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"Do You Think the Angels Will Speak Spanish?": Nurses' Experiences of Death in Pediatric Oncology

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“Do You Think the Angels Will Speak Spanish?”:
Nurses’ Experiences of Death in Pediatric Oncology

by

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A THESIS

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Abstract

Caring for children dying of cancer and families experiencing immense suffering is challenging complex work. Pediatric oncology nurses attend to the physical and emotional needs of children and their families during the illness progression, at the moment of death, and beyond, however, little is known about how they themselves are affected, and how this ultimately influences the care they are able to give. My intent with this philosophical hermeneutic research was to add to our understandings of these effects on pediatric oncology nurses and to translate this understanding into ways to support nurses in this challenging component of their work. Fifteen pediatric oncology registered nurses were interviewed to expand our understanding of this topic. These data were then analyzed according to hermeneutic tradition as guided by the philosophical hermeneutics of Hans-Georg Gadamer. Findings from this research revealed that nurses struggled to navigate the ideals of nursing versus the realities of practice when working with children who may die. This continual shifting of lines and positions called for them to maintain a fine balance between the personal and the professional. This ontological struggle is not absolute; rather, it is premised on a shifting continuum based on a complexity of personal and professional beliefs, experiences, and expectations. There needs to be a reminder that death continues to be an unfortunate constant in the work of these nurses. A reality, that in many ways, society has turned away from and hidden, a reality that has shaped the way death is experienced within pediatric oncology. This common middle ground is what nurses called for in order to be sustained and remain in their work. Research and transformative education that specifically addresses the tension created by insufficient

end of life and death education is required for nurses to feel more comfortable and competent within the ontology of death and dying. This necessitates a re-conceptualization of how death is processed in pediatric oncology.

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Dedication

To Florence E Morck

For all that you are and all that you do

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An Epilogue in a Prologue

It has been several days now since I successfully defended this work and several months since the completion of writing and placing this work into the academic arena for examination. I am called to reflect upon the effect of this topic on the pediatric oncology nurses who work in its midst and the effect upon myself. Along the way there have been questions and comments from friends, colleagues, and acquaintances of “why would you want to study a topic like this, it must be difficult, and there must be easier ways to get a PhD?” I suppose the easy answer might be that, with a father who was a Lutheran minister and pastoral counselor, and a mother who was a palliative care nurse, and as a member of a family decimated by cancer, death was never very far away in our family. Yet, I found this topic did unsettle me and make me uncomfortable. I had to fight my own need for safety and distance from a topic that provided me with little of either. It was, as one of my examiners noted, a tension filled journey of head and heart - - between the need for academic distance and the emotion the topic wrought. In entering into the world of pediatric oncology nurses and childhood death, as they shared stories of heartache and hope, I was marked in good and bad ways. Philosