim considered deliberation and enactment analytically separate, she stressed they are not linear or straightforward. Nurses often simultaneously engage in deliberation and engagement, such as when changing a wound dressing (enactment), but also planning to administer antibiotics in an hour (deliberation).

The Domain of Environment

Nursing practice occurs in a distinct working environment and according to Kim (2000), “environment is an essential part of human existence” (p. 166). Thus, an incomplete analysis may result from overlooking ways in which environment can influence nursing practice. Environment refers to both physical settings and cultural spaces in which nurse-patient interactions occur. Kim defined environment as “the entity that exists external to a person or to humanity, conceived as a whole or as that containing many distinct elements” (p. 167). She advised researchers to perceive and study environment as separate components and organizes it into three categories.

First, spatiality refers to how close or how far elements are to a person. Second, temporality is the presence or duration of identified factors. The third category is sub-environment, which Kim categorized into three areas: 1) physical environment, 2) social environment, and 3) symbolic environment. The physical environment has abiotic and biotic elements. It refers to tangible objects which make-up a setting. For example, a bed, IV poles, a floor, and monitors create a hospital room. Humans are considered physical entities existing among other physical, energy-generating objects. Conversely, in a social environment, humans are viewed as social agents existing in a social environment. A social environment is comprised of interactions between people, groups, and communities. Social norms, expectations, hierarchies, and other structures are embedded within the social environment and exert influence on individuals and their interactions. It is within a social environment, where meanings are created, communicated, interpreted, modified, and acted upon. The third sub-environment is symbolic, which refers to intangible objects or element within a setting. Such elements, reflect cultural values and social norms and are classified as ideational, normative, and institutional elements. Ideational elements are ideas, values beliefs, history, and knowledge. Normative elements are rules, laws, expectation, and constraints. Institutional elements are roles, organizations, institutions, societies, and culture. Like physical or concrete entities, symbolic elements shape and influence an environment but are more elusive.

Summary

Several areas of overlap are identified among the three selected theories. First, each theory is based in the assumption that meanings arise out of social interactions. Meanings towards objects are variable, evolving and dependent. From an SI perspective, meanings direct how people act towards objects. From an emotion labor theory, people form meanings from the expected feeling rules. From the perspective of Kim’s domain of environment, meanings are created through all levels of interactions, such as at the individual level and organizational level. Second, each theory has the underlying assumption that larger social institutions shape individual interactions. For example, emotion labor's central premise is that organizations control the management and expression of individual workers. Additionally, Kim assumed that social forces affect how nursing practice is enacted on an individual level.

These theories provided relevant background for a study exploring how nurses manage personal and professional boundaries in their care of children with life-limiting illnesses and their families. They foreground how nurses formed meanings in their work through their ongoing interactions. Kim's domain of environments provided a framework for exploring how work settings may constrain or facilitate nursing practice. It also framed an examination of differences and similarities between sites and among care units. An identified gap in the literature was found addressing how environmental cultures affect nurses providing PPC. These theories provided a lens for highlighting salient concepts and understanding the processes inherent to nurses in PPC.

Conclusion

This chapter presented the state of knowledge about pediatric palliative care. A critical review of the literature was presented regarding families' experiences when a child dies and nurses' experience caring for dying children. These studies identified a gap in the literature about how nurses negotiate personal and professional boundaries while caring for children and families in PPC. In addition, sensitizing concepts from the literature were presented, which guided data collection and analysis. The PPC field is growing, indicated by the proliferation of research in this area, and new programs and places of care being created. Because nurses work most closely with families and often are the primary providers of emotional support, further understanding of care provision by nurses was indicated. The following chapter will describe the method and research design for this study.

CHAPTER THREE: METHODOLOGY

In Chapter Two, the review of literature identified gaps in knowledge about how nurses manage personal and professional boundaries in a practice area which involves a high degree of emotional involvement. Grounded theory and situational analysis methods were selected for this study, since qualitative methods are a useful research design when little is understood about a concept. Grounded theory's historical lineage will be briefly traced from its inception to its contemporary rendering of constructivist grounded theory. A review of the core aspects of grounded theory and situational analysis will follow. The researchers' responsibilities for representation, reflexivity, validity, and ethical considerations will be discussed. Finally, the research design will be presented.

Qualitative Methods

Creswell (1998) advised that qualitative research methodologies are selected to explore phenomenon not well understood by established theories or identified variables. A qualitative design can also help researchers answer questions about processes (*how* or *what*), rather than providing answers about causal or associated relationships (*why*). Additionally, qualitative research approaches permits researchers to study phenomenon in their natural setting. The study phenomenon met Creswell's criteria for qualitative research methods. First, how nurses navigate personal and professional boundaries caring for children with life-limiting illnesses is a phenomenon without clearly identified variables. For example, there is no instrument which measures nurses' professional boundaries and it is not explained by an established theory. Secondly, qualitative methods enable the researcher to identify significant processes nurses use to navigate boundaries.

Third, studying nurses in their natural work settings may provide richer data than questionnaires or interviews. Studying individuals in their lived social worlds situates knowledge from the participants' perspectives (Guba & Lincoln, 2005). Thus, qualitative research design, specifically grounded theory, was a suitable approach for guiding the research question.

Grounded Theory Overview

Grounded theory was selected as a method for exploring how nurses navigate between personal and professional boundaries in a practice area which requires emotional support. Variants of grounded theory have developed from Barney Glaser and Anselm Strauss' original version. For the purpose of this study, the perspectives of Adele Clarke (2005) and Kathy Charmaz (2006) were selected to guide analysis. These two grounded theorists approach the method from a constructivist perspective which assumes that "people, including researchers, construct the realities in which they participate" (Charmaz, p. 187).

Sociologists Glaser and Strauss developed grounded theory as a systematic approach to make qualitative research reputable in sociology. Grounded theory debuted in their book, *The Discovery of Grounded Theory* (1967). They were responding to quantitative methods (e.g. surveys), gaining popularity in the field and sought to legitimize qualitative research (Charmaz, 2006; A. Clarke, personal communication, October, 11 2006). The original method was framed in post-positivist assumptions, such as that the researcher is separate from the data and remains unbiased while collecting and analyzing data.

Grounded theory shares assumptions with Blumer's (1969) theory of Symbolic Interactionism (SI), one of which is that meanings arise from social interactions and human being's actions are based on meanings they hold towards objects. A grounded theory approach focuses on actions and processes. It allows for the research to link actions to social processes and examine the consequences which arise from identified processes. Using grounded theory methodologies, the researcher explores processes and patterns in social interactions and how meanings direct and determine participants' actions. Charmaz (2006) defines process as "unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between" (p. 10). Glaser and Strauss originally created grounded theory to uncover a singular basic social process (BSP) that participants shared. In contrast, constructivist grounded theorists, like Charmaz and Clarke (2005), claim that a single BSP assumes a level of normativity, and researchers may find multiple BSPs in their data.

Over time, Glaser's and Strauss's perspectives diverged regarding the underlying assumptions and methodologies of grounded theory (see Charmaz' discussion, 2006, p. 6-8). Depending on their lineages and epistemological perspectives, conceptions of grounded theory are often referred to as Straussian and Glaserian. Researchers must understand these considerable epistemological and paradigmatic differences when planning their research design because of important differences in assumptions. Glaser remained committed to the post-positivist approach from grounded theory's initial debut, while Strauss aligned more with a constructivist perspective (Charmaz; Clarke, 2005). Glaser stated that he believed in the existence of pure data and that it can be rendered objective. His critique of Charmaz' constructivist position draws from his belief that grounded theorists should remain objective and separate from the data. He stated that, “Constructionism is used to legitimate forcing” (p. 4). He is referring to researchers forcing data to fit preconceived ideas and concepts, which Glaser and Strauss originally warned against. Clarke disagreed with the possibility that a researcher remains objective and noted that “Knowledges and knowledge productions are situated and noninnocent” (p.18). She asserted that researchers must remain reflexive about their own taken-for-granted meanings throughout the study process.

Charmaz (2006) also situated the researcher into the research process, as indicated by her statement that “We are part of the world we study and the data we collect” (p. 10). She acknowledged the researcher as actively constructing data. No piece of data is considered fact; individuals create all documents, interviews, and records. She stated that “Moreover, *each* stage of inquiry is constructed through social processes. If we treat these processes as unproblematic, we may not recognize how they are constructed” (2005, p. 510-511). Clarke (2005) wrote to “explicitly acknowledge the embodiment and situatedness of knowledge producers” (p. 20). These constructivist grounded theorists believe that researchers are not separate from participants, but that each is equally located within an historical and social place. Thus they co-construct knowledge from their unique place in time.

Whether knowledge is discovered or constructed is a significant difference in assumption among grounded theory variants. As Glaser (2002) contended, classic grounded theorists propose that data will reveal itself through the method’s tedious strategies, such as constant comparative method and theoretical sampling. The researcher is independent from the data to avoid bias. Social constructionists dispute this view and argue that interpretations are not isolated from the historical and social contexts in which they are made. They are constructed against “a backdrop of shared understandings, practices, language, and so forth” (Schwandt, 2000, p. 197). Constructivist grounded theory is rooted in the assumption that there is an ongoing, unfolding relationship between participant and researcher.

Clarke (2005) argued that classic grounded theory can create an “over-simplification” of the phenomenon (p. 15), especially through the identification of a singular BSP. Classic grounded theorists seek to tell “a simpler story” (A. Clarke, personal communication, November 7, 2006), rather than recognizing the natural range of variation across participants’ experiences. Clarke insisted that our stories must be “complicated” (p. 15) and should unveil the diversity within our data, instead of dismiss it. Clarke’s perspective parallels Strauss’ (1987) view in his later writings when he warned not to reduce a theory to “a simplistic rendering of a phenomenon” (p. 10). He emphasized that grounded theory methodologies necessitates a “detailed, intensive, microscopic examination of the data” (p. 10). Superficial or weak analysis will ultimately result in an oversimplification of participants’ experiences, regardless if the researcher identifies one or multiple BSPs (Clarke). In contrast, focused analysis and hard work will produce rich interpretation and insightful discovery (Charmaz, 2006; Strauss).

A grounded theory approach uses sensitizing concepts to allow for a “point of departure” (Charmaz, 2006, p. 17) and direct the researcher’s lens on where to look (Blumer, 1969). They do not define data, but rather frame research questions and organize data collection and analysis. Sensitizing concepts are flexible, whereas predetermined concepts may erroneously define participants’ experiences. Constructivist grounded theorists use sensitizing concepts to guide research, while acknowledging participants have multiple perspectives, diversity, and variation. Sensitizing concepts pertinent to this study were drawn from the review of literature and the theoretical framework, primarily Hochschild’s theory of emotion labor. First, suppression of undesired emotion was a sensitizing concept. It was identified in studies of nurses who care for dying children (Davis et al., 1996; Papadatou et al., 2002; Papadatou et al.,2001; Rashotte et al., 1997; Yam et al., 2001) and by researchers testing and extending emotion labor in nurses (Bolton, 2000; Bolton, 2001; James; 1992; Lewis, 2005; Lopez, 2005; Theodosius, 2005). Suppression was only one possible process in which nurses may engage in. Examining other coping strategies provided further insight into the process of negotiation between their personal and professional selves.

Hochschild’s feeling rules were a second notable sensitizing concept. Feeling rules refers to what one should feel in social situations and how people communicate these expected feelings through appropriate displays of emotion. Further exploration was needed on the extent that organizations control nurses’ emotional expression because researchers challenged Hochschild’s claim that organizations actively control workers’ behavior through feeling rules (Bolton, 2000; Lewis, 2005; Lopez, 2006). These studies suggested that nurses have more autonomy and agency in the emotion management of their own and others’ feelings.

Lastly, the language surrounding emotion was an important sensitizing concept for this study. Froggart (1998), in her study of hospice nurses, described how participants frequently used metaphors to describe feelings elicited from their care of dying patients. Their metaphorical descriptions indicated nurses’ physical actions. For example, when nurses spoke about “switching off” or “standing back”, they were maintaining both emotional and physical distance. Froggart wrote that, “In both the metaphorical and practical domains, there was integration in the use of language and the lives of the nurses” (p. 337). Froggart’s work indicated how metaphor and language can reveal the intersections between professional and personal selves. Paying attention to how participants used metaphors in their narratives provided insight into how nurses experience emotion in their work and personal lives and negotiate boundaries.

In summary, grounded theory provides tools to analyze nursing processes and to generate a theoretical conception derived from participants living in the phenomenon. In the post-modern era, the epistemological foundations of grounded theory encompass diversity, messiness, heterogeneity, and multiplicities (Clarke, 2005). The researcher is acknowledged as an active producer of knowledge (Clarke) and co-constructer of meanings (Mischler, 1986) with their participants. Constructivist grounded theory has an underlying assumption that phenomenon is situated in a unique historical place and time (Clarke) and that “truths are relative, multiple, and subject to redefinition” (Charmaz, 2004, p. 984).

Situational Analysis

Situation analysis is an extension of grounded theory which focuses analytically on situations of inquiry (Clarke, 2005). In doing so, situational analysis facilitates the researcher to analyze beyond an individual level and into broader social levels that shape the situation and participants’ interactions. According to Clarke, grounded theory was “based on profoundly universalizing and essentializing assumptions of the homogeneity of individuals and/or experiences” (p. 24). Clarke encouraged researchers to “complicate our stories" (p. 15) through presenting the complexities, variations, and contradictions reflected in data.

Situational analysis arises out of interpretive and constructivist versions of grounded theory. Clarke (2005) asserted that she is extricating grounded theory from its formative roots in positivism. She builds on Strauss' (1978) and Strauss and Corbin's (1990) conditional matrices, which appreciated how context and meso level elements influenced the phenomenon. Clarke's critique of the conditional matrix, however, is that it placed "conditions of actions *outside* of action" (p. 298). She argued that situations are constitutive of their conditions. Rather than only providing context for a situation, surrounding conditions are part of the situation itself. To analyze situations and their constitutive elements, she presented three cartographic approaches: 1) situational maps, include all human and nonhuman elements within a situation; 2) social worlds/arenas maps, which include meso level analysis, as opposed to mapping at an individual/micro level; and 3) positional maps, which identify and plot discourses, rather than individual positions. Clarke noted that these maps serve as entry points into analyzing data, rather than the final products of project. They help in "opening up" data and examining it from a different analytic perspective. These exercises are intended to supplement a project's grounded theory framework.

Clarke (2005) and Charmaz (2006) emphasized that the goal of constructivist grounded theory and situational analysis methodologies are not to produce formal theory about the studied phenomenon. Rather, the researcher's goal is to theor*ize* (Clarke) and generate new sensitizing concepts for further research or to refine old ones (Charmaz). This goal reflects the postmodern assumption that research is situated within time and place; therefore theories cannot be absolute, universal, or fixed. It also reflects the assumption that researchers are co-constructing knowledge with participants and they must remain reflexive of their contributions throughout the analytic process.

Rationale for Selecting Grounded Theory and Situational Analysis

Grounded theory and situation analysis were selected to study the processes inherent to how nurses navigate between personal and professional boundaries. A grounded theory approach focuses on actions, interactions, processes and patterns. According to Creswell, Hanson, Clark, and Morales (2007), researchers select grounded theory when they ask questions about how processes and experiences change over time. Charmaz (2006) noted that grounded theory “relies on interaction” (p. 179) and that “we make sense of our situations, appraise what occurs in them, and draw on language and culture to create meanings and frame actions” (p. 179).

Situational analysis offers a new lens to examine larger structures and social worlds. Clarke (2005) defined a social world as “groups with shared commitments to certain activities sharing resources of many kinds to achieve their goals and building shared ideologies about how to go about their business” (p. 46). Nurses, as a professional group, constitute a social world. Further, situational analysis pushes analytic thinking though attending to the nonhuman elements in a situation, and nurses practice among many nonhuman things (e.g. discourses, technology, physical objects). Clarke emphasized that situational analysis addresses power and hierarchy within data, and illuminates the empty spaces and silences which may have been historically overlooked, minimized, or ignored. These types of silences were named “invisible work” by Strauss and colleagues (1985/1997). Invisible work is a sensitizing concept for this research study. Situational analysis is a tool for examining how this concept might be present in nurses' experience in pediatric palliative care.

Grounded theory, in the interpretive and constructivist tradition (Charmaz, 2006; Clarke, 2005), is similar to phenomenological inquires. They each elicit how participants construct meanings, possess taken-for-granted assumptions, and move through their worlds. Similar to constructivist grounded theory, interpretive phenomenology is rooted in the assumption that participants' experiences are situated and temporal (Benner, 1994). Differences are found in how each method designs, collects, analyzes, and presents data. During analysis, grounded theory aims to fracture or rupture data and continually seeks to open up data. At times, word-by-word coding is used fracture data in order to access participants' meanings. Phenomenology, conversely, balances analyzing pieces of data without losing a sense of the experience as a whole (van Manen, 1990). In presenting findings, phenomenology describes what is common in the practical lived reality of a group of participants, as well as what is distinct. It often uses paradigm cases to illustrate identified themes (Benner; Creswell et al., 2007). Grounded theory methodologies have potential to produce formal theory, substantive theory, or theoretical conceptualizations about processes inherent to the studied phenomenon (Creswell et al., 2007). A final important distinction is the method's unit of analysis. Individuals or groups of people are the unit(s) of analysis in phenomenology. Constructivist grounded theory shifts the unit of analysis from individuals to actions (Charmaz) and situational analysis considers the situation as the unit of analysis (Clarke).

Researcher Responsibilities

Since constructivist grounded theory acknowledges the researcher as co-constructing meanings, researchers have responsibilities about representation, reflexivity, scientific rigor, and ethics. They are responsible to acknowledge the ways in which politics can influence and affect interpretation. Clarke (2005) stated that “we are, through the very act of research itself, directly in the situation we are studying” (p. 12). Similarly, Charmaz (2006) wrote that “researchers are part of what they study” (p. 178). Thus, researchers carefully balance their own experiences with their findings of participants’ experience, to avoid reporting a “series of autobiographical encounters” (Atkinson, Coffey, & Delamont 2003, p.186). Charmaz (2006) noted that respect is the key requirement for producing a quality study and through a respectful approach, researchers learn from participants’ views, perspectives, and experiences.

Reflexivity

Since researchers are part of what they study, reflexivity was necessary throughout this research process. Reflexivity enhances a study’s validity by producing more meaningful analysis, recognizing one’s own assumptions, and communicating the research process to readers (Hall & Collery, 2001). Reflexivity facilitates researchers to “stand *within* the research process rather than above, before, or outside it” (Charmaz, 2006, p. 180). Since I am a nurse studying nurses, reflexivity lead me to examining my own insider/outsider status. Nurses who study other nurses are not automatically granted insider status (Allen, 2004). I am researching a phenomenon close to my own experience as a pediatric nurse who has worked with oncology patients and their families. My work in this role directly led me to want to study nurses, their relationships and caring practices with children and families at the end of life. In this sense, I am an insider to the nursing "world". My insider status as a fellow nurse may grant me initial trust and acceptance because of the unspoken bond being a nurse affords. Nurses form a type of tribe and an understanding of a shared language, which may have facilitated an initial connection. Differences, however, between myself and nurse participants can designate me as an outsider. For example, I live in an academic world, which can set me apart from the nurses providing direct patient care. Also, I studied unfamiliar practice settings.

Being an insider *or* an outsider is not a clear binary, and Hammersley and Atkinson (1995) noted that researchers can simultaneously straddle both positions. Sharon Kaufman (2006), in her ethnographic work on end of life in hospitals, reflected that she continually fluctuated between both positions. As a medical anthropologist, her interactions with a range of participants (patients, their families, and health care providers) further complicated the distinctions in her insider/outsider status. Reflecting on the research process, she wrote that, "Yet my easiness, my lack of definite status, helped me think through the contradictions I encountered, the differences of feeling and understanding between doctors and nurses, between health professionals and families, indeed, among all the players" (p. 11). Ongoing reflection throughout the research process is necessary because of the ambiguities and entanglements, and requisite for thoughtful and meaningful analysis.

Scientific Rigor

Standards for acceptable rigor in qualitative studies are varied and occasionally contradictory (Guba & Lincoln, 2005). A universal standard for validity does not exist, and there are varied perspectives regarding how to define validity (Sparkes, 2001). Since the researcher is considered the instrument in qualitative work, subjectivity and bias has often been the basis for critiques of qualitative research. A constructivist grounded theory approach assumes that researchers are part of what they research (Charmaz, 2006; Clarke, 2005). Therefore, objectivity is not the goal in qualitative research, as Guba and Lincoln (2005) noted, it has “never existed, save in the imagination of those who believe that knowing can be separated from the knower” (p. 208).

Since constructivist grounded theory methodologies guided analysis, Charmaz’ (2006) evaluation criteria were used. The criteria focused on evaluating the richness of completeness of the generated theory and are organized into four areas: 1) credibility, 2) originality, 3) resonance, and 4) usefulness. I regularly examined the data and theory using the questions presented by Charmaz (see p. 182-183 for evaluation criteria).

Rigor was also achieved through ongoing presence in the study settings, frequent observations, discussion of findings with a peer group, and member checking. Preliminary theoretical conceptualizations were brought to participants for feedback on how well they fit with the nurses’ experience. Participants were also available to ask about the settings’ policies, procedures, and routines as questions arose through data collection and analysis.

Ethical Considerations

Although nurses were the study focus, vulnerable populations were indirectly studied through participants’ narratives and during participant observation. These vulnerable populations include seriously ill children and grieving families from a range of socioeconomic, cultural, and ethnic backgrounds. Vulnerable families present multiple methodological and ethical issues (Demi & Warren, 1995). This issue was addressed through various strategies. When I encountered families during observation periods, I obtained verbal consents from them. No patient or family member refused the researcher’s presence. Sensitive health information heard during observation periods and interviews was kept strictlyt anonymous and confidential in field notes, transcripts, publications, and presentations. Patients’ and family members’ names, ages, locations, and diagnoses were changed or omitted from all text to preserve anonymity.

Nurses were not considered vulnerable in the same ways that families and children were, but similar ethical issues existed. Interviews included questions pertaining to their emotions and difficult situations, which risked evoking a sense of vulnerability. When participants actively cried during interviews, they were sensitively attended to and reminded that they could move on to other questions or refuse to answer a particular question. When asked about the interview experience, nurses expressed benefit from sharing their emotions and experiences. Additionally, as with all patient and family information, participants’ names were kept anonymous and rigorous attention was paid to keeping all information confidential. In the presentation of findings, all participants were referred to as females, as to not identify the few male nurses that participated.

Study Design

In the following section, the study design will be discussed. The purposive sample included 18 registered nurses from two health-care settings: an end-of life facility and a children’s hospital. Data was gathered from a variety of sources, primarily interviews and participant observations. Data was analyzed using grounded theory and situational analysis methodologies. The goal of the study was to produce a substantive theory about how nurses manage professional boundaries in a practice area which can affect them in deeply personal ways.

Purpose and Aims

The purpose of this dissertation study was to explore how pediatric nurses in acute care units and an end-of-life facility negotiate professional and personal boundaries while delivering palliative care to children and their families. The study's three aims were to:

- compare and contrast among the settings and their influence on nurses' ability to maintain boundaries;
- describe how the nature of the relationship between nurses and patients and their families affect how nurses navigate boundaries;
- describe the range of nurses' work-related emotions and their influence on how nurses navigate boundaries.

Research Questions

In describing how nurses navigate boundaries in pediatric palliative care, this study was guided by the research question, "How do nurses negotiate personal and professional boundaries while caring for seriously ill children and their families?" Additional research questions were: "How do sites of care influence this process?", "How do nurses manage emotions?" and "What other contextual factors facilitate or hinder this process?"

Definition of Terms

The following definitions were used for the study's key terms, which were derived from the review of literature.

Pediatric Palliative Care: “In addition to the meticulous management of pain and other physical symptoms, palliative care emphasizes the emotional, spiritual, and practical needs of patients and those close to them – from the time of diagnosis through death and bereavement. Helping people live well in the presence of life-threatening medical conditions (and their treatments) requires both compassion and sophisticated strategies and tolls for measuring, preventing, and reducing the physical, psychological, and other burdens often associated with such conditions and their treatments” (IOM, 2003, p. 34). Palliative care begins at the diagnosis of a life-limiting illness and continues through the child’s recovery or death (AAP, 2000, IOM, 2003, Sepulveda, Marlin, Yoshida, & Ullrich, 2002).

Hospice Care: The IOM (2003), defined hospice care as “an organization or program that provides, arranges, coordinates, and advises on a wide range of medical and supportive services for dying patients and those close to them” (p. 34). Historically, hospice care was provided to dying patients near the end of life.

End-of-life Care: The IOM (2003) stated that end of life care “has no precise meaning” (p. 34). It often refers to the practical care in an anticipated death or managing a condition’s end stage.

Nursing: The protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations (American Nursing Association, 2007). Specifically, a Registered Nurse is a person (historically usually a woman) who cares for the sick or infirm; (now chiefly) specifically a person professionally qualified for this activity. (Oxford English Dictionary, 2004).

Boundary: That which serves to indicate the bounds or limits of anything whether material or immaterial; also the limit itself (Oxford English Dictionary, 2004).

Study Sites

Registered nurses were recruited from two sites: a pediatric end-of-life facility and an academic tertiary-care children's hospital with an active pediatric palliative care program. Nurses were recruited from three units within the children's hospital: the hematology/oncology/bone marrow transplant (hem/onc/bmt) unit, the Pediatric Intensive Care unit (PICU), and the Intensive Care Nursery (ICN). These units statistically experience the highest number of pediatric deaths (IOM, 2003). From 2000 to 2006, the number of children's deaths per year at the children's hospital ranged from 90 to 115. In 2006, approximately 60% of pediatric deaths occurred in the intensive care units (R. Kramer, personal communication, November 21, 2007). This 150 bed tertiary facility serves children and families from the greater northern California and neighboring states. Three dedicated palliative care rooms are located in the children's hospital. The pediatric palliative care program, implemented in 2001, is an integrative model which supports and trains providers to develop the knowledge, skills, and attitudes to become competent and confident providing PPC. The program provides resources for staff to promote competency in end-of-life issues, such as ongoing educational sessions, case conferences, action plans, and palliative care order sheets. It also provides support to patients and families as they navigate through a child's life-limiting or life-threatening illness, such as providers being present at family meetings and attending to siblings' needs. When a child is imminently dying, the program also provides comfort items to families to help in their grief and bereavement, such as donated quilts, baskets, or soothing music CDs.

The end-of-life facility, the second study site, is located in the Greater San Francisco Bay Area and cares for children with life-limiting illnesses and their families. Since opening in 2004, it provides end-of-life, transitional, and respite care to families from multiple counties across Northern California. From April 9, 2004 to June 30, 2008, it served 215 children from a range of ethnicities; 33% were under 2 years old, 31% between 2 and 12 years old, and 36% over 12 years old (C. Torkildson, personal communication, July 10, 2008). Respite care was provided to 73.2% of admitted children, 14.72% received end of life care, and the remaining 12.1% received transitional care (C. Torkildson). Children returned for multiple admissions to receive respite care since families are eligible for up to four weeks per year. Diverse care is provided by an inter-disciplinary team, including a social worker, a psychologist, a child life specialist, volunteers, physicians, and a chaplain. Nursing care is provided around the clock.

Participants

A purposive sample of 18 nurses (N=18) participated in the study (see Table 1, Appendix A for demographic data). Ten nurses participated from the end-of-life facility; nine females and one male. Eight nurses participated from the children's hospital; seven females and one male. From the children's hospital, three nurses participated from the hem/onc/bmt unit, three nurses from the ICN, and two nurses from the PICU. The sample ranged in age from 25 to 59 years old; three participants declined to state age. The overall sample had a mean of 3.8 years in their current work setting, 16.3 years in nursing practice, and 13.1 years in pediatrics. Participants were employed at the facility an average of 1.8 years. Self-reported ethnicities were 81% white, 16% other, and 3% black.

Inclusion Criteria

Since the purpose of the study was to look for a range of experiences, the only inclusion criteria were that participants were registered nurses who worked part- or full-time in one of the four study settings. Non-registered nurses were not eligible.

Protection of Human Subjects

Approval was obtained from the University of California, San Francisco's Committee on Human Research (CHR). The first approval was issued from July 7th, 2006 to July 7th, 2007 for the pilot study. Approval renewal was granted on January 10th, 2008 for continuance and completion of the study. No participants were enrolled or contacted during the lapse of approval between July 7th, 2007 and January 10th, 2008.

Recruitment and Enrollment Procedures

Nurses were recruited in two phases. From September 2006 to February 2007, six nurses were recruited from the end-of-life facility for the pilot study, which provided the foundation for this dissertation. In the second phase of recruitment, an additional 12 participants from all study settings enrolled from January 2008 to April 2008. Recruitment strategies included posting a study flyer in the break room of each site (Appendix B), sending an information email to eligible nurses (Appendix C), and attending two of the facility's staff meetings. Nurses contacted the researcher through phone or email if they were interested in enrolling or had questions about the study. Participants were also encouraged to talk to their colleagues about the study, which contributed to recruitment through snowball sampling. Snowball sampling is a costefficient strategy for recruiting participants, in addition to a strategy that establishes initial trust between the researcher and future participants (Polit & Beck, 2004). Sampling continued until theoretical saturation was reached.

After contacting the researcher about enrolling in the study, nurses chose a time, date, and location to meet for the first interview. Participants were encouraged to choose a quiet, private location where they felt most comfortable. Interview locations included reserved, private rooms in an academic library, the end-of-life facility, a participant's home, a restaurant, and a café. At the first interview, I reviewed the consent form (Appendix D), which included risk and benefits of enrollment and the option to withdraw from the study at any time. They were also reminded that all information was kept confidential and anonymous. All participants agreed that they could be contacted if further information was needed or for scheduling an observation time. The interview began after consent was obtained.

Data Collection

Data was collected from a variety of sources. According to Strauss, "different kinds of data give different views or vantage points" (p. 27). First, participants were interviewed using a semi-structured interview guide created to address the research questions and study's aims (Appendix E). Participants who enrolled towards the end of the study were also asked if their experience fit with emerging themes from ongoing data analysis. Interviews lasted approximately one hour and ranged from 45 minutes to one hour and 15 minutes. They were audio-taped and transcribed verbatim by a professional transcription service. All transcriptions were cross-checked to the original recording for accuracy. Participants completed a demographic data sheet before the interview commenced (Appendix F). A second interview was not necessary for any participant. Immediately after each interview, I wrote field notes, which included descriptions of the participant, setting, tone of interview, and initial hunches.

Second, field notes from interviews and participant observations served as data. All participants consented to an observation period, but observations of all participants were not needed. Each observation period lasted approximately four hours. A total of 52 hours were spent in participant observation at all study sites, during all shifts, and represented both week days and weekend days. Observations also included attending inter-disciplinary staff meetings at both facilities, shadowing the hospital's PPC nurse coordinator, and a hydro-therapy session at the end-of-life facility. During participant observation, I followed nurses through a typical work shift. I focused particular attention on nurses' interactions with patients, families, and colleagues. After the observation, I immediately wrote detailed field notes which documented important insights during the observation period.

Lastly, institutional documents were collected as data. They included blank nursing assessment sheets, standardized check-lists (e.g. post-mortem care), policies and procedures, and institutional pamphlets.

Data Management

All data was kept confidential and anonymous. All potentially identifying information was changed. Data was kept on a password encrypted computer and locked in a file cabinet. Transcribed interviews, field notes, memos, and other data were managed in the computer program, Atlas-ti, which assisted with organizing data and facilitating coding, memo-writing, and diagramming throughout analysis.

Data Analysis

Although grounded theory is comprised of specific strategies, it is not a rigid prescription of procedures. Charmaz (2006) described grounded theory method as flexible and innovative, allowing the researcher to substantiate ideas and follow leads throughout data collection. She described the analytic process as *abductive*, defined as “a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data” (p. 186). In analyzing the data, I followed grounded theory’s core characteristics, which are: 1) simultaneous data collection and analysis, 2) theoretical sampling, 3) coding of data, 4) memo writing, and 5) constant comparative method (Charmaz, 2006; Strauss & Corbin, 1990; Coyne and Crowley, 2006; Cutliffe, 2002; Duschscher and Morgan, 2004; Glaser & Strauss, 1967; McCann and Clark, 2003a, 2003b). These strategies are consistent with Charmaz’ (2006) presentation of grounded theory tools. With exception of the constant comparative method, she included four of these five characteristics in her figure of the grounded theory process (see p. 11). Although constant comparative method is missing from her figure, she emphasized that it “constitute(s) the core of the [grounded theory] method” (p. 178).

In accordance with Strauss’ (1987) advice, analysis started after the first interview in the pilot study. Data collection continued in conjunction with data analysis throughout the study. This interaction between collection and analysis allowed me to identify salient concepts in the data and then focus my attention on collecting data that substantiated the emerging theoretical ideas. Simultaneous analysis allowed for ongoing refinement of data collection (Charmaz, 2006). I paid careful attention to issues that participants defined as significant, critical or crucial. Questions, concepts, ideas, and hunches emerged from my close relationship with the data and served as a strategy to prevent forcing the data into existing theory or concepts.

Theoretical sampling relies on simultaneous data collection and analysis and works in tandem with constant comparison method. The purpose of theoretical sampling is to delineate categories' boundaries, as well as where they may overlap, link, or diverge. For theoretical sampling to be successful, the researcher must be engrossed in the data and wrestle with analytic challenges (Charmaz, 2006). Theoretical sampling began after the development of preliminary categories and was guided by the gaps and questions raised during memoing. Theoretical sampling did not include finding participants that met certain requirements. It followed Charmaz's guide that "You seek statements, events, or cases that will illuminate your categories" (p. 103).

All interviews were coded following the coding levels that were presented by Charmaz (2006): 1) initial coding, 2) focused coding, 3) axial coding, and 4) theoretical coding. Codes formed the building blocks of the emerging theoretical conceptualization, and were "naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data" (Charmaz, p. 43). I coded primarily chunk by chunk, but occasionally coded word by word or line by line when closer analysis was required. Initial codes condensed the data, which then allowed for the development of focused codes. The act of focused coding required decisions about which codes to pursue and their contribution to building categories (Charmaz). Developing focused codes arose from the constant comparative method by continually inquiring, "What are the similarities and differences between data?" (Charmaz, p.60). Next, the data was coded using axial coding, which was originally described by Strauss (1987). This type of coding attended to specific categories and aimed to contextualize the "axis" of a category (Strauss). Theoretical codes, the last level of codes, further refined focused codes into a sharper analytic conceptualization of the data (Charmaz). The central process was identified through theoretical coding. According to Glaser (2002), the act of theoretical coding links back together the fractured data into a cohesive and theoretically dense analysis.

I consistently wrote memos throughout the research process. Memos stitched together the fabric of the project and served as a historical guide of my analytic process. In summary, the act of memo writing is flexible and adaptive, but not optional. Memos "form a space and place for exploration and discovery" (Charmaz, 2006, p. 82-83) and actively engage the researcher in theoretical analysis. As Charmaz noted, memos are the "pivotal intermediate step between data collection and writing drafts of papers" (p. 73) and described two broad types: early and advanced memos. Early memos were written at the beginning of the research project. They elaborated codes, reflected gaps, directed data collection, described participants, or recorded actions observed in the field (Charmaz). Early memos were the initial descriptions of identified processes and their associated conditions, participants' responses, actions and situations' consequences. Advanced memos furthered the analytic work. They elaborated on categories by outlining their properties and their relationships to other codes or categories. Advanced memos also were a place to identify and describe variations of a process (Charmaz). In order to remain close to the data, segments of raw data were incorporated into memos to support theoretical ideas and arguments (Charmaz).

Memos were also the medium for the constant comparison method, an integral tool since grounded theory's inception (Glaser & Strauss, 1967). Because constant comparison method uses data for comparison, it "grounds" the researcher in the data, while elaborating theoretical conceptualizations (Glaser & Strauss; Walker & Myrick, 2006). I continually engaged in a process of comparing data to data, codes to codes, codes to categories, categories to categories, while looking for similarities and differences (Charmaz, 2006). Within memos, I compared interview statements to incidents, statements from different interviews, or observations of actions in different places. Comparisons became more sophisticated as analysis progressed (Charmaz).

I also used situational analysis mapping strategies to interrogate the data and push analytic thinking. Situational maps provided the basis for the internal and external contexts that shape nurses' practice and the emerging process. Social world maps moved analysis from the individual level and considered how larger environments, such as work setting and socio-cultural views, impacted participants. Positional maps were not used in this study.

Conclusion

In this paper, the historical lineage of grounded theory, the differences between Glassarian and Straussarian, and the foundational assumptions of constructivist grounded theory were presented. A discussion of the methods' core strategies followed. Researchers' responsibilities for participant representation, reflexivity, ensuring validity, and ethical considerations were discussed. Finally, the intended research design was presented, which included study sites, inclusion criteria for sample, data collection and analysis methods.

Constructivist grounded theory and situational analysis methodologies are useful tools for building a substantive theory about the range of processes nurses use to navigate between personal and professional boundaries. Each method is comprised of analytic exercises which will push theoretical thinking in this area. For example, grounded theory’s constant comparison method is a strategy which will help to identify the variations and similarities between sites and among care units. In addition, situational analysis maps can stimulate theoretical insight into the larger social structures which impact nursing practice.

CHAPTER FOUR: EXTERNAL AND INTERNAL CONTEXTS SHAPING NURSING PRACTICE

Findings from this study are divided into two chapters. This chapter will describe the external and internal contexts that influence how nurses construct and navigate professional and personal boundaries and in turn, impact their delivery of palliative care. Chapter Five will describe the process of how nurses navigate boundaries. The external context refers to the physical and social environments within which participants worked. An overview of the four settings will be described, which will include descriptions of the physical environments, nurses' roles, and similarities and differences among the settings. Then, how each setting managed patient deaths will be discussed, which provided insight into nurses' role expectations. This section will include a discussion of the actual care of deceased patients, in addition to institutional support offered to nurses following a patient's death. The external context also included the larger socio-cultural views about death and dying. Next, the internal context will be described, which refers to participants' unique perceptions. Nurses' definitions of palliative care, hospice care, and end-of-life care will be discussed and compared across settings. Then, nurses' world-views about death and dying, values, and past experiences will be presented. Lastly, types of boundaries will be described since the process of navigating boundaries was influenced by nurses' perceptions of them.

Overview of Physical and Social Settings

The physical layout in the four settings vastly differed. In order to provide a visual picture of the study sites, I will describe the physical environment of each unit; the end-of-life facility, the hem/onc/bmt unit, the PICU, and the ICN. I will follow with how participants described nursing care in their particular unit. Lastly, this section will conclude with the salient similarities and differences among hospital nurses and end-of-life facility nurses, with regards to their nursing care. To ensure participant confidentiality, all participants are referred to as females throughout the findings, in order to not single out or identify the two male nurses who participated in the study.

The End-of-life Facility

The end-of-life facility was created as a home-like setting to be a bridge between the hospital and families' home. Immediately upon walking through the front door, the house appears bright, clean, and cheerfully decorated. Administrative offices are to the left and a large family room is to the right, which is commonly used for nursing staff meetings, weekly inter-disciplinary meetings, family conferences or just a place to relax in. Down the hall from the front door, a cushioned sitting area is surrounded by windows. An art-room, computer room, and tactile room are located off the main hall. The eight patient bedrooms each have bright murals painted on the walls, built-in bookshelves, large bathrooms, doors leading to the outside, and medical equipment concealed in the walls. The house also has two family suites, each equipped with a kitchenette, sitting room, and a bedroom. The dining room includes three big tables where families and staff eat freshly prepared meals by the kitchen staff. During one of my observation days, I accompanied a participant to the dining room for lunch:

> [field note] *The nurse and I enter the dining room and at the large rectangle table a teenage patient sits in a wheelchair next to her father and a visitor. A father and his two sons also sit at the table. The nurse and I walk to the counter where lunch is laid out. There is baked chicken, mixed salad, potato salad, garlic bread, and three kinds of freshly baked cookies. She offers me lunch, but I decline since I have just eaten. Instead, I choose hot tea. A box of many tea packets sits on a*

> *table where there is hot water and coffee. We walk to a empty round table in the corner of the room. It is surrounded by windows. I look outside and notice a gas grill. Inside, there is a large fireplace with two comfy chairs in front. The nurse tells me the food is very good.*

The facility grounds are exceptionally landscaped with trees, flowers, and grass areas. A play structure is outside the play-room's French doors. A non-denominational sanctuary is separate from the house and accessed by a short, herb-scented path. Families used the sanctuary as a quiet place to pray or sit, or have their child's memorial or funeral service. Towards the front of the house, various colored tiles make-up a portion of a sitting wall; the tiles were created by siblings of deceased patients during an annual memorial event.

Depending on the patient census, typically two nurses and a certified nurse assistant work each shift. The nurses' station is centrally located near the eight patient bedrooms. It has two computers, a fax machine, various binders, patient charts, and a sink. Children's artwork and photographs decorated the station. On the back wall is a large white board designating patients' rooms, anticipated patient admissions, and the names of staff on shift. A locked medication room is on the left of the nurses' station. All medications, formula, and medical supplies are kept in this room. During my visits, I noticed the nurses' station as a hub of activity for the facility. I observed that nurses, aides, families, children, and volunteers gathered in the space around the nurses' station. On one visit I noted that "[field note] *against the wall across from the nurses' station there is (from right to left) – a baby swing, a chair, a glider, a stroller, a large dresser, a couch under the window, a side table with drawers, a red bean-bag chair with a blanket over it, a chair that I sit in and a red plastic wagon.*" I observed people holding babies on the couch or rocking chairs, children sitting in their wheelchairs, or laying asleep on a bean-bag chair.

The station's central location allowed for informal gatherings of families and staff alike. Conversations occurred among nurses, staff, volunteers, families, and patients while nurses charted, gave medications, assessed patients, or regulated feeding pumps. On weekend-shifts, the security guard would walk through this space and stop to talk with people gathered near the nurses' station. Most of my informal conversations during observations occurred in this area. What I found most striking is that the nurse's station was not strictly nurses' territory; it was a shared, neutral space. A participant remarked that facility in general is "*…neutral territory. So we're all coming into neutral territory here. And yeah, I have the advantage because I've been here before, over maybe some families coming in for the first time. But aside from that we're equal; we're all coming into a place of equality.*" The following note additionally illustrates the milieu of the facility's equality.

> *[field note] "S" sits back on the couch across from the nurse's station to finish her charting. It has been 1 – ½ hours since she first pulled the charts out to write in. A patient's girlfriend, who is his primary care-giver, walks by and sits behind the nurses' station in the computer chair. The cook walks out of the kitchen's back door and hands her* [the girlfriend] *a paper plate with two corn dogs. As she starts to eat the corn dogs, "S" looks up and start to laugh, saying "Something looks wrong with this picture." She then asks the girlfriend if she would like to switch places. It made more sense for "S" to chart at the station and the girlfriend to eat at the couch on the tray. The girlfriend laughs as well, saying she was just going to say something. They trade positions.*

Perceptions of Nursing Roles and Care

End-of-life facility nurses summarized their primary role as supporting families and children. Despite challenging family situations, difficult decisions or conflicts, nurses ultimately strove to find ways to provide support. They regarded each family and child as unique and as requiring individualized care and attention, as one nurse noted:

> *Now, you know, in every kid that walks through the door is a* ***child*** *walking through the door. It's not a patient that-- we're not taking the square patient trying to shove it into a circular hole and saying, "You've got to conform to this." We-- as to the best of our ability-- we've got to conform to that patient.*

Participants often relayed stories about situations in which they conflicted with families' decisions or actions. For example, one nurse had a strong belief in allowing a natural and peaceful death, free from medical intervention. This belief conflicted with a family's decision to call emergency services when their infant stopped breathing. Despite repeatedly referring to the resuscitation scene as "ghastly", this participant emphasized that her role was to support the family's decisions, regardless of how they differed with her own. She stated:

> *I was sad that they felt that they had to go that path. But it was theirs to chose, you know? And I don't feel like it's my choice to make. And it isn't my choice to convince them of what I think. I see myself as a support person.*

She continued to explain that parents must live with the medical decisions they make for their ill children. In this case, she stated that the parent's grief may have been compounded if they felt they had not done everything possible to save their child, which necessitated calling emergency services. Another nurse echoed this sentiment in her assertion that "*It is not my choice. But it is also not my burden*."

Other participants similarly reconciled conflict through reiterating their role as a support person to families and children. They often used terms, such as "path" or "journey", to metaphorically refer to accompanying families rather than leading or directing them. One participant remarked that it was challenging to care for families who refuse pain medications for their dying child. She stated that, "*That's the part where I* *just, I have little tolerance, but yet you have to go on that journey with them."* Similarly, another participant described that working at the facility eased her previous moral distress when working in a bone-marrow transplant unit, where patients frequently died after heavy, aggressive treatments.

> *I know where they're goin'. And I, my job is to totally focus differently than hurry up and make them as well as possible. And that has really helped me. Because I'm there to make their journey better. I'm there to make them comfortable for their journey.*

Nurses described the facility as offering a more relaxed setting, which in turn facilitated more trust among care providers and families. Nurses felt more open, as if they could be more themselves when working at the facility than in their previous work settings. They remarked that families frequently commented that they could "*let down their hair*" and be "*less defensive*" when at the facility than when they were in the hospital. Participants hypothesized that families' defensiveness partly derived from repeatedly receiving bad news about their child. When at the facility, families were not on guard or continually hearing bad news, and were more amenable to having nurses more easily establish a trusting relationship with them. One participant relayed a story about a father's reaction to how the facility conducted family meetings in comparison to his experience in the hospital:

> [The father said], *"but those conferences at that hospital, I don't like it and I'm telling that doctor, I'm not gonna sit in another one. He can come talk to me outside." He goes, "Here, it's okay." He's like, "I'm telling you, we were a little nervous at first. You say you want a meeting and we're a little nervous." I said, "I know." And another nurse said, "You know what? But we don't want to have a meeting with you, we just want to have check-ins with you. And make it an ongoing discussion. Are you guys okay today? Is she* [the child] *okay today? Just regular check-ins. That's all we want to do here. We shouldn't call them meetings." And he goes, "yeah, yeah. Now I know. It's okay to have meeting here, but we're not gonna have those conferences there anymore."*

Nurses frequently commented that an important aspect of their care is playing with children when appropriate, especially near the end-of-life. Playing was important to nurses and an extension of their nursing care because it validated the whole child, rather than exclusively focusing on a disease. When asked to describe nursing care at the end-of-life facility, the following participant stated that:

> "*…to make sure that they're allowed to get the most play time in or whatever that is for them depending on their age. Whether it's being an infant or being a young adult, whatever's appropriate for them and whatever they enjoy in their life. Getting as much as that in, getting as much as feeling like a whole person and not a patient in a room."*

Because play was a significant part of the child's experience at the facility, there were many opportunities for play, such as toys being available in the play-room, child-life specialist interventions, plentiful art supplies, and spending time with a hydro-therapist in the pool. All nurses remarked that they enjoyed working at the end-of-life facility because part of their job was having fun with children and encouraging play. Play activities occurred as part of nurses' care, in addition to routine nursing tasks, such as giving medications, assessing vital signs, bathing children, or monitoring feeding pumps. Two nurses described particular play activities:

> *So, we play games. We - I take kids in the pool. Or you know, we just, we have fun. We watch movies. You know, I do hair. You know, it's really fun. And I - we laugh a lot, too. You know, people don't think at a hospice you laugh a lot, but you do. You have a lot of fun.*
>
> *But you know, there's almost more of the fun stuff you get to do- you know like taking them outside to play or playing video games or sitting around and talking to them or getting ready for a nap, or holding babies.*

Lastly, some end-of-life facility nurses mentioned that there was an ethereal quality to their work, in addition to required clinical nursing skills. They usually labeled this aspect of care as the "art of nursing", and participants struggled to elaborate on its meaning. A nurse stated that, "*…like I said before, 'this* [working at the end of life facility] *is the art of nursing,' because there's so much that you can't define because so much that goes on is unexplained."* Often, nurses expressed that the art of nursing encompassed developing human connections with children and families, such as two nurses described below:

> *Some nurses have a connection that is evident and they're the ones that get things done with that particular family. And, I always yield to that. Because that is just part of the art of nursing.*
>
> *Yeah, the art of nursing is the part of nursing that doesn't involve skills, clinical skills. It's how you, it's how you treat people and how you handle families, and how you…and it's an art, when it's - it's dying.*

Nurses also stated that the art of nursing involved unquantifiable actions. For example, participants expressed that the art was more the *quality* of the interactions with children and families, rather than how much time they spent with them. These unquantifiable actions usually occurred when a child was actively dying, such holding a child's hand or sitting at the bedside with the family. One participant emphasized that these actions were equally important and critical as the performance of more clinical interventions:

> *Just as you can jump in and do CPR, do a code, push those drugs, do an AED. You've got to be able to… hold on and let it go, while they are letting go of their life. You-- that's nursing, the good, the bad and the ugly. We've got to do it all.*

The participants felt that their end of life facility elicited the art of nursing because of its emphasis on holistic care and establishing relationships with children and their families, evident in a nurse's statement that "*we are to be ourselves with the family being themselves and moving to better grounds."* She viewed the facility as one of the only health settings in which "*true nursing*", or the art of nursing, existed.

The Children's Hospital

The children's hospital is located on three dedicated floors in a university-affiliated tertiary-care hospital. Three pediatrics units were studied within the children's hospital: the hematology/oncology/bone marrow transplant (hem/onc/bmt) unit, the PICU, and the ICN. Each unit has its own unique layout. The hem/onc/bmt unit is located in one wing of the hospital. One enters the unit through one of two sets of brightly colored doors. Patient rooms, a mix of private and shared, are located along the outside walls of two parallel hallways, thus every room has a large window that looks outdoors on the far wall. Closed doors are located at the end of each hallway, which enter into the seven room BMT unit. A large nurses' station is located in the middle of the hallways. The station is occupied by various providers, such as nurses, physicians, medical students, dieticians, physical and occupational therapists, and social workers. A ward clerk sits at one corner of the station. A smaller nurses' station is located in the BMT unit. An enclosed anteroom is located outside each patient room. Doors to the anteroom and patient room are always kept closed because patients are severely immune-compromised. The anteroom contains a sink, cabinets, and counter space. Outside of the BMT unit and down at the end of one hallway, is a palliative care room, called a Comfort Care Room, usually reserved for patients at the end of life and their families. This room differs from the other patient rooms: it contains a small refrigerator, rocking chair, pull-out couch, wood floors, and concealed medical equipment. Nursing assignments vary from caring for two BMT patients to four hematology or oncology patients.

The PICU is accessed through double doors on a separate floor than the hem/onc/bmt unit. At the end of a short hallway, the unit opens up to enclosed patient rooms most of which are located around the unit perimeter. Each room has a wall of windows facing inwards to the unit. Nursing notes are kept on a wooden lectern outside each room. Nurses stay close to the bedside, either inside the room or monitoring right outside the window. Nursing assignments are either one or two patients, depending on patient acuity. Patient rooms provide either a crib or a bed, depending on the patient's age. A cart is stored in each room, containing various medical supplies, such as diapers, wash-clothes, or saline flushes. A monitor screen in each room records patients' heart-rate, blood pressure, oxygen saturation, and respirations. If a child is intubated, a ventilator is positioned on the opposite side of the bed. Each room also has a small sink. During observation, I noted that a patient's wall was covered in photographs, drawings, and cards from class-mates, which a participant remarked can spark conversation and assist in getting to know what the child was like before their medical event:

> *A lot of times, if they're with us for awhile, the parents will bring in pictures and they'll put up pictures either in the bed where the child can see them or on the wall, or that kind of thing. And so that helps a lot, too, to be able to see their face of what they looked like beforehand. Um, sometimes I'll learn just by asking about the pictures.*

Additionally, there is an over-flow unit for patient use when the main PICU space is full. This unit is located outside the double doors and at the end of the main floor's hallway. Typically, patients are assigned to this area when they are in less critical condition, but not ready to transfer to the acute care floor. A palliative care room is also located in this area and families are offered the option of transferring to this room during the child's end-of-life period. This room is intended to offer children and families a quieter, more private, and less hectic environment.

The ICN is located on a separate floor than the PICU and the hem/onc/bmt unit. The ICN is separated into two wings, a large one for premature neonates and a smaller one typically for full-term newborns with medical diagnoses or who require surgery. Each wing is additionally separated into bays which hold up to four isolettes. Depending upon patient acuity, nurses are usually assigned to care for two to three neonates, which are grouped closely together. Therefore, the nurse is constantly within a few feet of each patient. Nurses, who are assigned within the same room, work closely with one another through the shift. One participant remarked that *"it can make or break your day"*, depending on how well the nurses' personalities match. Charts are kept next to each isolette and a monitor screen is placed above. While visiting their baby, parents will usually sit in a rocking chair beside the isolette. Occasionally, a screen is placed around the parent and infant to provide privacy. If a neonate is intubated, the ventilator is usually placed towards the front of the isolette.

The children's hospital has a play-room which offers toys, games, or art supplies for patients and siblings. It also has a school room for school-age patients that is staffed with a full-time teacher. The hem/onc/bmt unit is the only unit in this study in which some patients might be stable enough to leave their rooms and visit the play-room or school room. Severely neutropenic patients and critically-ill children do not leave their rooms. Child-life specialists, the teacher, or volunteers will visit patients' rooms to bring video games, toys, art supplies, books, or school work.

Perceptions of Nursing Roles and Care

Hospital nurses stated that nursing care encompassed a host of different roles, responsibilities, and activities. They often were simultaneously engaged in many aspects of nursing care, such as tending to patient and families' physical and emotional needs, coordinating interventions, prioritizing care, and making and adapting plans. The following oncology nurse summarized:

> *I mean then there are 1,000 things. I mean then there's the whole, the time management things. There's…prioritizing. I mean that's kind of-- you're ready to give chemo and somebody's in pain and some other parent steps out of the room and says, "Hey, where's the socks?" Like putting out fires in a way sometimes.*

Nurses depicted their jobs as primarily task-oriented and completing tasks was a major aspect of their role. Examples of nursing tasks included giving medications, administering chemotherapy, monitoring health status, and coordinating scans. Hospital nurses described a typical shift:

> *I mean there are a lot of tasks. There are too many tasks.*
>
> *So generally speaking, the job is very task-oriented, like you have checklists and you complete these tasks by the end of your shift.*

Participants viewed nursing tasks as necessary to and important for patients' physical well-being and health care. They cared for often very sick patients who required multiple medical interventions, such as intubation, chemotherapy, and close monitoring. Tasks were necessary to ensuring patient safety:

> *…I mean everything from medications, to getting them, doing them correctly, making sure they're in the right one, I mean all that stuff to paperwork to IV pumps. So the mechanics kind of things to me are important because what if you're doing it wrong you know?*

Nurses became more task-oriented when their sense of urgency in the situation increased. During these times, participants' focus turned to meeting patients' critical, physical needs. For example, a PICU nurse became more task-oriented following a code:

> *There's an adrenaline rush, in a bad way and a good way. I mean, you're stressed, definitely. You become very task oriented. Um, I think that night [after a*

> *patient coded] I had a list that was just, "this is what I need to do." I need to sit and cross off this list. Um, you become the ultimate task oriented. You're trying to do critical thinking but it's very difficult.*

Attending to multiple tasks resulted in positive benefits for the patient, such as maintaining safety, meeting urgent physical needs, and restoring health. However, being consumed with tasks sometimes hindered nurses' ability to spend time with patients and families and talk to them, address concerns, answer questions, teach, or provide support. For example, a PICU nurse explained that sometimes she had to tell parents she could not spend a lot of time answering their questions because their child's health needs demanded her attention. The urgency of completing tasks also contributed to hospital nurses' description of the rushed, busy nature of caring for acutely sick patients:

> *Cause you're just running all day long, you're non stop. You're running and you're running…,*
>
> *There are times where it's just go, go, go and nobody stops.*

This constant "running" limited nurses' opportunities to be physically present with patients and families. An oncology nurse stated that she was unable to attend to patients and families' psycho-social needs because, *"number one we're not given time sometimes to do that more than for 30 seconds at a time."* End-of-life facility nurses, who previously worked in hospital settings, also noted the task-oriented nature of their nursing care, in the hospital setting compared to nursing care at the facility:

> *You're not running in there* [the patient's room] *every four hours to do vital signs. You don't have to dip all of their urine. And so you have more time, you know the structure of it. And you're not doing interventions. You have more time to talk.*

Although completing tasks was the major component a typical shift, participants also described other aspects of their work. Hospital nurses emphasized the importance of paying attention to the "bigger picture" and not becoming unilaterally focused on numerous tasks. Some hospital nurses suggested that they were able to do so after their first year of nursing. Once they felt competent with the required clinical skills (e.g. administering medication, performing assessments, or monitoring lines), they were able to focus more on the interpersonal aspects of caring for children and families. When asked about advice she would give a new nurse, an oncology nurse answered:

> *To not walk around with blinders on like, "This is what I have to do, this is what I have to do." But to try to see what else is going on with the bigger picture and prioritize your tasks for later.*

In addition to patient acuity, multiple tasks, and nurses' experience, the physical environment of the work settings contributed to nurses' ability to spend time talking with patients or their families. As previously discussed, the nurses' station at the end-of-life facility became a hub for nurses, staff, children, and families to gather and spend time together while nurses carried out their work. Since nurses in the intensive care settings spent the majority of their time directly at the bedside, the physical environment facilitated nurses talking with families as they cared for the patient. PICU and ICN nurses described establishing relationships with families over time because of the proximity between themselves and parents:

> *I feel like you learn a lot just because the parents are always there, um and there usually is one parent by themselves and they're stuck in a room, and especially with us they can't talk to their child. And so they usually end up talking to us because there's nobody else to talk to (laughs).*

Although, as previously stated, a patient's urgent health needs may interfere with nurses' ability to spend time engaging in conversation with parents or families.

Similarities and Differences among Participants' Perceptions of Roles

Hospital nurses more frequently described their nursing care as completing numerous tasks and the high acuity of patients in the hospital necessitated that nurses attended to their nursing tasks. In contrast, end-of-life facility nurses felt that their patients were less critically-ill, and in turn, they were responsible for fewer tasks. At the facility, patients received fewer medications, less monitoring, and fewer medical interventions, such as CT scans. However, patients still often had demanding needs and nurses stated that their shifts were often busy, especially when a child was actively dying.

> *We have maybe three other kids here who are in various stages of dying, and the families are scared and the families don't know what to do. And the kids have, you know, pain control issues and that's every bit as demanding. As you know, working in a PICU or something like that.*

Nurses in all settings described working within a team-oriented environment, both with their fellow nurses and other providers. They felt that quality pediatric palliative care depended upon a well-established and functioning inter-disciplinary team. Participants stated that working as a team was also essential for optimally caring for patients and families, overcoming barriers, and easing work burdens. A PICU participant expressed pride in how well her unit worked as a team and described how nurses from other units react when they floated there.

> *They'll always say they don't necessarily like the assignments but they like the people, that our unit is very team-oriented. Where, a lot of other ICUs, because you get a lot of detail oriented people, they get-- they are people with blinders on. "This is my assignment." Where, I think it helps that our unit is very team oriented.*

End-of-life facility nurses felt that they were recognized and acknowledged for their role as a nurse on their inter-disciplinary team. A nurse stated that, *"I've definitely feel more confident as a nurse now and especially in the* [facility's] *environment because we're so acknowledged as individuals of the team. My role is appreciated. And so, it's nice."* Both end-of-life facility and hospital nurses deeply valued the support among fellow nurses and nursing assistants, who were available to help with patient cares, listen to families' concerns, and spend time with children. Nurses across settings also worked with volunteers, although they had a more regular presence at the end-of-life facility. One or two volunteers worked each shift at the facility and were often observed playing with children, taking them for walks outside, holding or rocking them, and engaging in art projects. As one nurse noted, "*We couldn't do what we do without the volunteers.*"

Another difference between study sites was that nurses at the end-of-life facility did not have a standard stock of patient supplies. They relied on patients' home-care supply agencies for stocking medical necessities, such as IV pumps, g-tube feeding supplies, medications, and syringes. Hospital nurses, in contrast, had access to essentially unlimited supplies. End-of-life facility nurses felt frustrated that at times they were trying to secure needed supplies through calling the patient's medical supply companies or reconciling problems, which took them away from being with the patients and families or attending to other important issues. Additionally, nurses were responsible for learning the intricacies of a variety of feeding pumps, IV pumps or other medical devices, since they varied from patient to patient.

Nurses across settings expressed deriving significant satisfaction working with seriously-ill children and their families. Many participants demonstrated a strong dedication to their nursing specialty, often stating that they were meant to be a PICU nurse, or a hospice nurse, or an oncology nurse.

> *I always wanted to work in PICU. Even when I was in nursing school, I knew exactly that that's what I wanted to do.*
>
> *I went to school because I wanted to be a hospice nurse.*
>
> *I always knew I wanted to do oncology.*

All hospital participants had continuously worked in their nursing specialty since graduating nursing school. Supporting children and families through death also contributed to nurses' feelings of satisfaction. Participants often stated that it was an honor and privilege to be with a family during such an intimate time. They did not take their role lightly, as one nurse said:

> *Well, I just think that there's just a few things in your life that are sacred. And I just think that those are such intimate, and no matter what your faith or practice is, in just being human, those are such intimate moments of life. That to willingly choose to share that with someone, I think is the compliment of a lifetime.*
>
> *I think that that's the best compliment you can get as a nurse, if they* [the family] *thank you for the way that their child died. There's nothing better than that.*

Management of Patients' Deaths in Each Setting

In addition to the differences among the physical environment and nursing care in each setting, there were also differences in how each setting handled patients' deaths. A striking, contextual difference is that hospital nurses cared for patients who unexpectedly die. Although an uncertainty of when death will happen exists at the end-of-life facility, nurses usually had time to prepare the patient and family for an anticipated death. Unexpected deaths typically occurred when patients were receiving aggressive, curative treatments and nurses felt discouraged because they did not have adequate time to prepare the child or family for a peaceful, painless death.

Other differences centered on how much space children and families have, how much privacy they are given, and how much time they have with their child after death. In the end-of-life facility, children are in spacious, private rooms, or at times in a family suite. The facility can accommodate more visitors than the hospital units. For example, an end-of-life nurse stated that 30-40 visitors were not uncommon near or after a child's death. Although hospital units do not have specific limits on the number of visitors, the physical setting could not accommodate numerous visitors. For increased privacy, families at both settings may or may not choose for nurses to be with them, and nurses emphasized that they respected families' individual choices. An end-of-life facility nurse described honoring families' decisions.

> *Generally at the time that the child is actually dying, some parents want that to be a completely private event. Some parents want you at the bedside constantly. Some parents are happy if you just kinda come and go. They know you're there, but you don't have to be there. And I think it's, maybe because I've been a hospice nurse for so long, I have a certain sensitivity to that, that other people don't have.*

Nurses at each setting followed standard procedures after a child died. Nurses performed post-mortem care of the child's body, which typically involved bathing and dressing the child, changing linens, or removing any lines. End-of-life facility nurses cleansed the body usually by giving a tea-bath, which one participant described:

> *Basically, it's bathing the body afterwards, but instead of soap and water you use tea because soap and water will actually either do nothing or promote decay and breakdown. Whereas, tea will have some preservative effect to the skin…It won't allow it to start decaying and flaking very quickly.*

Nurses at each setting allowed families to decide whether or not to assist with bathing and dressing their deceased child. An end-of-life facility participant explained that frequently she will start the bathing process and parents, who previously elected not to participate, will slowly start to help and end up finishing it.

Some nurses across settings referred to completing a checklist after a child died. The checklist at the end-of-life facility included activities such as performing a physical assessment, contacting relevant staff, bathing and dressing the child, documenting pertinent information, and discarding controlled medications. One nurse expressed that having the checklist distracted her from becoming overly emotional in the situation by keeping her focus on the family, and stated:

> *I have a family to be there for. I can't be there for myself, just yet. I will be. But not yet.*

The end-of-life facility could accommodate a child's deceased body to remain at the house for up to three days, if a family elected. In contrast, the hospital settings did not have the resources to allow families to stay with their child's body for more than a few hours. At the end-of-life facility, a family could choose to stay in the child's room or move their child's body to a dedicated room. This room is located at the end of a long hallway, and can be screened off to allow for more privacy. While in the room, the child's body is kept cold using ice or a cooling blanket to slow the decomposition process. Being in this room enabled the family to have a wake and viewing for themselves and other loved ones, which allowed for extended time to say good-bye to the child. Some participants felt this time benefited the family's grieving process. A participant described a child who transferred to the facility from an outlying PICU for compassionate extubation. She felt that the family's grieving process was immensely helped by having more time with their child after they passed away.

> *Mom was still here, and dad, family members, they stayed for up to three days and that's another part of the beauty of this place is that families can stay here and grieve and this is what we find that you can't do in the unit [PICU]. And I've had a couple other families that I've tried to convince to come here because some families just need that time.*

After a death, nurses continued to attend to the child's body, such as ensuring their eyes were closed and monitored for signs of decomposition, which could be disturbing for families to see. Primarily, however, nurses provided support to and cared for the grieving family. A participant described how she saw her role after a child dies.

> *So what we really need to still care for them because it's-- aside from any personal beliefs in caring for them post-mortem, you're caring for the family. So you still need to treat them with dignity, with respect. You need to keep them* [the child] *clean. Do the best that you can because you know, nature will overcome and rule out. So we do everything we can to keep it-- keep the nature at bay and delay it, so we can allow a family to go through the grieving processes and stuff. And we never rush the fact.*

This participant addressed the notion that families are not rushed to leave the facility. They were allowed to choose how much time that they needed and desired to be with their child. Sometimes, families chose to accompany their child's body to the mortuary. Families also had the choice to return to the facility to conduct their memorial services, attend special events, receive bereavement services, or for informal visits. Nurses stated that often families found comfort in returning to the last place their child was alive.

In contrast to the facility, hospital settings were not equipped to allow families to be with their child's body for long periods of time after the death, due to several challenges. Staffing needs, new patient admissions, space constraints and an inability to properly cool the body are major barriers which limit the time families might have chosen to stay with their child's body. An end-of-life facility participant compared her previous experience of working in a PICU and described the painful consequences after having to abruptly end a family's time to say good-bye. The reasons for this abrupt good-bye were not given.

> *I mean, literally, literally almost had to pry the child out of the mother's arms and she's screaming the whole time. Aunt is screaming. Dad's crying. Very, very traumatic for everybody. Very traumatic. And sad.*

Unlike end-of-life facility nurses, hospital nurses were responsible for transferring the child's body to the hospital morgue, which some participants, including one ICN nurse, found distressing. She stated that:

> *Going to the morgue is always freaky because you know, you like to think that there's a place for your little friend, but sometimes it's just-- they're like all stacked up and then there's no place. And you have the baby at the feet of somebody else. And, you know, you want them to be comfortable, you know, and even though they're dead you still want the little bodies to have some respect and I have to sit you with a strange person who I don't even know who's in a shroud and I have to sit you on their feet because there's no place open there.*

Some nurses stated that families have found it distressing to watch nurses place the child in a body bag, as per hospital policies for taking them to the morgue. Even after years of experience, participants never became accustomed to transporting a child’s body to the morgue. The morgue was located in the hospital’s basement and nurses viewed it as a cold and distant place. Although participants knew intellectually that their patient was no longer living, it still felt unnatural and inhumane to leave a child’s body in drawers or on tables. A PICU nurse recalled her first experience going to the morgue five years ago and how she continued to feel distressed.

> *Actually, that's another thing I remember about that event* [her first patient’s death] *is going down to the morgue for the first time and it just being, it's so cold and removed. Like you just open up drawers and basically in some cases you put them on there and there's potentially another dead infant or something on there. Then it's very, yeah, it's very unexpected, and shocking, and, you know, there are times when I've had to go down there by myself and that was also disturbing. So yeah, I hate the morgue.*

Upon returning from the morgue, nurses were often not given adequate time to recover from the emotionally and physically taxing experience of their patient’s death. Instead, nurses described being expected to continue caring for their other patients, or sometimes responsible for admitting a new patient. However, some participants stated that if staffing needs are met, nurses were allowed to go home after their patient dies.

Hospital units varied on how much space and privacy were given to families during a child’s end of life. The open lay-out of the ICN was a challenge for giving families privacy during such a sensitive time. To provide privacy, a nurse described placing a screen around a deceased infant's bedside, yet families were still exposed to the unit's disrupting noise and activities.

> *So we'll have a dying patient in a room with four other babies, and we'll have, you know, they're not able to be moved to the palliative care room, and we'll have a screen around that bedside, and we'll having family members wailing right there, and that doesn't feel good. That we don't have the physical space to allow them to grieve in private. So that is a bit of a barrier. And just the noise that goes on in there, and then people come through and they're talking about, you know, what they did last night, and there's no privacy. So, that is one of the biggest challenges.*

As previously mentioned, palliative care rooms were located in the ICN, the PICU and on the hem/onc/BMT floor, and allowed for more privacy. Families were always given a choice to move into palliative care rooms, and some families elected to stay in regular rooms. They were also intended to be less medicalized, and more home-like, than a typical patient room, thereby creating a more comfortable environment for children and families. At times, hospital logistics prevented patients from transferring into the dedicated palliative care room, such as if they were already occupied with another patient. Patients were admitted or transferred to these rooms if they had transitioned to palliative care status. Therefore, patients who die unexpectedly while receiving curative therapies were rarely in a palliative care room.

In contrast to hospital nurses, end-of-life facility nurses frequently described that death in their setting was handled naturally and humanely. One participant stated that, "*this is as good as death gets*." Many factors contributed to this assertion. Children were often free from invasive medical interventions and had access to a high-level of pain and symptom management support. Families were given privacy and allowed as much time as they needed with their child after they died. Also, families could opt to accompany their child's body to the funeral home, rather than nurses transporting a child in a body bag to the hospital morgue. Children's deaths in the hospital were not handled in this same way, which caused some participants distress. End-of-life facility nurses who previously worked in hospital units usually compared their experiences in each institution. They all agreed that they felt much more at peace with their patients' deaths at the facility than they did working in the hospital.

Institutional Support

Institutional support available to nurses is an additional aspect to how settings managed patient deaths. Formal and informal support can reveal a unit's implicit or unspoken values about nurses' expectations in caring for dying children. Hospital nurses stated that occasionally there were meetings to discuss particular patients and the circumstances surrounding their death. Some participants did not find these meetings useful for expressing or processing their experiences after caring for a patient who died. Some nurses felt that their patient was not discussed at the meeting, or its focus was on more clinical end-of-life issues (e.g. pain management), rather than the event's emotional impact on staff. For one oncology nurse, an hour long palliative care meeting was incorporated into their monthly nursing staff meetings. Other providers, such as physicians and social workers, attended the palliative care portion of the staff meeting. She felt that the meetings often ignored the nurse's experience and stated that:

> *At the supposed RN staff meeting, the palliative care part, the nurses never talked. But it's always the docs and the social workers and maybe the manager. And it always struck me as weird, like, well those aren't the people that spend 12 hours a day at the bedside.*

In comparison, the end-of-life facility convened a meeting on the day or the following day that a child died. These meetings were usually facilitated by the spiritual care coordinator and open to all staff. A participant found these meetings extremely helpful because she was able to share her emotions and concerns in a non-judgmental and supportive space, in which she called a "*safe zone*".

Participants across all settings described forming an emotional network with their colleagues. Some nurses found that their primary source of support was their relationships with trusted colleagues. Nurses dealt with work-related emotions and stress by sharing it with other nurses. Participants frequently emphasized that their colleagues, rather than friends or spouses, could more easily understand because they had similar experiences. It was important to nurses that their colleagues could recognize that their work could be challenging. For example, an ICN nurse explained that she tries to check in with other nurses after the death of an infant. She stated that, "*But I definitely find now that for other staff I try and reach out to them sooner and say, "Oh, how did it go? How do you feel about it?" And since then I've noticed that I've had other nurses also in turn offer that same thing to me.*" This reciprocity represents an implicit understanding that it was acceptable to have emotional reactions to their work experiences.

Nurses' Description of Socio-cultural Views of Death and Dying

In addition to the work setting influencing nurses' practice and their care to seriously-ill children and their families, they also worked within a larger socio-cultural context, which impacted how they delivered care. Participants spoke of socio-cultural beliefs, discourses, and misconceptions regarding issues of death, dying, and caring for children at the end of life. Specifically, they discussed society's fear of death, avoidance talking about death, the taboo of dying children, and frequently confronting misconceptions about their job.

Participants were acutely aware of society's fear and avoidance of death, especially regarding children. Participants across settings described other people's reaction when they described their job, which was often quickly followed by an abrupt change in topic. When nurses stated that they cared for sick, sometimes dying children, people frequently responded with apprehension and questioned how participants could do that kind of work. Nurses found it difficult to fully explain the breadth of their work, that sometimes it was sad and challenging, but also rewarding and enjoyable.

> *I tell them I'm a PICU nurse. And then I try desperately to avoid the question of, "Oh, that must be so hard," because you're kind of, like, "well, it is and it isn't and you really don't understand at all."*
>
> *In the beginning, I kind of ignored those comments. But now, I've gotten comfortable with them and I said, "you know what though? It's the best job in the world."*

End-of-life facility nurses often used the term hospice, rather than palliative care, to describe where they worked to other people because the term was more easily understood. However, using the word hospice raised more apprehension because it conjured misconceptions within the hospice discourse. For example, a participant tried to overcome the myth that hospice is associated with euthanasia. She stated that, "*A lot of people think that hospice is, people help people die. We help them die comfortably."* Another participant responded that people frequently view hospice as *"giving up, like it's over and that's all you can do, and there nothing good left, it's all dreary*." She continued to elaborate on people's inaccurate perception of what a pediatric hospice might look like.

> *It paints the picture of like a white place, you know, with white walls and little kids with bald heads (laughs). And misery.*

Whether participants mentioned hospice or palliative care in association with their work, nurses were acutely aware that, in general, seriously-ill children and death were taboo subjects in American culture. They remarked that the topic could easily trigger undesired emotions and that people want to deny the possibility that children die. A participant described telling others about working at the end-of-life facility.

> *Nobody wants to hear about sick kids. I had one friend who, um, used to refer to me as "the grim reaper" until I told him to "stop!" (laughs). That's most people's response. Unless they've had an experience like that in their own life. They don't talk about it. You know, children don't get sick and they don't die. Much less 50 year old women and 80 year old people. They don't want to talk about that either, but it's really taboo for kids, I think.*

Most participants found that other people actively avoided talking about death. They sensed a discomfort in others when the topic arose, and even noted it when talking with other medical professionals. When mentioning that their job entailed providing palliative care, people would often stop the conversation or change the subject.

> *I used to tell people "oh, I work at a pediatric hospice", and I'd be all happy about it. People were like, "that's really depressing." (laughs) And like sort of end that conversation and people would get all depressed. And I'd be like, "No, no, it's really great."*

> *I just say I work with sick babies…you know, I don't go into a whole lot of detail unless people ask me, because some people find it upsetting, you know, to talk about that.*

Since nurses experienced first-hand the taboo nature of talking about pediatric death, they could easily empathize with how families are frequently isolated in their grief. Nurses noted that families often have few people that they can talk with about their children due to others' distress and discomfort. Sometimes strangers shared their own experiences of losing an infant or child after nurses mentioned talked about their job.

> *People have stories and they want to tell them but most people don't want to hear things about your dead baby. I have strangers telling me about their dead babies.*

> *It's really remarkable stuff and it's just, you know, they have so many stories that don't get told, that don't get honored.*

Participants were aware that parents are prevented from talking about losing their child because society is generally uncomfortable with the issue of death. Thus, nurses became a significant confidante to families both in and out of their work setting. In doing so, participants tended to derive increased work satisfaction from knowing that they could support children and their families and ease their feelings of isolation.

Participants hypothesized that part of the societal discomfort is compounded by the general avoidance of discussing death. One participant surmised that death was no longer seen as a natural part of life. People avoided talking about the inevitability death and preferred to ignore the issue.

> *I mean I think in general, in our society there's not much consciousness around that you're going to die these days, maybe. In the old days, you know on grandpa's farm it's more natural to kind of have this* [awareness of death].

This participant was also pointing to changes in how death is handled in society. Historically, "on grandpa's farm", people were routinely exposed to death and it occurred more often in families' homes. Deaths now primarily happen in hospitals, which are detached from the normal, natural routines of home life. The rapid advancements of medical technologies have also altered the previously natural dying process. Patients can remain alive for an indeterminable amount of time, especially in a PICU setting where patients have access to life-sustaining therapies.

> *Usually, it's that we've coded a patient and "saved" (uses finger quotes) them, and then end up telling the family, like, "we've saved them and the fact that they're on six inotropes, intubated, you know, and they're probably going to do it again and we can't guarantee that we're going to get them back again and, if we do, we can't guarantee what state it will be in."*

This participant stated that families had a difficult time accepting the inevitably of their child's death when medical interventions created an illusion of life. A few participants described patients who were kept on life-sustaining treatments in order to give their families time to recognize their child's prognosis.

Nurses' Definitions of Hospice, End-of-life and Palliative Care

The majority of this chapter focused on the external context in which nurses cared for seriously-ill children and their families. However, nurses have an internal, personal context which additionally influenced their practice. The next section will describe how participants defined and regarded hospice, end-of-life, and palliative care in their work setting. A description of nurses' world-views, previous experiences, and views on death and dying will follow. Lastly, how nurses' discussion of types of boundaries will be described.

Participants differed in their definitions of palliative care and often overlapped their definitions with the terms end-of-life or hospice care. Across all settings, participants commonly felt that palliative care involved keeping children comfortable, managing pain or other distressing symptoms, maintaining quality of life, and preparing families for their child's death. End-of-life facility nurses, more so than hospital nurses, generally used hospice and palliative care terms interchangeably. Half of the end-of-life facility participants (n=5) had previously worked in pediatric or adult hospice care settings, and two assertively identified themselves as hospice nurses. One participant, however, distinguished between hospice and palliative care and felt that "*palliative care is the best term for pediatrics.*" She continued:

> *Essentially for me, hospice is a benefit, is an insurance coverage and a term that's used and isn't received very well in children and families. So, essentially*

> *it’s a family deciding to forego any curative treatment and that they know that their child is not going to live six months or more. But with what I’ve learned with children is that that never happens, families aren’t willing, it’s rare to meet a family who truly goes on to the hospice benefit.*

Participants agreed that discussions between providers and families about palliative care must acknowledge the potential a child may not survive their illness. Although most patients in the hospital are at some risk for dying, participants did not see palliative care discussions occurring early on the illness trajectory. Rather, they viewed patients shifting to palliative care status after curative, aggressive treatments were deemed futile. When this shift occurred, curative care usually ceased and patients are labeled as “palliative” patients. Two nurses, from the PICU and the hem/onc unit, described how discussions about the possibility for death routinely happened near the end stage of an illness.

> *Generally the culture on the floor where I work, the kids that are palliative are actively dying or we have reached a certain point where we say they will die of their disease. And from that point on, sometimes they sign a DNR, sometimes they don't, but at some point, it becomes clear that our goal is not to cure.*
>
> *If you’re actually saying is death on the table, everybody knows about it, whether it’s a month out or a year out, um I don’t think that happens as often until the very end so that acceptance of or the transition from cure to, I mean fighting to end of life comfort, I think that doesn’t happen usually until the end so much.*

As these nurses testified, palliative care and curative care were usually not seen as coexisting together, and were often mutually exclusive from one another in practice. As many hospital nurses described, palliative care usually occurred when all curative therapies had been exhausted and death was inevitable. Thus, the possibility of a death is not typically discussed until the end of an illness’ trajectory and nearing the end of a child’s life. This trend is partially attributed to the structure of the unit, for example the intensive care settings are more curative focused because they are trying to restore children’s health during a medical crisis. Patients transitioned to a palliative focus of care when their chances for survival were determined to be low. Because of the strong focus on curative care in the PICU, intensive care nurses described a shift to palliative care typically occurring in the last day of the child’s life.

> *In our case, usually right up until 12 to 24 hours before the person dies, we're still trying to be curative. And then there's definitely a shift that's made but it's typically in the instance of we have done absolutely everything we can and there's nothing more we can do.*

Additionally, this participant regarded the shift in care when death was quickly approaching as more end-of-life care than palliative care, as did other hospital nurses. The nature of each care (end-of-life care and palliative care) required nurses to prepare and support families, plan for a comfortable death, and address patients’ pain and symptom management. When asked to distinguish between end-of-life and palliative care, an ICN nurse viewed them similarly:

> *I'm sure there are just definitions for palliative versus end of life, but, you know, with a baby, it seems so-- all on some level to be the same. Make sure they're well medicated and they feel no pain, they're comfortable and that they get what they get and need.*

Participants commonly agreed that the primary goals for palliative care included planning for the death. When patients transitioned to palliative care status, nurses felt they had more time to talk with the family about what to expect, take memorializing hand and foot prints, and provide emotional support to families. Other actions that nurses described as planning for a death were talking with families about their preferences, supporting their decisions, and discussing the child’s expected physical changes. An end-of-life facility nurse stated that much of her job is, “*…making memories for these families. Or helping them make their own memories.*” Having adequate time to prepare families for a death was comforting to nurses. However, if palliative care was not discussed with families or arose very late in the illness course, then nurses felt troubled that families did not receive optimal grief and bereavement support or that patients' quality of life suffered from the ongoing futile life-sustaining interventions. They stated that often providers' and families' reluctance to discuss important death and dying issues prevented nurses from actively preparing families and patients for a child's anticipated death. Delays or avoidance of talking about death arose because providers lacked a level of comfort about discussing death. Nurses felt that delays in talking about palliative care to families at times occurred because other providers, namely physicians, were fixated on curative care and hesitant to address that children may not survive their illness, as the following ICN stated:

> *It always depends on the physician as well. Some doctors have a real hard time letting go. And we're going to try one more thing and one more thing and one more thing.*

Although nurses were a constant presence at the bedside, they stated that they were not in a position to bring up these issues with families.

Description of Nurses' World-views, Values, and Past Experiences

This internal context also includes nurses' worldview, their values, their degree of comfort with death, and their past, personal experiences with death. Their views of death usually conflicted with the larger socio-cultural views and beliefs that were discussed previously. Most participants acknowledged that death is a natural part of life. One participant stated that "*part of it was just acceptance, that that's part of life and these things happened*" and identified that this view helped her manage work-related emotions. An acceptance of death did not, however, diminish feelings of sadness. Rather, it afforded nurses an openness in talking about death and sharing the experience with patients and their families, which in turn helped them cope with the sadness.

Nurses' intimate and ongoing proximity to pediatric death also brought them a sense of appreciation for their own and others' life and health. One participant described that she returns home from work and hugs her children. She stated that her work with dying children placed normal childhood illnesses or accidents in perspective. For example, below she described her reaction to her son's broken leg in relation to the knowledge that he was alive and otherwise healthy.

> *I'm like, "Oh you're so healthy for me!" So what you have a broken leg, you know? It's gonna heal. And you're gonna be fine.*

Participants discussed valuing life differently than from before they began working in their particular work setting. After working in pediatric palliative care settings, nurses felt inspired by how children and families faced challenges. Participants found that they took fewer things for granted in their own life and valued more deeply their relationship to loved ones. An end-of-life facility nurse described feeling inspired by one little boy.

> *He was always ready for new things. Just like a four year old would be. And so it was kind inspirational. You know, when you get up in the morning and like me, I'm (states age) and sometimes I have a sore elbow or something. I'm like, "Oh I don't want to do anything." And then you look at these kids who are just faced with these huge conditions that are going to take away their lives. But yet, they meet life every day with a sense of joy. It's really amazing.*

Similarly, an oncology nurse relayed an important lesson she has learned from her work, which carried over into her own life, "*…to be thankful…just for everything, for every day that you're healthy.*"

Nurses also entered situations carrying their own personal, past experiences with illness or death. These experiences shaped their role in supporting children and their families, respecting family choices, and acknowledging death. Some participants discussed dealing with deaths of their own family members and how it affected their work. One participant lost a parent at a young age and expressed that it was never talked about. For her, it was beneficial and therapeutic to work at the end-of-life facility where the topic of death is openly discussed. After struggling with making end-of-life decisions for her adult brother, another participant felt that she could more deeply empathize with families' anguish in ceasing curative treatment for their child.

> *You always second-guess yourself. Did I make the right decision? I know intellectually I did because he would not have recovered. He would not have been the same person, but every now and then, you know, kind of like, you know, and I'm sure that this is what parents go through. Intellectually you know you have to make the decision what you should do, but it's the heart that grabs you that says "this isn't right, I can't do this."*

Nurses' Description about Types of Boundaries

During interviews, all participants spontaneously mentioned boundaries, limits, and lines in their work. They described multiple types of boundaries, some of which they controlled and some that were defined by others, such as administrators, professional codes of conduct, patients, or families. At times, nurses found it challenging to simultaneously manage these various boundaries. The process of how nurses negotiated boundaries will be discussed in Chapter Five. The following section will present and describe an overview of the types of boundaries that nurses discussed.

When nurses talked about personal boundaries, they described ways that they protected themselves from the emotional effects of their job by maintaining a distance between themselves, patients and families. Some participants also protected themselves through keeping a clear separation between their personal life and their work. An end-of-life facility nurse characterized personal boundaries as how much she "*exposed of* *herself*'. Other nurses concurred that personal boundaries were defined by how much they "*opened up*" to families and shared personal information with patients or families. Personal boundaries served as a buffer against becoming overwhelmed by work-related emotion and also to maintain the focus of care on the patients and families, not themselves. A PICU nurse stated that, "*The families, no matter how close to them I am, it was always mainly about them.*"

Participants commonly stated that their first year of nursing shaped how they established personal boundaries with patients and their families. Many participants were overwhelmed and confused about boundaries at the beginning of their career, such as a PICU nurse who stated that, "*as a new nurse it was very, very hard distinguishing boundaries.*" Defining and negotiating boundaries was an evolving process and nurses learned and relearned the process through experience. Many participants could acutely remember and describe their first experience caring for a patient who died. One nurse said that, "*I remember the very first patient I ever had die. The exact date, the time, just everything about it.*" Like this nurse, other participants recalled specific details of the death: how they felt, how they were treated by colleagues and managers, how they coped, and especially how it affected their nursing care and boundaries. A participant described her first experience caring for a patient who died and recalled staying over her shift to be with the dying child. She questioned her decision to stay over her shift, and stated that, "*You don't know as much about boundaries (laughs), which I've learned a little bit more about.*" Other participants had similar experiences in their first year of nursing where stated that they became "*too close*" or "*too attached*" to a particular child and their family. When the child died, they realized they had formed a deep personal connection and experienced an undesired emotional response to the child's death. In future interactions, they strove to maintain distance between themselves and patients in order to buffer their emotional response when a child died and prevent becoming overwhelmed by the death. For example, an end-of-life facility nurse redefined her personal boundaries after becoming exceptionally close to a dying infant and her family. She questioned the extent of the attachment when the overwhelming sadness affected her work and personal life. She described in the following statement how she viewed her personal boundaries as a balance between supporting patients and their families and protecting herself:

> *I can still be there for them and help them grieve. But I don't necessarily buy into personally. I think that is something that is an art. I think it's taken me this long to really figure out how I can protect myself and being empathetic, but not suffer because of it. Because there was a period of time where I didn't really know that fine dance of how to do that well.*

In addition to personal boundaries, nurses also described professional boundaries. When nurses talked about these boundaries, they discussed professional codes of conduct, such as maintaining patient safety, treating patients and families fairly, and behaving ethically. Participants also frequently discussed these boundaries in terms of how attached they became to patients or families and for these nurses, in that professionalism meant maintaining a level of detachment. Often, nurses used the terms "appropriate" or "inappropriate" when referring to professional boundaries, such as the following end-of-life facility nurse.

> *You always are afraid when you say you get close to a patient that you're like going beyond the appropriate boundaries.*

It is unclear what nurses saw as the source of their perceptions of appropriate action. Nursing school, professional discourse, administrative guidelines, or personal opinions may have all influenced how they determined appropriateness. Most participants across all settings, however, stated that they were not aware of clear administrative rules about professional behavior. An oncology nurse refers to nursing literature as a source for determining appropriate nursing care:

> *There's one kid that was dying that I came in and visited on a day off. So, I've read articles about boundaries, yeah, I should never come and do that kind of stuff or you should never get involved with their family outside of the hospital. Something like that would definitely be crossing your professional boundaries.*

Nurses also confronted boundaries set by others, such as administration, patients, and families. Although most nurses were unaware of their unit's rules about boundaries, some stated particular violations. For example, an end-of-life facility nurse felt that often rules were discovered once they were broken. In one case, staff members were warned not to assist families outside of the facility, such as finding a job or housing for a family member. Participants also assessed and sought to understand patients' and families' boundaries on an ongoing and individualistic basis, such this ICN nurse:

> *I feel like you kind of have to feel out each family. We have so many cultures that come through, that each family kind of lets you know how comfortable they are with touch and medical staff. So I think that you have to kind of feel each situation out and see what's appropriate for that family, even though maybe I'm more touchy, I have to recognize maybe this person isn't as touchy and it's okay to have more boundaries and let them have their personal space.*

Nurses were continually relearning and redefining their own and others' boundaries through training, experience, professional discourse, emotions, and relationships with patients and families. Boundaries were also specific to the vast array of patient and family situations and were altered in response to ongoing interactions and experiences. Despite setting, participants regulated and organized their own boundaries, rather than depending on external rules or guidelines for setting boundaries. That is, personal and professional boundaries emanated outward from nurses, rather than imposed onto nurses from external sources. Professional discourses and explicit codes of conduct did influence how nurses constructed boundaries. However, nurses retained primary control in establishing, constructing, and defining their own boundaries and how they carried it out into their practice.

Nurses not only dealt with multiple types of boundaries, but also with the infinite sites of where boundaries intersected. Personal and professional boundaries were presented in this chapter as though they are clearly and simply delineated. However, they have numerous points of overlap and intersection, which posed challenges to nurses in their care of seriously ill children and their families. The complicated process of how nurses described maintaining and regulating boundaries will be discussed in the following chapter.

CHAPTER FIVE: MAINTAINING INTEGRITY: HOW NURSES NAVIGATE BOUNDARIES

Chapter Four presented and discussed the external and internal contexts which shaped how nurses navigated boundaries in their work caring for seriously-ill children and their families. This chapter will specifically describe the identified process of how nurses across settings managed their personal and professional boundaries when caring for seriously ill children and their families. In navigating boundaries, participants strove to *maintain integrity* by integrating two competing aspects of their nursing role, which were *behaving professionally* and *connecting personally*. Although nurses viewed their role as comprised of multiple important parts, these two aspects were primarily relevant for the process of navigating boundaries. This chapter will elaborate on the process of maintaining integrity, including when integrity was threatened, compromised, and restored (see Appendix G for diagram depicting this process).

Maintaining Integrity

In their work with seriously-ill children and their families, all participants had numerous experiences of providing end-of-life and palliative care to patients and their families. Working with dying children evoked various emotions, which extended outside the work setting. The nature of their work required participants to actively navigate personal and professional boundaries in order to deliver competent and compassionate care. Although there were identified differences across settings, all participants shared a similar process for navigating boundaries through maintaining integrity in their nursing role. Integrity refers to nurses' feeling a sense of wholeness and being true to self when they were able to successfully navigate boundaries. The Oxford English Dictionary (2007) defined integrity as, "*the condition of having no part or element taken away or wanting; undivided or unbroken state; material wholeness, completeness, entirety,*" in addition to, *"soundness of moral principle; the character of uncorrupted virtue, especially in relation to truth and fair dealing; uprightness, honesty, sincerity."*

Navigating boundaries can be understood as analogous to navigating a row-boat through the terrain of a river. Like nursing, river navigation is both an art and a science. Nurses steer the boat by maneuvering two oars and must navigate through occasional turbulent waters, fluctuating water flow, and hazardous conditions. Nurses paddle to stay the course between the banks of the river, seen as their personal and professional boundaries. The altering shoreline affects the river's width and thus, at times nurses are challenged to navigate narrow channels. They also encounter other challenges down the river, such as fallen trees, hidden rocks beneath the surface, or islands, which require skillful maneuvering. All the while, nurses aim to run the river without injury or accident to themselves or others.

Nurses do not row in a straight line between the banks of the river, since they are pulled towards one bank or the other depending on the river's conditions, but they strive to stay in the deepest waters between the river banks in order to ensure the integrity of their boat and of themselves. Nurses actively steer by maneuvering two oars, which are akin to the two dimensions of maintaining integrity, *behaving professionally* and *connecting personally*. Both oars are necessary for successful navigation. In order to maintain professionalism, nurses kept a separation from patients and families. Yet, nurses simultaneously felt that their role required connecting personally with patients and families. In the process of striving to both distance from and engage with patients and families, nurses experienced tension, similar to the tension of a rower when pulling the oars in opposite directions. Yet, when the oars are stroked together, the rower can steer the boat straight. At times, however, the rower may depend on one oar to steer the boat towards one side of the river; so it was with the nurses.

Rivers present numerous conditions that require skillful maneuvering to avoid problems, and similarly, nurses encountered various situations which *threatened integrity*. In these situations, nurses more acutely felt the tension between behaving professionally and connecting personally and sought to mitigate this tension. This phenomenon will be described in detail later.

When nurses were unable to *mitigate the tension*, they experienced *compromised integrity*. Consistent with the metaphor, these times were akin to injuries, accidents, collisions, or getting lost while navigating a river. The boat provides a protective layer between a rower and the elements. The body of the boat is fragile, yet sturdy; it is light enough to float through the water, but must also withstand the river's elements. An intact boat allows a rower to move through the water and protects her from harm. When a nurse's boat was threatened - filling with water, sinking, or become stuck in shallow water - her rowing was compromised. During such periods of compromised integrity, emotional and behavioral indicators alerted the nurses to the problem and she aimed to *restore integrity* through strategies that *focused on self*, such as taking an extended break from work. These breaks were comparable to a rower landing the boat near shore for a rest. When integrity was restored, nurses returned to their work setting with a renewed sense of wholeness. Their boats were patched and repaired and once again they could row down the river. With experience, nurses learned strategies to better navigate boundaries and became more skillful as they learned to “read the river.”

Behaving Professionally

Nurses described *behaving professionally* as keeping an emotional separation from patients and families, which meant that nurses maintained professional boundaries and limited the extent of their personal involvement in their interaction with patients and families. Participants discussed reasons for their separation; for example, they distanced themselves to remain loyal to professional codes of conduct (e.g. not favoring particular patients or families), to focus their care on patients’ and families’ needs rather than on their own emotional needs, or to protect themselves in order to prevent developing overwhelming emotions in response to patients’ deaths. Nurses also associated expression of emotion with behaving professionally. They often questioned their professionalism when recounting situations where they had demonstrated excessive emotions in front of patients or families. For example, an end-of-life facility nurse became angry with a teenage patient’s mother when she repeatedly broke promises to her child about visiting. During an encounter, this nurse became visibly angry with the mother and expressed her disappointment for the parent’s behavior. After recalling this experience, the nurse stated she regretted the way she confronted the mother because she did not behave professionally. She stated, “*I was not speaking out of a professional response at that time at all. It was very personal.*” Participants also questioned their professionalism in situations where they exhibited excessive crying or sadness in front of a family.

As described in Chapter Four, nurses often used the terms "appropriate" or "inappropriate" when describing professional behavior. Inappropriate behaviors were often labeled as "crossing the line" and frequently these actions occurred outside of the work setting, such as visiting patients and families during time off, socializing with them, helping families find housing, or buying presents for particular children. These actions indicated a unique closeness to patients and their families and establishment of a personal connection. When asked to describe an example of crossing the line or inappropriate behavior, an end-of-life nurse replied:

> *I am tempted sometimes, I wish I could take one of the kids with me over to my family's house and hang out with my nieces and nephews like they're a part of my family. That would be crossing boundaries to me.*

Participants' professional boundaries were challenged during instances when families invited them to significant occasions, such as birthday parties or a boy-scout pinning. Nurses considered attending these events as crossing the line. Although nurses knew these events were important to families, they struggled with keeping a separation. How nurses made decisions to attend or not depended on the individual and their particular relationship to families. One participant recounted the complexity of deciding to attend a patient's birthday party in light of maintaining professional boundaries:

> *And I was really close with the parents, and that I always remembered struggling with* [boundaries] *because they want to make you part of their family, and so that's difficult when they invite you, for instance, to a birthday party for her and I find that it's hard to say no to. And I would always talk about it with the social worker I worked with because she's always so good at boundaries. And I would go to a couple of them but I would feel, cause on one hand you feel, well, this could be her last* [birthday] *and you want to enjoy it with them and, you know, they* [the family] *really want you to be there. And then on the other hand, you're not going to be there forever, and so it's, it's very difficult.*

Nurses also abided by professional boundaries in order to maintain fairness and justice to all patients and their families. Favoring one family over another frequently led to unprofessional consequences where patients or families perceived that they received sub-optimal care. Nurses unanimously agreed that special treatment was always noticed by other families and recounted situations where patients or families questioned why another family received a gift or visit that they did not, as a PICU nurse described:

> *Everyone in the unit knows if nurses really like one patient or they don't, you know, they don't do that extra special care with another patient. And families talk. They know who's getting presents and who's getting specialized treatment versus everyone else.*

When asked how she avoids giving preferential treatment to one family over another, she emphasized that she remained fair and consistent with every patient and their family.

> *Absolutely no presents and then I just always say that I'm fair. Like, anything that I'm saying to a family or doing for the family I would do to any patient. I keep it very consistent so that no one ever does feel like I haven't treated them as well as the next patient - I've done my best job with their child that day.*

Connecting Personally

Although nurses stressed that behaving professionally meant keeping a separation, they also emphasized that *connecting personally* with patients and their families was an important aspect of their role and of providing quality nursing care. *Connecting personally* reflected participants' compassion, a core value of nursing, and required engaging with patients and families. For participants, *connecting personally* meant providing emotional support, feeling empathy, becoming attached to particular families, or sharing commonalities with patients or their families. Connections frequently deepened through nurses' admiration for how patients and families coped with terminal illness or overcame tremendous challenges. Nurses formed connections with families through a period of getting to know them, often during long hospitalizations. In Chapter Four, it was described how nurses became close with patients or families after spending long periods of time being with them and talking. Some participants knew patients and their families over many years, especially children with chronic illnesses who had repeated hospital admissions. For example, when a chronically-ill teenager was admitted to the end-of-life facility, one participant described having known him and his family from when she worked at the local children's hospital:

> *I knew everything about that kid. You know, just everything about him. I knew like, what his parent's names were, how long they've been married. How long they've been divorced. I – I knew all about them.*

An integral part of connecting personally for nurses was relating their own personal experiences to patients and families' situations. Connections developed when nurses identified with a family member or patient, either due to similar ages to their own children, their role as a parent, or relationships to their own parents. An oncology nurse described becoming tearful when caring for newly diagnosed leukemic patient the same age of her own child; "*…but it's true what they say, that if they're at your kids' age, it could be your kid.*" Sharing commonalities led nurses to identify more with families, which often caused nurses to feel more emotional. An end-of-life nurse recalled crying excessively during her first few months of work. Although her grief did not stem from a singular cause, she stated that it was partly affected by thinking of her own children dying:

> *I knew that I was grieving by crying by association. That if it had been one of my kids, or if it – there's a lot of overlap and intermingle. There's nothing that's black and white. I knew that I was feeling empathy for the parents and the family. I knew I was feeling how I would feel if my children died.*

In terms of connecting personally, some participants described attaching to a particular child or family. They described attachments differently from ordinary connections, in that they felt personally invested in patients' and families' welfare. For example, nurses thought about families on their days off, wanted to stay beyond their shifts to care for them, or experienced profound sadness and grief when a child died. An end-of-life facility nurse recounted feeling tremendous grief following a toddler's death after she became particularly attached to the patient and her family:

> *Getting attached to her, getting attached to them, and perhaps personalizing the situation. There were a lot of things that triggered, yeah, those feelings. And so, it was one of those things that there was a lot in common and it didn't take much to go from A to B. You know?*

As this participant and others described, complementary personalities or shared commonalities contributed to feeling attached. Attachments often indicated to nurses that they had overstepped personal boundaries because of how they were emotionally affected when the child's health worsened or if they died. Thus, in subsequent patient and family interactions, these nurses strove to prevent forming attachments as a self-protection strategy.

Threatened Integrity

In providing nursing care, participants sought to simultaneously behave professionally and connect personally with patients and families. Nurses felt that they maintained integrity when they were able to successfully balance both aspects. However, these two aspects have competing and conflicting goals, since behaving professionally meant keeping a separation and connecting personally meant engaging with patients and families. Tension inevitably occurred and nurses strove to mitigate this tension. *Mitigating the tension* occurred when participants repeatedly encountered situations where integrity was threatened. The following section will present and describe common situations where nurses were challenged to maintain integrity.

Division between Work and Personal Time

As previously described, nurses struggled with maintaining professional boundaries when they were asked to attend patients' special events outside of the work setting. Nurses may have connected personally with the family, but also wanted to uphold professionalism by not attending these events on their personal time. At the heart of nurses' struggle was the desire to separate personal and work time. Participants used their personal time to attend special events outside of work, including funerals and memorials. In all study settings, some participants kept a strict division between their personal and professional lives through clearly separating between work and personal time. Their goals was to behave professionally, but also to protect themselves from experiencing overwhelming emotions associated with caring for seriously ill children. Nurses described separating their work and personal lives:

> *I do try to keep that – maintain that professional separation at all times with anyone I work with. You know, like the old adage, "Family's family, business is business," and I really try to adhere to that to some level.*
>
> *Like I said, for me, it needs to be separate. I couldn't do what I do if it was personal for me. Like I took her* [patient] *death hard, but I don't think ever as hard as I know other people have taken deaths and it's because I never let them in fully. Because I know that, if I did, I wouldn't be able to do it.*

Separating was also necessary to cope with the stress of working in their particular units which, in turn enabled them to continue behaving professionally.

Some participants who used the strategy of keeping a strict division between their work and personal lives through clearly delineating work and personal time, rarely visited patients or families on days off, called the unit for updates, or stayed in contact with families after they were discharged or when their child died. Other examples of staying in contact included sending holiday cards, exchanging emails or phone calls, or visiting families at their home. These nurses viewed these behaviors as crossing professional boundaries, since their role was to care for the family and child while in the hospital or end-of-life facility and that their relationship ended when the family went home, as one nurse stated:

> *…but I don't like really stay in contact, no. You know, I don't like feel like it's a necessary thing. I know, I mean it's just part of a boundary thing I think. You know, it's like you keep a little line between you and work, you know?*

In contrast, other nurses did engage in these activities. For example, one end-of-life facility nurse stated that it was nearly impossible for her compartmentalize her life into work and personal segments. For her, these segments blended together for the most part and she did not struggle with trying to keep them separated. Some nurses perceived it as a continuation of their professional role and not a violation of professional boundaries. Oftentimes, they became closely connected to particular families and felt a need to continue contact in order to show their support. These nurses recognized and acknowledged important dates, such as the child's birthday or day of death, and sent cards to the family. Emotional risks were associated with continued family contact and some participants spoke of their limits. These limits reflected the edges of nurses' personal boundaries, such as the end-of-life facility nurse, who felt overwhelmed by staying in contact with more and more families:

> *I keep in contact with them, and I've kept in contact sometimes with patient's families for a short period of time afterwards* [the child's death]. *And then, I just kind of like I can't do it anymore. It's too exhausting, there's too many.*

The decision of attending patients’ funerals was another point of contestation for most participants and reflected the tension they experienced in balancing behaving professionally and connecting personally. It also indicated nurses’ distinguishing between their work and personal lives. An ICN nurse acknowledged that attending funerals was important and significant for families, since nurses were often among the few significant people who knew the baby during its brief life. She stated that, “*We're there at the beginning and we're there at the end*.” Attending funerals honored this special relationship, provided continuity for the family, and was an extension of her professional duties in supporting bereaved families. For participants who strove to clearly divide their work and personal time, attending funerals caused a conflict in upholding this separation because funerals or memorials required nurses to attend on their personal time. A PICU nurse explained why she chose not to attend funerals:

> *If you go to the funeral, then you're mixing your personal life and your work life, like, the family is seeing me outside of work but I'm still* [stated name]*, the nurse.*

This participant described how she made the decision to attend her first patient’s funeral after nearly five years of nursing. She had grown close to the family and patient over many months while the child was in the ICU and was at the bedside the night the child died. Ultimately, she attended to demonstrate her support to the family:

> *It was for me but it was also for the family. I knew that, if I wasn't there, it would kind of be a big deal because the other nurses and doctors were going. Since I was there when she died and I was the primary in the ICU, I felt like I kind of needed to be there.*

Some participants also experienced conflict because they viewed attending funerals as part of their professional duty in supporting families, but subsequently, they were emotionally affected. For example, an end-of-life facility nurse recalled attending her first funeral for a patient and then coming to work the evening shift. After seeing the small casket and witnessing the parent's grief, she could not stop crying and she recalled that she "*was a mess basically when I got there* [to work]." Additionally, participants' work units experienced frequent and ongoing patient deaths, and sometimes the sheer number of patient funerals added to nurses' emotional burden. A participant described the emotional impact of attending patients' funerals and her decision to stop attending them in order to protect herself.

> *Maybe I shouldn't cry there* [the funeral]. *And I cry at funerals. I bawl. And you know, I'd rather do that in private. Because, I don't know, I just don't like people to see me cry…. I used to go and it used to wear me out. I mean, I used to get depressed afterwards.*

Of special note, at the end-of-life facility, families often held their child's memorial or funeral service at the non-denominational sanctuary on site. For nurses at this site, attending these services became part of their work lives and they felt less tension in mixing their work and personal lives.

Being Friends versus Being a Caregiver

Connecting personally set up the potential for nurses to become friends with patients or their families, a relationship which complicated their care-giver provider role. Some participants viewed being friends as unprofessional because it confused the nurses' role and could potentially remove the focus of care away from the patient and/or family. Being friends with family members also indicated a personal relationship, rather than a strictly professional one. Thus, becoming friends with families was another source of internal conflict for nurses trying to balance connecting personally and behaving professionally.

Nurses defined being friends with families as sharing personal information, having a mutual relationship, seeing or talking to each other outside the work setting, or sharing common interests. Some nurses emphasized that they do not become friends with families because it was not congruent with their care-giver role. For one participant, the care-giver role kept her focus on the child and family, unlike in a friendship where there is a mutual focus.

> *I mean as much as I really felt close to a lot of people there* [the hospital unit], *and I talked to a lot of people and felt close to them, I don't know how appropriate it would be to leave work and go over have dinner at their house or something. I mean you're really serving a different role there. Your role there is a caregiver, that's your job. It's not a mutual relationship. And to enter in that relationship outside of work seems what are you…are you expected to continue that caregiver role or is it going to become a mutual friendship? And to keep a care-giving role, just suddenly a care-giver out of work doesn't seem that healthy. You need friendships that are mutual, right?*

Further, for these nurses, keeping a clear separation between being care-givers and being friends served as self-protecting strategy, similar to separating work and personal time. Becoming friends with families more easily led to feeling profound emotion if the child died. When focused on care-giving, these nurses could provide compassionate care, while not becoming deeply attached to or entrenched in families' lives:

> *But I think kind of taking on that care-giving role protects me in a way because you don't get so invested because you're not their friend. Maybe you're friends there at work, but you're not like enmeshed in their life, you know?*

Other nurses, however, regarded certain actions during personal time as extensions of their care-giving role, rather than as friendships. Specifically, they did not identify attending funerals, keeping in contact after a death, helping a parent find housing, or checking in with patients or families during time-off were not viewed as dimensions of friendships. Despite using their personal time in this way, these nurses perceived these actions as extensions of their care-giving role through caring and supporting families.

Friendships often developed during long hospitalizations or stays at the end-of-life facility when nurses got to know families closely and they shared some personal information. However, they did not talk with families as they would with their close friends outside of work, as this ICN nurse stated:

> *They want to know if I have a boyfriend at the time or if I'm dating or, you know, "How was your day?" and "How was your evening?" And I'll learn about their relatives, and their in-laws, and all this kind of thing, and that's great. And I don't let a lot of personal stuff because it's not about me. You know, you can share some things but they don't know my personal, personal stuff. Yeah, that's <inaudible> but it's just not the place to do it. So I do definitely have lines drawn.*

This participant considered her relationship with family members as a friendship but one that was limited to the hospital setting, on work time, and to a specified limit. It was not a mutual relationship outside of the work setting or during her personal time. The relationship had clearly ended when patients left the hospital, either through discharge or death.

> *And then when you leave, I say goodbye and I love you and I pick up a new primary. I move on. And it's hard because I'm friends in the hospital and for a little while afterwards and then I move on. I think sometimes for parents, it's very difficult for that because they want to stay in touch. But then, you know, you have nothing in common except for this baby, but it becomes not a baby anymore, it becomes a toddler… you know, we don't have anything in common, except your baby.*

Crying in Front of Families

Many nurses spontaneously discussed crying in front of patients and families. They noted that crying may be perceived by others as unprofessional, but it also demonstrated that nurses felt empathy and shared families' sorrow, and reflected connecting personally with children and their families. Additionally, participants' internal context, such as past experiences, worldviews on death and dying, personal relationships, or grief contributed to their crying. For example, as previously described, a participant was tearful when caring for a newly diagnosed leukemic patient the same age of her own child. This participant empathized with and shared the family's fear and shock not only as a nurse, but as a fellow parent. Another participant similarly cried when patients' deaths triggered thoughts about her own children.

Crying in front of families characterized the tension between behaving professionally and connecting personally. For some participants, a public display of emotion, such as crying, has the potential of being unprofessional behavior. But they also acknowledged that crying is a natural response to the gravity and tragedy of their work, echoed in a nurse who stated, "*There's nothing normal about a two month old dying*." Participants acknowledged that death and dying, especially concerning children, transcended them beyond strictly professional spaces and into the overarching human experience. An oncology nurse stated: "*If you're distraught, you're distraught, and that it's okay because you're human and you're supposed to be emotional*." Participants recognized that crying showed nurses' human care and compassion and reflected their personal connection to patients and families.

Nurses had difficulty identifying the source of the view that crying is unprofessional. They were unsure at the beginning of their career about openly crying, and thus, they may have learned in nursing school that professionalism was associated with stoicism. One participant, in her first year of nursing, struggled with knowing an appropriate emotional response when her first patient died and stated that, "*I kept feeling like is it okay if I'm emotional? Or maybe I shouldn't cry?"* Other participants observed that newer nurses were fearful about crying in front of families because they were unsure if it would be regarded as unprofessional or incompetent nursing care. They asked more experienced nurses how to remain detached in order to avoid crying. One ICN nurse described how inexperienced nurses grappled with wanting to control their emotional responses in order to remain professional:

> *"…and we talk about stuff with the new girls and their big concern is, what happens if you cry? It's like, I cry. I'm very sad. But I'm not on my hands and knees though, you know? You let sympathy show and you love the baby, but I mean you don't make a mess of yourself. You really have to take care of you.*

As this participant indicated, crying was acceptable in front of families, but it had its limits. These limits were indicative of the boundaries that nurses created to mitigate the tension the between acting professionally and connecting personally. On one end, uncontrollable, hysterical crying was viewed as acting unprofessional and on the other extreme, a veneer of stoicism was perceived as not connecting personally. Uncontrollable bawling was unprofessional because it removed the focus of care from the family or patient and onto the nurse. An oncology nurse stated that, "*I don't think they [families] need a tearful provider*." In the following quotation, another oncology nurse agreed with the notion that excessive crying could be a disservice to families and patients:

> *I think that I-- just because I haven't fallen apart in front a family doesn't mean that I shouldn't or can't. I don't think that it would make a bad nurse to do-- I mean to a certain degree, I wouldn't want someone to be like hysterical in front of a patient.*

Nursing school may have socialized nurses into the perception that crying equated with unprofessionalism; however, participants did not believe their current work setting promoted this viewpoint. Their work settings, colleagues, and managers acknowledged that crying was a natural response to the tremendous losses they all experienced. No participant stated that there was a work-place rule against crying or that they were discouraged from doing so. Participants at the end-of-life facility stated that the setting's milieu encouraged staff to show and share emotion, not only nurses, but security guards, volunteers, and housekeepers. An end-of-life facility nurse recounted a time she cried at work and the response she received from colleagues.

> *I was rocking this baby, the other day, one of the babies that's in the house right now. And I was looking at him 'cause he looked so perfect and I thought, how can every cell in his body have this genetic flaw in it. And yet, he looks so beautiful and perfect and whole on the outside. And that's where the sharing with other people, you know 'cause another nurse walked in and said, "What are the tears for?" And I said, "Because this isn't fair."*

A week after our interview, I observed the same nurse during her shift. The baby she previously described was having seizures and struggling to breathe. Although the other day-shift nurse was caring for the patient, the participant was also involved. As we entered the room, the housekeeper held the baby in a rocking chair. No family was present.

> *[field note] We walked into the room where the other nurse sat on the day bed with papers next to her (probably the medication record). There was no bed in the room, only a small crib, so it felt very open and empty. In the corner, next to the outside door, the housekeeper sat cradling the baby wrapped in a blue blanket, up close to her face. She was sniffling and had a few tears. The baby was small, its skin jaundiced. His eyes were half closed, and mouth slightly agape. T. walked over to the nurse and asked what she had given him. The nurse answered she had given him medication for his seizures. They both agreed it probably wouldn't be long before he died. They looked at each, sort of pursed their lips and then looked at the housekeeper holding the baby. Silence. The housekeeper pulled the baby closer and leaned down into his face, rubbing his nose with hers and kissed him. The baby's family had chosen not to be with him when he died. So, it was the facility's employees who held and comforted him during his last moments.*

As this vignette demonstrates, nurses and other staff at the end-of-life facility shared in the sadness and grief of patients' deaths. There was an underlying acknowledgement that they worked in a setting which evoked deep feelings and that crying was a natural, human response. The nurses indicated that this acceptance of crying and grief was critically important to her ability to continue working in such a highly emotional environment.

Feeling Ethical or Moral Distress

The last situation where participants struggled with mitigating the tension between behaving professionally and connecting personally was when carrying out aggressive treatments, usually at a patient's end of life, and feeling that they were causing pain or prolonging a child's suffering. They did not feel that they were behaving professionally or adhering to their professional duty of relieving suffering when they engaged in these aggressive treatments, as an ICN nurse articulated when caring for an infant on extracorporeal membrane oxygenation (ECMO:)

> *Taking care of this baby and changing her chest dressing every day, and seeing that she was dead, you know, I mean we could keep her alive, because her heart didn't really even pump. And it was very, a lot of moral distress involved with that patient. And carrying on when we knew that we were just causing pain and distress to the patient in spite of what the family wanted, and they really wanted the best for her, but, it was difficult.*
>
> *Alyssa: Describe more of that moral distress.*
>
> *Well, that, we have all this technology. We have this machine, this pump, that takes over the heart and lungs for this pat- this baby, and, really, you can keep almost anybody alive on that, but what is the quality of that baby's life? I mean, she's laying, she's paralyzed, she's got an open chest, she's at risk for infection, we're using all the blood products in the hospital that could be going to other patients, you know, because we knew she was going to die. I mean, she really was…*

Moral distress developed when participants provided care that conflicted with their self-defined professional role. For example, one participant valued safety as the core aspect of her nursing role. Her values and professional boundaries were challenged one shift when her teenage patient, who was on palliative care status, requested their nurse to rapidly administer pain and nausea intravenous medications. The participant suspected that the patient's request was from her desire to experience a "rush" when the medications were quickly pushed intravenously. However, the nurse did not feel this behavior was safe care because it was not in accordance with the medication administration recommendations and thus, challenged her professional boundaries. She refused to do it for the patient, which resulted in conflict between her and the patient, as well as with other colleagues who supported fulfilling the patient's request. She elaborated below:

> *For me, I mean, I don't know, it was just a great big ball of wax. It was like, I've got my legal and professional ethics going on and the whole drug-seeking rush questions and then just ideas of palliative care is, let's get her high when she want to get high, you know? I mean, because it was like well, yes she had pain, yes had nausea, but obviously it was crafted a little more to get a feeling when she got his meds. So, I don't know.*

In this situation, the participant experienced a sense of ethical distress when her professional boundaries were challenged.

Nurses also experienced ethical distress when they felt their nursing care conflicted with families' or patients' desires, such as an end-of-life facility nurse who stated: "*I had a lot of problems, internal problems, dealing with situations where children's desires weren't honored. And all you can really do is reaffirm what you see, and have heard what the child wanted.*" Participants across settings described experiencing ethical or moral distress which challenged both their personal and professional boundaries. They were uneasy when following physicians' orders, yet felt obligated to do so. They used words like "torturing", "horrible", "ghastly", and "awful" to describe what it was like implementing or witnessing procedures that caused pain or prolonged suffering. This distress was usually intensified in situations where nurses believed that the child would likely not survive the illness. One participant recounted a patient with particularly fragile skin who required many intensive dressing changes and the distress she experienced when she felt she was causing him unnecessary pain:

> *And they* [dressing changes] *were just so painful and you knew they were painful for him, no matter how much pain meds you gave him and we were just, like, "why are we all still doing this?" Because you just felt like you were almost torturing, him and you're just, I know that not only is this sore, and really painful, but what I'm doing is not to the betterment of him and it would be better if we could just make him comfortable and let him go. I feel like there are lots of times when we're just, like, it would be better if this patient was allowed to be…(pause), to go, rather than continue to have me do all of this stuff to them.*

Participants enacted orders that families or physicians requested, but struggled with their own differing opinions on what treatments they thought would be best for the patient, as did one end-of-life facility nurse. She indicated that the situation tested her professional boundaries because she sought to behave professionally by respecting the family's decisions, but that she also had personal conflicts with prolonging or exacerbating a child's suffering:

> *I think the areas where I struggle the most with, are when they do want to be really, really aggressive and drag the child through transfusions and IV chemo and keep on going and going and going and you see this decline and the suffering of a child. But I just have to still be professional…*

An ICN nurse similarly felt distressed when physicians continued to try treatments in hopes of saving the patient. She attributed their aggression to their personal discomfort with issues of death and dying.

> *It always depends on the physician as well. Some doctors have a real hard time letting go. And we're going to try one more thing and one more thing and one more thing. We're going to try Viagra and we're going to try something, you know?*

Nurses also experienced distress when families' decisions conflicted with their own views of optimal care, such as when families chose not to medicate their child's pain or anxiety at the end-of-life because they feared opioids would hasten death. Nurses' distress grew as they witnessed firsthand the child’s unrelieved pain. Participants indicated that these cases sometimes were brought to an ethics committee where they worked on resolving the conflict between the family, who refused pain medications, and health care providers, who believed pain medications were in the best interest of the dying child. During an observation of a hospital inter-disciplinary meeting, a staff member spoke of a case where a family chose to withdraw life-sustaining support for their child. The family’s decision, however, was difficult for nurses to accept because they felt that the child had a high probability of surviving the illness. The nurses felt uneasy and uncomfortable with the parent’s decision largely due to the patient having a semi-alert level of consciousness and being aware her surroundings. Likewise, an ICN nurse felt a sense of moral or ethical distress when an infant was placed on end-of-life care status and had do not resuscitate (DNR) orders. Nearing the end of life, the infant struggled to breathe and nurses - who were accustomed to resuscitating patients - felt helpless when they could not ventilate the baby. She stated that:

> *And she* [another nurse] *felt real uncomfortable with those* [DNR] *orders, but he* [baby] *was getting end of life care. And, you know, plenty of drugs but that--that's a hard way to go. You stop breathing and you turn black and you're not on a ventilator. It's hard for the nurses to watch. It really is. And our attending was one who was very, very clear on “don’t do it* [hand ventilate baby]. *They're trying to die. And we need to honor that and his parents' decision.” But, you know, they're gasping here and you're like, “oh great, this is lovely.”*

Compromised Integrity

In an effort to maintain integrity, nurses struggled with mitigating the tension between behaving professionally and connecting personally. Sometimes, nurses were successful at mitigating the tension and felt that they could maintain integrity. However, at other times, the tension was not mitigated successfully and conflict between the two aspects resulted in *compromised integrity*. That is, nurses felt they were either too separated from patients or families, or they felt that they connected too personally and were not maintaining professional behavior. Compromised integrity was a result of violated personal and professional boundaries, which framed nurses' sense of integrity and led to nurses feeling a fractured whole. Frequently, death and dying issues accelerated these periods of compromised integrity, such as when nurses were anticipating a patient's death, the time following a death, or after nurses experienced a number of deaths in a short period of time. One participant articulated the feelings she experienced after several patients died in close succession:

> *I definitely noticed it when if you have a group of deaths together, which invariably, for whatever reason they do seem to come in threes, you get that lethargy of grief, that compilation of one after the other and it affects your heart and your soul, so you just feel weighted down…*

Nurses recognized compromised integrity through emotional and behavioral indicators that served as signals of disintegration. The imbalance between connecting personally and behaving professionally triggered feelings of not optimally fulfilling their professional role. One end-of-life facility nurse recognized this imbalance because she had "*a little bit of an edge on me*." As she elaborated below, compromised integrity occurred because she had difficulty tolerating specific patient or parent behaviors:

> *I can sense in myself that I've gotten a little bit of an edge on me. When it has come, it's usually a very temporary, I've maybe worked too many days in a row and I'm tired of dealing with the whining. You know? Fifteen year old, whatever. Or a mom rubs me the wrong way and I have a hard time being empathetic and listening to her. Those tend to be fleeting moments, but when they come they almost are red-flags for me.*

Other participants recognized compromised integrity through feeling "*immobilized",*"*a heaviness"* or that they were "*hitting a wall*." Nurses deemed uncomfortable emotions, such as grief or anger, as problematic when they affected their personal life through dreaming of dead patients, crying uncontrollably at home, or withdrawing from their family or friends. An ICN nurse recounted her first patient's death and how she recognized a problem:

> *Afterwards* [her first patient's death] *I was like, "Oh gosh, I'm exhausted and drained." And, I remember I went to sleep and I was dreaming of the baby, and just all these things that kind of stick with you because you didn't deal with it yourself. You were trying to help everyone else deal with it that you're like, "Oh wow, I need to do some self care."*

Other participants were alerted to a problem by their own physical symptoms, most commonly fatigue, headaches, or general malaise. Lastly, a problem was also indicated by particular behaviors, such as not wanting to come to work, not wanting to interact with patients and their families, or feeling distant from colleagues and their own families. For example, a PICU nurse recognized a problem when she did not enjoy her work as she usually does and avoided interactions with a patient or their family.

> *In general, I really enjoy my job. I like it. I get a lot of fulfillment out of it and it got to the point that I didn't want to come to work. Like every day, it was a struggle, and I just kind of was, "I need to explore something different." Because I was having these days where I was, "I just don't want to deal with a family today, you know? Can I please have the kid who's intubated and sedated and has no family?"*

Nurses experienced compromised integrity when they felt they were not in accordance with their self-defined standards of care, specifically when nurses felt ill-prepared to provide end-of-life care to patients and their families, when they avoided work due to ongoing losses, when they felt overwhelmed by needy or challenging families, or when they felt "burnt out" by work. As a result, nurses were unable or unwilling to engage with families or children. They worried that they were unprofessional during these times, since connecting personally is an essential and valued aspect of nurses' role integrity. Participants frequently used the term "*putting up walls*" to metaphorically depict the distance they created between themselves and patients and their families. Nurses put up walls when they experienced overwhelming emotions in an attempt to protect themselves from additional pain and future losses:

> *You know, after you get really connected to a few and then you lose them, I think you kind of put of a wall, you just think, okay, I'll be here and I'll take care, but you invest so much emotionally, that it's draining.*

A PICU nurse also described distancing herself during periods of feeling burned out.

> *That's another thing I noticed when I was becoming burnt out is that I would distance myself. I would still do a good job and do everything I could, but I would distance myself. Or I wasn't as thoughtful of thinking of the big picture of what the patient was going through. It was almost like you were there, you did your job, and you left. It wasn't like anything else.*

Although putting up walls and distancing served as personal protection strategies, they also prevented nurses from connecting personally with patients and families, which, as previously stated, was essential to their role integrity. Participants valued supporting patients and families by anticipating and attending to their emotional and physical needs. When nurses could not connect personally because they had put up walls, they experienced the emotional and behavioral indicators previously described. One particularly poignant story serves to illustrate. An oncology nurse recounted caring for a teenager at the end-of-life and dealing with the patient's mother, who wanted to continue aggressive, curative treatment. The patient was experiencing considerable pain, not responding to the treatments, and according to the participant "*…the mom, couldn't hear that, couldn't hear that it was not treatable.*" Throughout her 12 hour shift, the nurse had frequent conflicts with the mother, which subsequently diverted her energy from attending to the patient's significant physical and emotional needs. She tearfully said that, "*I felt like I couldn't care for the girl because I couldn't deal with the mom*." The next day's shift, she chose not to care for the family because of the previous shift's ongoing conflicts and due to the anger she had felt when dealing with the mother. Instead, she helped her colleague, who was assigned to the patient, and stated that she focused her attention on attending to the teenager's emotional needs, as she described below.

> *So, when I was helping the other nurse, I just tried to hold her hand or to rub the arm that was on my side of the bed…I just wanted her to know I knew she was hurting. And, I wanted to comfort her more. I just wanted to like give her a hug and say it's okay.*

The patient died a few days after this shift. The participant was visibly upset when recounting this narrative because she felt she could not give the type of care she valued, which was connecting personally through giving emotional support and showing care and compassion. She described feeling guilty when finding out the teenager aspired to be a pediatric oncology nurse, and that she did not model the nursing care consistent with her professional role.

> *And, I felt so guilty cause she wanted to be an oncology nurse (laughing and crying), which I would never have guessed because her family was very angry with medicine. And then I felt bad because she never got to see the best of me, you know? But I didn't ever get to be what I thought was a good nurse for her, because there were so many barriers involved.*

The nurse experienced compromised integrity because she felt an imbalance between the two aspects of her professional role. She was unable to connect personally in the ways that she wanted. She experienced emotional indicators, such as anger and sadness over the situation. When asked during the interview to share a patient or family that was not an ideal death, she began the narrative by stating, "*the one that I'm still dealing with…*", which occurred several months prior to the interview.

Strategies for Restoring Integrity

When nurses sensed emotional and behavioral indicators of an imbalance, they recognized a need to pull back and *take care of self.* Aspects of taking care of self are *advocating for self, taking time for self,* and *focusing on self.* Advocating for self served as a strategy to restore role integrity. Identified actions associated with advocating for self included requesting not to be reassigned for an emotionally-draining patient or family, taking a “mental health day”, or seeking help from colleagues. After caring over many months for a baby, an ICN nurse felt she could not care for a new admission in the same crib immediately following the patient’s death. It was important that she was clear with the supervisor or charge nurse and assert that, “*You know what, I can’t go back in that room, you need to put me somewhere else.*”

Advocating for self required that nurses recognize their needs and limits. Participants frequently found it difficult to ask for what they might need because they may not know. Therefore, nurses monitored one another for emotional and behavioral indicators and provided support when needed, especially after caring for a patient who died, such as this ICN nurse:

> *But I definitely find now that for other staff I try and reach out to them sooner and say, “Oh, how did it go? How do you feel about it?” Because especially when you’re newer to it not having anyone to ask you, you just get so overwhelmed so quickly and it’s just nice to have outlets. And since then though I’ve noticed that I’ve had other nurses also in turn offer that same thing to me. “How did it go? How are you feeling? You know, do you think it went okay or do you think…”*

By supporting one another, nurses acknowledged that caring for a child dying is stressful and it was acceptable for colleagues to respond emotionally to their work. Nurses also supported colleagues by assisting them in demanding situations. An end-of-life facility nurse recounted that a fellow nurse stayed overtime to help her care for other patients, while she completed post-mortem care for an infant and their family. Another end-of-life facility nurse stated that colleagues relieved nurses who might become overwhelmed caring for a challenging family:

> *And if there's a really difficult family, if one person is taking care of that family all the time, we try to help each other so, we all take care of that family two days a week and have a break.*

The culture of the unit facilitated the type and nature of support nurses received. How the unit supported nurses when a patient died was revealing. Nurses felt unsupported and their loss unacknowledged when assigned other patients while caring for a child actively dying, or when admitting another patient right after completing post-mortem care on a child. In the PICU and the end-of-life facility, colleagues encouraged the nurse to go home when a patient died, as long as minimal staffing needs were met.

Nurses also provided self-care through *taking time for themselves,* a common strategy for reconciling compromised integrity. One PICU nurse, recognizing the indicators of compromised integrity said: *"I think when I was dreading going to work was kind of the biggest time when I needed the break."* Most often, nurses took times for themselves by taking a break from work and spending time away from direct patient care. Breaks ranged from a few minutes in the staff room to months off for vacation, teaching, or volunteer work. Like the PICU participant, nurses usually recognized their need to take a break when they felt unable or unwilling to connect personally with patients and families, such as when they felt they were putting up walls. An end-of-life facility nurse emphasized that when nurses become distant from families and patients, then it was imperative that they take a break.

> *I know that the moment you do* [become distant]*, then you kind of need to check out of the field together. Take a leave of absence of take a vacation. Like when*

> *you know you're getting frustrated at work – either if it's staff people or families and stuff, then you know something's bothering you. You need to take a break.*

Taking a break ultimately enabled nurses to return to their positions and be emotionally present with families. After taking time off, nurses usually returned to their work setting and felt capable and comfortable investing on an emotional and personal level. A few participants, however, told about ongoing compromised integrity from situations occurring in their previous work settings and for a variety of personal and professional reasons, they left those positions. Various stressors contributed to their choice to leave, including cumulative deaths, administrative barriers, and ongoing moral distress from providing aggressive, curative treatments. These nurses did not choose new positions where children did not die. For example, half of the participants who worked at the end-of-life facility had previous experience in hospital or home hospice settings. One such participant compared her experience working in a pediatric bone marrow transplant unit to working at the end-of-life facility:

> *It was really rough. So after that, I'm like, "I can't do this." I mean, I can't do my job if I think that every single person who walks through the door is gonna you know, die, right? It's like, even though we're doing heroic efforts most the time, but if - but I've noticed how my perspective have changed since I've worked at the* [end of life facility]. *I know where they're goin'. And I, my job is to totally focus differently than hurry up and make them as well as possible.*

This participant found that working in the end-of-life facility restored her role integrity because she could optimally balance behaving professionally and connecting personally with the patients and their families.

Often when taking breaks from work, nurses spent time *focusing on self*, a third strategy for taking care of self. Participants listed a variety of activities central to their ability manage the stress and emotion of working with seriously ill children and families.

The common thread in these activities is that they occurred *outside* of the work setting. Many participants valued spirituality in their lives and attended church regularly or more frequently during difficult times. Others schedules massages or facials, took quiet walks, or exercised. Some participants actively sought out a therapist to help process emotions associated with work. Therapy also assisted them with learning strategies to navigate boundaries. Nurses valued spending time with their friends, significant others, or their children. An oncology nurse remarked that "*I think that being around healthy children is kind of therapeutic*." Another participant said that a nurse from her unit frequently coordinated fun group activities outside of work, such as parties, going to dinner, or seeing movies. On the day of my observation, nurses, including the participant, were signing up for massages or facials at a local day spa.

Restored Integrity

Participants employed various strategies when they recognized emotional and behavioral indicators of compromised integrity as presented and discussed above. These strategies helped nurses to take care of themselves in order to return to work and care for patients and their families. When they returned, participants felt that they could optimally integrate behaving professionally and connecting personally and they described feeling a sense of wholeness again in their role integrity. Nurses' sense of integrity is framed by their self-defined personal and professional boundaries. Thus, restoring integrity required nurses to redefine their personal and/or professional boundaries. For example, many participants described becoming too close to a patient and their family, and subsequently endured overwhelming grief when the child died. These participants then adjusted their personal boundaries and were able to effectively provide necessary emotional support, but be less personally involved with subsequent patients' and families' affairs. They did not actively distance themselves and engaged with patients and their families without suffering personal consequences. One participant described the continual and ongoing balancing of personal and professional boundaries as "*a dance*." She elaborated that:

> *It's okay to experience that with someone and to walk beside them. Not necessarily in their footsteps, but next to them. And that you can be professional enough and yet intimate enough that you can save that skill for the next family…She* [therapist] *and I have talked over this many times – about how to go to work and express myself as best I want to and need to as a person, and that is a commitment of my career, and yet protect my heart, lean on my faith as much as I can, within reason as a human being, and yet move forward and still be able to do this again tomorrow or three months from now or five years from now.*

Even with years of nursing experience, participants still underwent the process of maintaining integrity and adjusting their personal and professional boundaries over the course of their career. A participant stated that she is "*growing and learning how to do that* [maintain boundaries] *better every day*", despite over a decade of pediatric nursing experience. Although nurses had become more adept at the process, they still continued to face situations which challenged, and at times, violated their boundaries.

When integrity was restored, participants described feeling a sense of satisfaction and reward in their work. They enjoyed working with seriously-ill children and their families, rather than burdened or overwhelmed. They also frequently described having energy to give to others, not depleted or "burned out." Participants acknowledged the difficulty and emotional stress of working in settings where children frequently died. However, they also identified their work as fulfilling and they felt privileged to share such intimacy with another human being. An end-of-life facility nurse articulated how she grew personally from caring for dying children in a work setting that was both difficult and rewarding:

> *This can be a very difficult place to be, but it still can be a phenomenal place of joy and appreciation of the moment. That has been a true life lesson for me. Is to just stop and smell the roses. Sometimes, literally. In this, the gardens, stopping with a child and picking flowers, you know? And maybe three days, they're gone. And the flowers are gone too.*

Participants across settings agreed that the best part of the job was the honor of helping children and families at such vulnerable times in their life. Specifically, end-of-life facility nurses derived satisfaction in knowing that they were providing a better death experience for families and children than in hospital settings. They felt that the facility gave families essential space and emotional support, and that patients could die peacefully and naturally surrounded by loved ones. One participant stated that, *"I mean I get goose-bumps just saying all this. There's no death like this. This is as good as death gets."*

Conclusion

Despite their work setting, all participants experienced the process of *maintaining integrity* in how they managed personal and professional boundaries. They often were confronted with situations which intensified the tension between behaving professional and connecting personally. If they were not able to mitigate the tension, they recognized the emotional and behavioral indicators which signaled compromised integrity, where participants felt they were not optimally fulfilling their nursing role. They used strategies to restore integrity by pulling away from work and focusing on their own needs. Often, they could restore role integrity through modifying personal and professional boundaries. Nurses in all practice areas likely experience a similar and continual process of managing boundaries. However, facing death and dying issues with children may have intensified the process for study participants because they were more greatly affected on a personal level. In the final chapter, I will discuss how this identified process relates to extant literature on boundaries, as well as the larger theoretical framework. I will also describe study implications, strengths, and limitations, in addition to directions for future research.

CHAPTER SIX: DISCUSSION

The purpose of this study was to explore how nurses in acute care units and an end-of-life facility negotiate boundaries between their professional roles and personal selves while delivering palliative care to children and families. The process of *maintaining integrity* was important to how participants navigate boundaries and manage the tension between behaving professionally and connecting personally with patients and families. In Chapter Four, I discussed the relevant contextual factors which influenced this process, including the contribution of the settings themselves. In Chapter Five, I described the process of *maintaining integrity*. In this chapter, I will discuss how the findings relate to existing literature and contribute to the field of pediatric palliative care. I will first summarize the major findings and then discuss how they support or contradict previous studies. Next, practice implications and directions for future research will be discussed. Lastly, I will summarize the study's strengths and limitations.

Summary of Major Findings

This study's major findings center on how nurses construct, perceive, and negotiate boundaries. Boundaries are flexible, rather than rigid. They emanate from within nurses, rather than being externally imposed on them. Participants engage actively in a process for negotiating boundaries in their work with seriously-ill children and their families. They strive to maintain integrity through both behaving professionally and connecting personally. The process was ongoing and in continual flux. Nurses learn new strategies for negotiating boundaries as they moved through their career, but the process never became static. Nurses always encounter new and challenging situations, as every patient and family is unique. Further, complex external and internal contexts, such as work setting milieu, socio-cultural views of death and dying, nurses' palliative care definitions, and nurses' personal past experiences, shape the process' unfolding. Additionally notable was the influence of nurses' emotional and personal reactions to caring for children at the end-of-life. The following discussion will focus on these findings and how they fit with the literature on professional boundaries, emotions and coping strategies, as well as within the study's theoretical framework. Another important finding is the range of nurses' definitions of pediatric palliative care in their work and this too will be discussed in relation to existing literature.

Professional Boundaries

This study provides insight into how nurses construct, perceive, and then negotiate professional boundaries in care of seriously-ill children. The National Council of State Boards of Nursing (NCSBN) defined professional boundaries as "the spaces between the nurses' power and the client's vulnerability" (2007). The council added that boundaries "allow for the nurse to control this power differential," and that nurses should aim for the "zone of helpfulness" which is the middle ground between being overly involved and under involved. The study findings contribute to the understanding of *how* nurses successfully act within the zone of helpfulness. Other authors, primarily in the nursing administration field, have written about maintaining professional boundaries using the NCSBN's guidelines (Holder & Schenthal, 2007; Hudspeth, 2000; Thompson, 2007; Sheets, 2000; Wright, 2006). In these articles, terms were used such as, "staying in the lines" (Sheets), "watch your step" (Holder & Schenthal), and "boundary crossings" (Hudspeth), all of which connote a rigid, fixed, and singular boundary. This narrow conceptualization of professional boundaries does not account for the full, rich, and complex process participants used to accomplish their goal of behaving professionally. This narrow view also assumes straight-forward and predictable situations and relationships. Findings, however, point to a more varied and fluid process, where nurses confront and adapt to new and challenging situations on an ongoing, continual basis. Rather than existing boundaries structuring the situation, new and varying situations define boundaries.

Participants alluded to standards of professionalism when they spoke of the appropriateness of behavior. For example, participants described particular inappropriate behaviors as hysterically crying in front of families or showing preferential treatment to particular patients. Nurses equate crying with unprofessionalism, but it was difficult to ascertain from the findings where their views of this unprofessionalism originates since they do not perceive that their work settings mandate specific rules about professionalism. For example, participants disagreed that their managers or other administrators enforced rules about crying in front of families. Nursing school (Jacobson, 2002) and professional discourses likely contribute to participants' perceptions of what constitutes crossing professional boundaries, which then equates to inappropriate behavior. Professional discourses include the American Nurses Association's [ANA] Code of Ethics, which issues this statement regarding professional boundaries:

> While the nature of nursing work has an inherently personal component, nurse-patient relationships and nurse-colleague relationships have, as their foundation, the purpose of preventing illness, alleviating suffering, and protecting, promoting, and restoring the health of patients. In this way, nurse-patient and nurse-colleague relationships differ from those that are purely personal and unstructured, such as friendships (ANA, 2001).

The ANA’s statement warns nurses not to form friendships with patients, but does not explicate what defines friendships. Findings of this study demonstrate that being friends with patients or families is a point of contention for participants because developing friendships modifies their care-giver role and could potentially turn nurses’ focus from the patient’s health needs. Thus, even though participants know friendships are signs of crossing professional boundaries, they have difficulty defining what determined a friendship. For some, it is continuing a relationship outside of the work setting or divulging personal information to patients and families. For others, continuing a relationship after the discharge or death of a patient is an extension of their care-giving role, such as staying in contact to provide support. The ANA Code of Ethics is an example of how nurses’ negotiated boundaries are influenced by larger nursing discourses, but how they also confuse and complicate the issue.

The ANA (2001) Code of Ethics complicates the issue for nurses because general and universal standards for professional boundaries cannot exist. Participants stress that every patient and family situation is unique because it involves the element of *human* interaction and contact. Subsequently, boundaries are open to modification in order to adapt to ongoing situations. Most importantly, *nurses* modify their own personal and professional boundaries within a complex contextual environment, rather than following external boundary guidelines or rules.

I do not argue for nurses to not have boundaries, but rather for consideration of the developing human relationship that is at the center of nursing practice, and is the goal for PPC (IOM, 2003). There are clearly unprofessional behaviors which threaten or violate patients’ needs, such as neglect, abuse, or divulging too much personal information. However, participants do not talk about “crossing the line” in these ways. They articulate navigating boundaries in terms of their relationship to patients and families, ongoing human interaction, and in line with Milton’s (2008) view that “boundaries exist in the labeling of the professional role of the nurse as something between professionalism and friendship” (p. 29). Professional boundaries are primarily the limits they place on maintaining a professional and care-giving relationship, where their focus centers on attending to patient and family needs.

Pediatric palliative care literature stresses that developing an emotionally supportive and caring relationship with patients and their families is essential and important for quality care (Browning, 2002; IOM, 2003), and even argues for more research on how relationships at the end-of-life aids in the relief of suffering (Kane, Hellsten, & Coldsmith, 2004). Findings suggest that death and dying issues intensify nurse-patient-family relationships, in that they spark distressing emotions, increase nurses’ identification with patients’ or families’ situations, or deepen nurses’ attachments. These findings are consistent with other studies on nurses caring for dying children (Davies et al, 1996; Rashotte et al., 1997; Papadatou et al., 2001; Papadatou et al., 2002). Working within the context of death and dying seems to transcend nurses’ professional boundaries and enter them into the larger human experience. Subsequently, nurses challenge and question their personal boundaries, evident by a participant’s statement of “*There’s a part of you, this person is gonna die, I mean, why would we have boundaries on this?”* This study provides a deeper understanding of the process nurses use to navigate complicated boundaries while still providing therapeutic and professional care.

Findings suggest that participants were not only managing professional boundaries, but also determining their personal limits, which was a highly individualized process.

Little is written in the pediatric palliative care literature about how nurses or other health-care providers negotiate boundaries in such a highly emotional and intimate practice field. Participants primarily learn how to deal with and manage boundaries through personal experience, rather than through their professional education or in the settings where they practice. Learning through experience is consistent with a study by Jones and colleagues (2007) of nurses and physicians in a PICU, who felt more comfort and confidence giving palliative care after eight years or more experience. In this study, most participants were unsure how to act when their first patient died because they had received no preparation for this situation or how to deal with the feelings of loss that arose. Training and education of health-care providers in PPC is recognized as deficient (IOM, 2003) and some organizations created educational programs and curriculum to meet this urgent need (Browning & Solomon, 2005; Malloy, Ferrell, Virani, Wilson, & Uman, 2006; Papadatou, 1997; Schiffman et al., 2008).

Emotions and Coping Strategies

In navigating boundaries, participants discuss their emotional responses and coping strategies. Findings suggest that nurses' work with seriously-ill children and their families affects them on a personal level. Nurses experience varying degrees of sadness and grief resulting from patients' declining health or death. How participants talk about emotions provides insight into how they perceive and delineate personal boundaries in their work. For example, when nurses feel overwhelming grief after a particular patient's death, they create more distance in their future patient/family interactions in order to protect themselves from similar situations. Distancing is an often cited strategy that nurses caring for dying children use to maintain professional boundaries in highly emotional situations (Davies et al., 1996; Rashotte et al., 1997; Papadatou et al., 2001; Papadatou et al., 2002), as well as in a sample of pediatric nurses who cared for unaccompanied (i.e. without parents present) hospitalized children (Livesly, 2004). In addition to maintaining professional boundaries, nurses in this study distance themselves as a self-protection strategy, which further contributes to an understanding of distancing.

Like participants in this study, other nurses described suppressing distressing emotions as a short-term coping strategy (Davies et al., 1996; Papadatou et al., 2002; Papadatou et al., 2001; Rashotte et al., 1997; Yam et al., 2001). Delayed processing allows some participants to keep their focus on patients' and families' clinical needs, get through their shift, and then attend to their own emotional needs. Long-term suppression, however, negatively affects nurses' practice because they remain distant and avoid engagement with patients and families. Nurses in this study recognize distance as a sign of disintegration and seek to reconcile their compromised integrity. Common strategies for reconciling integrity are taking breaks and focusing on self, similar to Clarke and Quin's (2007) findings in pediatric palliative care nurses. Taking extended breaks from their practice setting enables nurses to extricate themselves from their work identity, which supports Hochschild's (1979) argument in her theory of emotion work, that workers should have a "healthy estrangement" from their organizations. She asserted that burnout easily resulted if workers identified too much with their work. Participants frequently comment that they are able to cope with the intensity of the jobs and avoid burning out by regularly taking breaks when they recognize signs of threatened or compromised integrity.

Findings also show that participants cope with work-related stresses and emotions through talking with and being supported by colleagues. Fellow nurses shared an unspoken understanding of the intricacies and complexities caring for seriously-ill children or experiencing patients' deaths. Other nurses caring for dying infants and children similarly derived comfort from sharing with colleagues and from peer support (Davies et al., 1996; Rashotte et al., 1997). Like the PICU nurses in Rashotte and her colleagues' study, participants in this study dislike being forced to talk about their experiences in what they perceive as a contrived setting or at an inopportune time. Participants informally create their own small group of trusted colleagues in which they feel comfortable sharing experiences.

The majority of participants do not find formal support resources useful. Such resources include meetings to talk about palliative care issues, having a designated staff person as a "counselor", or organized retreats. Commonly, participants are not comfortable sharing their experiences under these circumstances. Or, they feel the focus was more on clinical issues, such as pain management, rather than on participants' emotional or personal responses to patients' deaths. Participants do, however, find some organized resources helpful, such as a designated nurse who planned recreational activities outside the work setting, remembrance ceremonies led by a spiritual coordinator, and debriefing meetings convened shortly after a patient's death. Other hospital providers have found debriefing meetings beneficial to their grief and bereavement following patients' deaths (Rushton et al., 2006).

Nurses perceive implicit unit support through how patient deaths are handled in their settings which in turn, shapes participants' ability to cope with stress and emotions. When participants have to care for another patient immediately following post-mortem care of a child, they feel profoundly unsupported by their unit. Not being given the time to recover from such a physically and emotionally taxing situation conveys to nurses that grief is not be tolerated or acceptable. Consistent with Blumer's Symbolic Interactionism, participants' meanings about death and dying are based on implicit and explicit meanings in their work settings. In the end-of-life facility, children's deaths are handled with the use of less technology, families are allowed to stay with their child's body, and nurses are not required to transport the body to a morgue. Consequently, findings show that end-of-life facility participants perceive death as a more natural part of life than hospital nurses.

Defining Pediatric Palliative Care

Another notable finding is participants' wide range of definitions of palliative care, end-of-life care, and hospice care. Hospital participants perceive little philosophical difference between end-of-life and palliative care, because palliative care is initiated so close to patients' deaths. Conflicts and confusion in definitions are found across the pediatric palliative care literature. The major point of contention is *when* pediatric palliative care begins. The leading definitions assert that it begins at the diagnosis of a life-limiting illness and exists concurrently with curative care (AAP, 2000; IOM, 2003; Sepulveda et al., 2002). Yet, in practice, hospital health-care providers described palliative care as a shift in care from curative care (Docherty et al., 2007). Since deaths are difficult to predict, providers were reluctant to stop aggressive curative treatments, even in the last hours of a child's life (Fowler et al., 2006; McCallum et al., 2000; St.

Laurent-Gagnon, Carnevale, & Duval, 2008; Tan et al., 2006; Wolfe et al., 2000). Hospital nurses in this study describe a similar trend, in that palliative care discussions usually do not occur until a child's death is deemed inevitable and curative care stops. In these cases, palliative care and curative care infrequently co-exist. Participants feel the lack of initiating palliative care discussions for patients with life-limiting illnesses may contribute to patients' suffering at the end of life and have a negative impact on families' anticipatory grief. These findings support those of another study of children dying of cancer, in which they more often received aggressive treatments and experienced suffering in the last month of life from a lack of palliative care planning (Wolfe et al., 2000). In comparison, children and families more optimally benefitted when palliative care services were initiated earlier in the illness trajectory (Wolfe et al., 2008).

Conversely, end-of-life facility nurses view palliative care more broadly than occurring only at the very end of life. They also perceive it co-existing with curative care, rather than mutually exclusive. This finding is important because it is consistent with the widely accepted definitions of pediatric palliative care (AAP, 2002; IOM, 2003; Sepulveda et al., 2002) and differs from how hospital providers often view palliative care as a shift in care (Docherty et al., 2007). Examining the goals of care among the end-of-life facility and hospital units may explain the differences among participants' definitions of palliative care. Findings indicate that curing children's illness is the overarching goal of care in the hospital units, especially in the PICU where care centers on aggressive treatments. Because the focus is on restoring children's health, the possibility of death is rarely acknowledged unless inevitable. Thus, palliative care and end-of-life are indistinguishable from one another, but mutually exclusive from curative care. The focus on curative care and prognosis uncertainty are known barriers to initiating palliative care services in hospital settings (Davies et al., 2008; Harper et al., 2008; Mack & Wolfe, 2006). In contrast, the overarching goal of care in the end-of-life facility is to provide palliative care for life-limiting illnesses; end-of-life care and curative care are seen as sub-categories. Within this framework, death is acknowledged as possible, but not necessarily inevitable.

Offering bereavement support is another major difference between the hospital and end-of-life facility. Founders created the end-of-life facility as a place for families to return after the death of a child, where they could participate in grief groups, memorials, or other remembrance events. In the hospital, partly due to the large number of patient deaths, nurses encounter challenges in providing bereavement support to families. Due to these differences in the goals of care, end-of-life facility participants more easily work across the continuum of palliative care. That is, it begins at the diagnosis of a life-limiting illness and continues through bereavement. End-of-life facility participants view bereavement support as more integral to their jobs than do hospital participants; they support and encourage families to return for memorials, remembrance events, anniversaries, or simply for a visit at any time they chose. In the hospital, the palliative care program offers some bereavement support, but nurses are unlikely to be part of this service. Consequently, nurses do not provide support to families after a death, unless it was on their own accord.

Grief and bereavement support is important to families (Contro et al., 2002; D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008; Davies et al., 2003; Heller & Solomon, 2005; IOM, 2003). Family members have expressed that they need continued contact with staff who cared for their child, and feel abandoned when they do not receive it (Contro et al.; Davies et al.; Heller & Solomon; Macdonald et al., 2005; James & Johnson, 1997). Moreover, attending funerals is a form of bereavement support and families were comforted when health care providers were at their child's funeral (Macdonald et al.). Findings show that attending patients' funerals or memorials is nurses' personal decisions. Some participants choose to attend as part of their care-giving role to show support to families and recognize the patient's life. Attending funerals, however, carries emotional ramifications and other participants choose not to attend to protect themselves against excessive grief or sadness. Also, for some participants, attending funerals creates too much confusion and overlap between personal and professional boundaries. These findings provide insight into attending funerals from nurses' perspectives, since little is written in the literature regarding this important issue.

Practice Implications and Future Research Directions

Findings suggest nurses' personal and professional boundaries are flexible and adaptable, rather than fixed and rigid, which leads to important practice implications. Additionally, findings indicate that nurses incorporate significant emotion work into their daily practice caring for children and families. Participants describe the process as internally regulated. Although egregious boundary violations sometimes exist (e.g. patient abuse or neglect), participants essentially determine the limits of their own boundaries. Similar to a rower learning to navigate a river, nurses prepare for what conditions to expect and strategies to use when they encounter hazards. But, nurses will also develop their own individual skills and strategies for maneuvering through the landscape and meeting challenges. Therefore, training and preparing nurses to provide palliative care should include discussion of strategies for successfully navigating boundaries, accounting for the human relationships that develop among patients, families, and providers. PPC training programs include information on providers' emotional responses and feelings of loss associated with caring for seriously-ill children at risk for dying (Browning & Solomon, 2005; Malloy et al., 2006; Papadatou, 1997; Schiffman et al., 2008). In addition to the information presented in these modules, educators can advise nurses about potential threats to integrity and discuss how to manage attachments to patients and families, deal with work-related emotions, and cope with moral or ethical distress. Nurses can also learn how to recognize common emotional or behavioral indicators which signal compromised integrity. In doing so, nurses learn how best to actively manage the process of navigating professional boundaries, beyond simply following rules or guidelines set by others. Newer nurses may feel more supported by their work settings if trainings acknowledge that working in palliative care can elicit a range of emotions and employers offer strategies and resources for coping with the emotions.

Secondly, findings also point to implications for developing and implementing resources to support nurses who work in emotionally demanding practice settings, which is a gap recognized by others in the field (IOM, 2003; Liben, Papadatou, & Wolfe, 2007). It is important to discuss with nurses their suggestions for beneficial resources since participants in this study decried many formally structured forms of support. However, support can be given in various ways, such as bereavement debriefing groups (Rushton et al., 2006), improving lines of communication among providers, acknowledging the intensity of a death by allowing nurses to take time off if needed, or providing outlets for nurses' emotional expressions. Professional support can also be provided through organizing remembrance ceremonies or other memorials to honor past patients since participants clearly remembered patients who died, even after many years. Remembrance ceremonies give nurses an outlet for expression and may help with the grief and sadness elicited from their work. Lastly, organizations can implement more formalized assessment of nurses' emotional integrity, for example through ongoing check-ins or monitoring for emotional or behavioral indicators.

Organizations can also support nurses through providing resources for therapeutically reflecting on difficult experiences since talking about their work, especially with trusted colleagues, is a positive coping strategy for participants. Nurses, however, emphasize that being forced to talk about their experiences is not helpful. A handful of participants see professional therapists to specifically address the challenges and emotions of their work. Whether talking to colleagues or a licensed therapist, participants find that reflecting on difficult experiences is beneficial for both their personal and professional growth. Nurses often gained insights into how to structure and negotiate boundaries after particularly intense experiences. Participants also find it helpful to talk about experiences during study interviews because at times, they were surprised with the depth of their feelings about past situations. Therefore, organizations can contribute to nurses' professional and personal growth through offering them one-on-one therapeutic services, such as by a designated psychologist or social worker.

Nurses additionally derive comfort when their workplace affirms their emotional responses to a patient's death by being allowed to go home after a death, taking a break, or talking with their manager. They feel reassured that their sadness or grief is a normal and natural response to the gravity of their work. Thus, pediatric units can explore and expand resources for nurses to assist in navigating boundaries and coping with emotions. Having an open, non-judgmental, and safe place to share experiences is important, since reflection can be beneficial for personal and professional growth. In its curriculum, the Initiative for Pediatric Palliative Care (IPPC) teaches providers to use reflection and journaling, based on the work of Donald Schon (1983), to promote professional competence and attitudes (Browning and Solomon, 2005).

This study also found that hospital nurses more likely describe palliative care as a shift from curative care which conflicts with the widely accepted integrative model of care (AAP, 2000; IOM, 2003; Sepulveda et al., 2002). Participants state that a shift in care poses multiple problems. Since it was challenging for providers to accurately prognosticate when a child is at the end-of-life, patients are often needlessly subjected to continued treatments, nurses are limited in their time to prepare families for death, and families suffer from a lack of preparation. A distinct transition in care can also affect nursing care; participants spend more time with patients and families or advocate more for their needs. This study reinforces an observed gap between the theoretical intent of palliative care and its execution into practice (Docherty et al., 2007; St. Laurent et al., 2008). Practice implications include addressing the well-studied barriers that have been identified for executing an integrative model of care for patients with life-limiting illnesses when they are admitted to the hospital (Contro et al., 2002; Davies et al., 2008; Harper et al., 2007).

The integrative model of care also asserts that pediatric palliative care continues from the diagnosis of a life-limiting illness to bereavement (AAP, 2000; IOM, 2003;

WHO, 2002). One form of bereavement support is attending funerals or memorials, since family members derived comfort from having health care providers attend (Macdonald et al., 2005). Participants, in all study settings, discuss a personal struggle with attending funerals which conflicts with showing support to families, but feeling emotionally taxed from the experience. Practice settings must recognize the significance for families when nurses attend their child's funeral, yet also acknowledge that some nurses find it difficult. Practice implications include exploring ways to make attending funerals part of nurses' job and compensate providers for their time in supporting families in this way. Findings show that participants closely distinguish between work and personal time. Since going to funerals occurs on personal time, some participants do not view them as part of their nursing role. If receiving compensation, attending funerals would occur on work time, and nurses might feel more of a professional obligation, rather than a personal struggle. This issue has not been addressed in the literature and provides insight into alternative strategies for meeting families' bereavement needs, while retaining nurses' professionalism.

Findings from this study provide several possible directions for future research. Further inquiry is needed to study how well the process fits with other pediatric nurses' experiences. This study highlights a need for more support and training to nurses working in PPC settings, therefore continued research about positive resources may enhance nurses' professional competence and ability to cope with emotional responses. For example, research into developing an instrument that systematically assesses nurses' emotional integrity and can alert a nurse or supervisor to compromised integrity. Lastly, this study contributes a deeper understanding of the complex process nurses use to navigate boundaries and how work settings may influence the process. Further research can address environmental factors which constrain or facilitate nurses' navigation of boundaries.

Strengths and Limitations

A major strength of this study is that it is the first to present a theoretical conceptualization of how nurses work in an emotional and intimate practice setting while maintaining integrity between personal and professional boundaries. To date, this is the first study to describe *how* nurses navigate boundaries caring for seriously-ill children and their families. This study demonstrates how the complexities of human relationships and emotional responses influence the process of navigating boundaries. It also shows the various contextual factors which shaped the process, including the contributions of nurses' work setting.

Secondly, grounded theory methodologies allowed for rich descriptions of nurses' experiences. The methods enabled nurses to express a wide range of emotions and coping strategies, rather than narrowly focus on a few. During interviews, I witnessed firsthand nurses' emotional responses, since many openly cried when recalling memories of patients. I saw how deeply they were personally invested into their work. Quantitative measures, such as a survey or questionnaire, are not able to elicit such vivid findings or account for subtle differences across experiences because these study designs focus on a few identified concepts which may or may not fit with nurses' experiences. This study also used observation as a data collection strategy. During observations, I familiarized myself with the setting, developed more trusting relationships with participants and staff, and broadened the scope of data.

Lastly, to date, this is the first study to include both hospital nurses and end-of-life facility nurses in one sample. Since few pediatric hospices or end-of-life facilities exist across the world, little is known about the similarities and differences between nurses in each setting. Although all participants share a similar process for navigating boundaries, significant differences are found in how their work settings contributed and influenced the process.

One limitation is the lack of generalizability of the findings to other nurses who provide palliative care in other settings, such as emergency rooms where sudden and traumatic deaths occur, or home-care programs where care may focus on children with complex chronic illness. However, it is not an expectation that findings from studies using qualitative approaches are generalizable since the experiences described by participants are unique to that sample. But, theoretical categories and relationships arising from this study can be used to explore if other nurses share a similar process for navigating boundaries. By studying nurses in other settings, the initial grounded theory can be extended and deepened.

The sample itself may contribute to three limitations. First, the small sample size (N=18) obtained from four sites may pose issues for capturing the range of nurses' experiences across these sites. However, a considerable amount of data was collected from each participant interview and participant observations, as well as from relevant documents, attending palliative care conferences, and conducting interviews with the hospital PPC program coordinator and an end-of-life facility administrator. Moreover, saturation of core categories occurred as the study progressed. Second, nurses self-selected to participate in the study. Since the study was advertised as a pediatric palliative care study, those who volunteered to participate may have been those who were more comfortable discussing death and dying issues compared to those who did not volunteer. They also may have perceived palliative care as integral to their nursing care, in contrast to other nurses who might not consider palliative care issues as significant to patient care. This hypothesis is supported by the observation that nurses at the end-of-life facility were more willing to participate and easier to recruit, despite having a significantly smaller population of nurses than the combined hospital units. Third, the sample does not include any participants who indicated that they became friends with patients or their families, although participants describe how other colleagues became friends with families outside the work setting and engaged in activities such as babysitting, visiting family homes, or going on vacation. This study does not capture the perspective of nurses who engage in these practices. Including such nurses in a future study is another direction for research.

Conclusion

This study provides insight into how nurses in palliative care settings navigate boundaries. The identified process is complex and individualistic. Continued exploration into how health care providers are able to both behave professionally and connect personally with patients and families is needed to expand this beginning theoretical conceptualization.

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Appendix A

Table 1

Sample Characteristics

Demographic Data (N=18)	n (%)
Work Setting	
End of life Facility	10 (56%)
Children's Hospital	8 (44%)
Hem/onc/bmt unit	3 (17%)
PICU	2 (11%)
ICN	3 (17%)
Gender	
Female	16 (89%)
Male	2 (11%)
Ethnicity	
White	15 (83%)
Black	1 (5%)
Other	2 (11%)
Age*	
Overall	39.2 (25 – 59)
End of life Facility	44.0 (29 – 59)
Children's Hospital	27.4 (25 - 42)

Education	
Diploma	1 (5%)
Associate’s	2 (11%)
Bachelor’s	10 (56%)
Master’s	5 (28%)
Years in work setting	
Overall	3.79 (0.4 – 15.5)
End of life Facility	1.77 (0.4 – 2.75)
Children’s Hospital	6.31 (2.5 – 17.0)
Years of nursing experience	
Overall	15.69 (2.5 – 44.0)
End of life Facility	21.40 (6.0 – 44.0)
Children’s Hospital	8.56 (2.5 – 29.0)
Years of pediatric experience	
Overall	12.75 (2.5 – 42.0)
End of life Facility	16.10 (3.0 – 42.0)
Children’s Hospital	8.56 (2.5 – 29.0)

* Three participants declined to state age

Appendix B

Flyer posted in break rooms to provide information to nurses about the study

Pediatric Nurses' Stories Needed for Research

Alyssa Erikson, RN, a doctoral student at UCSF, is interested in hearing stories from nurses who work at [omitted]. She will ask you about your experiences caring for children and families.

Your work is important and we want to hear about it.

Eligibility criteria: You must be a registered nurse!

If you're interested, please contact Alyssa at [omitted] or email her at [omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Pediatric Nurses Study
[omitted]

Appendix C

Email sent to nurses providing information about the study

Alyssa Erikson, RN, is a doctoral student in the School of Nursing at USCF. She is working with Dr. Betty Davies. She is conducting her dissertation study and is interested in talking with pediatric nurses who work at [omitted]. She hopes that the nurses' perspectives about care will help understand nurses' experiences in pediatric palliative care.

Here's what would happen if you decide to participate in the study:
- You will be asked questions about nursing care in general and your experiences in caring for families. Pseudonyms will be used to protect your privacy. The conversation will be recorded, but only Ms. Erikson and the research team will know what you said.
- The interview should last about 60 minutes. After the first interview, a follow-up interview may be necessary.
- You may also choose to allow the researcher to observe your activities during work hours.
- You will receive a $15 gift certificate for appreciation of your participation.

If you think you might be willing to be in the study or have questions, please call Alyssa at [omitted] or email her at [omitted].

Appendix D

Consent Form for Participants

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

How nurses navigate personal and professional boundaries while providing palliative care to children and their families across practice settings

This is a research study about nurses' perspective on palliative care to children and families at [omitted] and [omitted]. The study researchers, Betty Davies, RN, Ph.D or Alyssa Erikson, RN, MSN, PhD(c) from the UCSF Department of Family Health Care Nursing, will explain this study to you.

Research studies include only people who choose to take part. Please take your time to make your decision about participating. If you have any questions, please ask the researchers.

You are being asked to take part in this study because you work as a nurse at [omitted] or [omitted] and work with children and families.

Why is this study being done?

- The purpose of this study is to understand how nurses provide emotional support to children and families, especially at the end of life. Specifically, this study's goal is to explore nurses' emotions and their coping strategies in this practice area.

How many people will take part in this study?

About 30 nurses will take part in this study; ten nurses from [omitted] and 20 nurses from [omitted].

What will happen if I take part in this research study?

If you agree to be in the study, the following will occur:

1. You will be interviewed for 60-90 minutes at a location of your choice. The researcher will ask you to describe your experiences with families at [omitted] and to use pseudonames in reference to patients, families, and staff.
2. The interviews will be audio-taped. The purpose of recording the interviews is to allow the researchers to accurately transcribe what you said during the interview for analysis. Any mention of names will be removed during transcription. All audio recordings will be destroyed after the study is complete.

3. The interviews are semi-structured, with open-ended questions to allow you to tell the research your thoughts.
4. After the first interview, the researcher will observe you in your work setting for about 2-3 hours. You may choose not to be observed.
5. The researcher may also ask you for a second individual interview to clarify information or pursue a new topic. The interview will take place at the location of your choice and last no more than 60 minutes. The structure will be similar to the first interview and audio-recorded.

- **Study location:** All these procedures will be done at the location of your choice.

How long will I be in the study?

Participation in the study will take a total of about 3-4 hours over a period of two months.

Can I stop being in the study?

Yes. You can decide to stop at any time. Just tell the study researcher or staff person right away if you wish to stop being in the study. You may also choose not to be observed or participate in a group interview or second interview.

What side effects or risks can I expect from being in the study?

- Some of the interview questions may make you feel uncomfortable or upset. You may request not to discuss a topic or you can choose to stop the interview at any time.
- Some of the focus group discussion questions may make you uncomfortable or upset, but you are free to decline to answer any questions you do not wish to answer or to leave the group at any time.

Are there benefits to taking part in the study?

There will be no direct benefit to you from participating in this study. However, the information that you provide may help health professionals better understand/learn more about nursing care of children and families receiving palliative care.

What other choices do I have if I do not take part in this study?

You are free to choose not to participate in the study. If you decide not to take part in this study, there will be no penalty to you.

Will information about me be kept private?

If information from this study is published or presented at scientific meetings, your name and other personal information will not be used. We will do our best to make sure that the personal information gathered for this study is kept private. However, we cannot guarantee total privacy. Your personal information may be given out if required by law.

What are the costs of taking part in this study?

Your time and potential travel expenses are the costs related to taking part in this study.

Will I be paid for taking part in this study?

In appreciation for your participation, you will be given a $15 gift certificate to your choice of Starbucks, Barnes and Noble, or Target for taking part in this study. The gift card will be given after you complete the first interview.

What are my rights if I take part in this study?

Taking part in this study is your choice. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you in any way.

Who can answer my questions about the study?

You can talk to the researchers about any questions or concerns you have about this study. Contact the researcher, Alyssa Erikson, RN, MSN at [omitted].

If you have any questions, comments, or concerns about taking part in this study, please first talk to the researcher (above). If for any reason you do not wish to do this, or you still have concerns after doing so, you may contact the Principal Investigator, Adele Clarke at (415) 476-0694. If you do not wish to do this, please contact the office of the **Committee on Human Research**, UCSF's Institutional Review Board (a group of people who review the research to protect your rights).

You can reach the CHR office at **415-476-1814**, 8 am to 5 pm, Monday through Friday. Or you may write to: Committee on Human Research, Box 0962, University of California, San Francisco (UCSF), San Francisco, CA 94143.

CONSENT

You have been given a copy of this consent form to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. You have the right to decline to be in this study, or to withdraw from it at any point without penalty or loss of benefits to which you are otherwise entitled.

If you wish to participate in this study, you will sign below.

____________ ____

Date Participant's Signature for Consent

Appendix E

Interview Guide

How nurses navigate personal and professional boundaries while providing palliative care to children and their families across practice settings

I am interested in understanding how nurses care for families and seriously ill children. I would like to know about your experience, there is no right or wrong answer. Please feel free to provide any other examples, details, or additional information that may come to mind as we talk.

1. Tell me about how you came to work here?
    a. Where did you work before?
2. In general, how would you describe what nurses do?
    a. How would you define palliative care? How do you see the nurses' role?
    b. When you tell others of your job, what do you tell them?
    c. How do you think families would describe what nurses do?
    d. What do you think families see as important in nursing care?
3. Describe a family and child you cared for that stands out in your memory and tell me the story of caring for them.
    a. When did you first meet this family?
    b. How long did you work with this family and patient?
    c. Why does this particular family stand out in your memory? Why did you choose this family to tell me about?
    d. Can you remember a particular moment you had with this family?
4. I am also interested in knowing the nursing care you provided this family. What did you do for this family?
    a. How would you evaluate the care that you gave? Was it good? Could you have done more?
    b. Looking back, would you now do something different?
5. Caring for children and families at the end-of-life can be emotionally stressful. How would you describe how you manage this part of the job?
    a. What type of emotions have you experienced? What helps to cope with the emotion?
    b. What type of support does the facility provide for nurses' professional growth?
    c. Do coworkers provide each other with an emotional network? Do you talk about your emotions? Do you feel allowed to share emotion if desired?
    d. Is it important to you to stay in contact with the families? If not, how do you manage ending the relationship?

PROBES:
Tell me more about…
Can you give me an example of what you are sharing?
What does this mean to you?
Is there anything else I should know about?

Appendix F

Demographic Information Sheet

Code: ______________________

Age: _________

Please Circle:					
Gender:	Female	Male			
Ethnicity:	White	Black -American	Hispanic	Asian	Other
Highest Degree:	Associate	Bachelor's	Master's	Doctorate	

Job Title ____

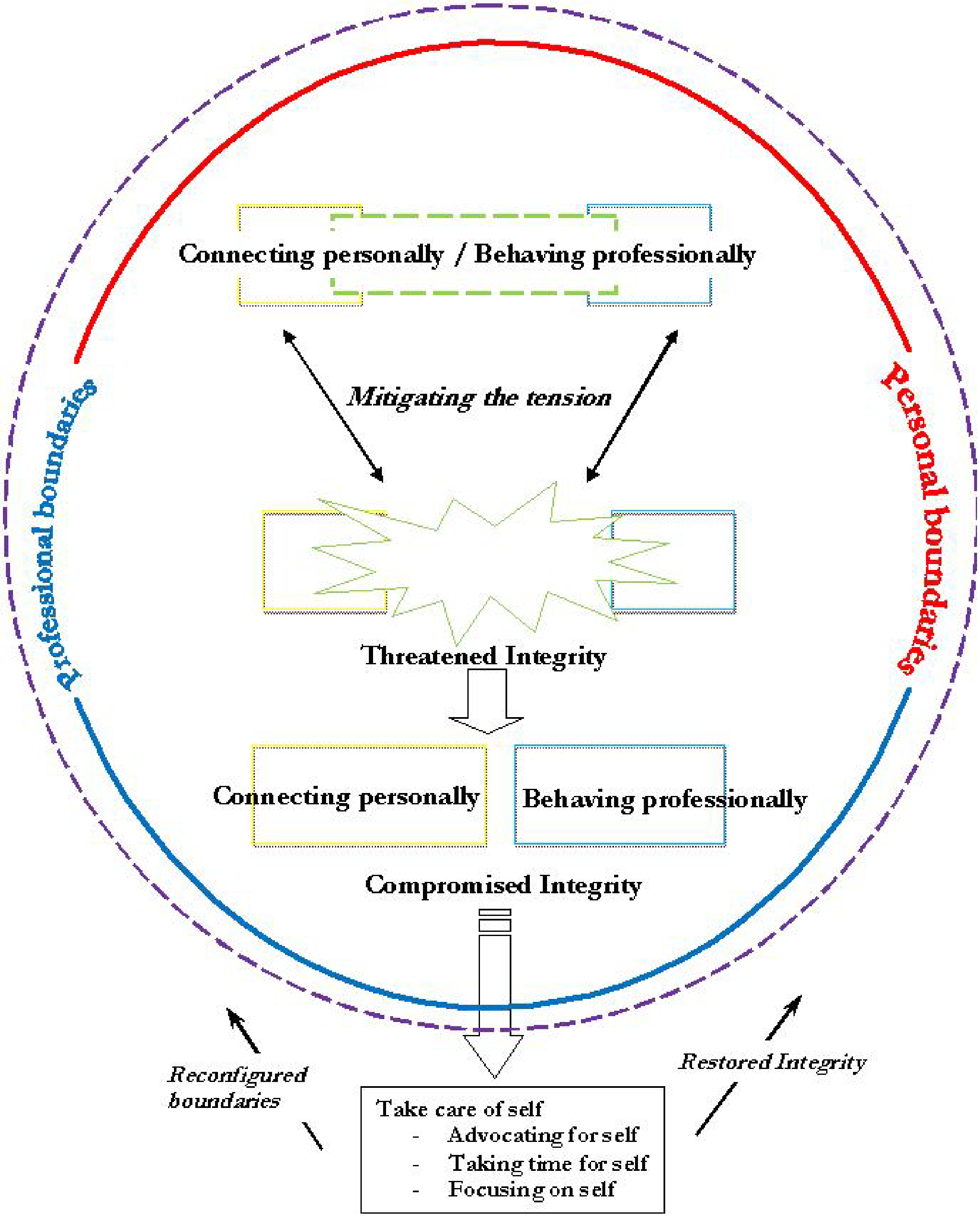
How many years at current work setting ______________________

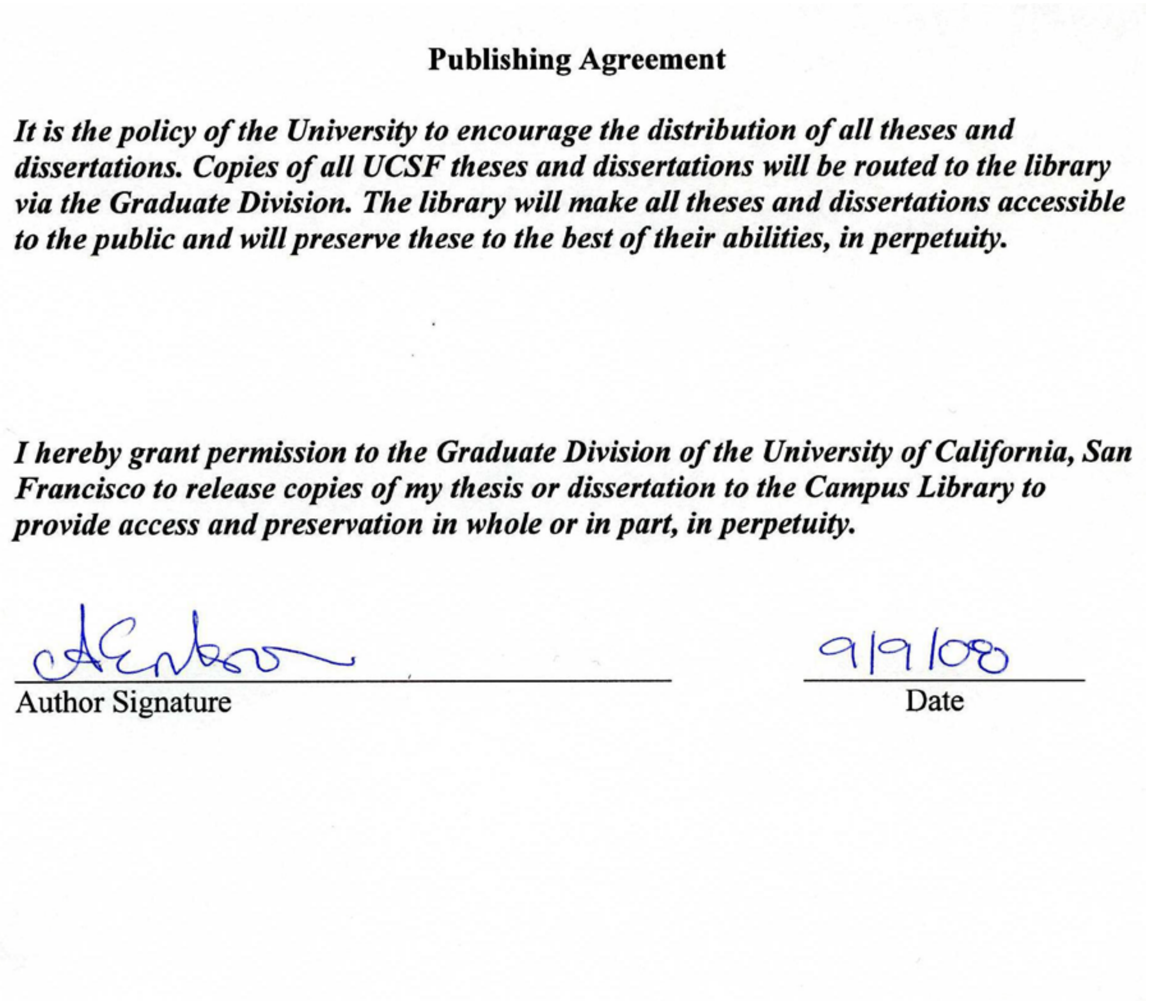
How many years in nursing practice __________________________________

How many years in pediatric practice ____

Appendix G

Figure 1. *Diagram of maintaining integrity: how nurses navigate boundaries*





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9/9/08

Date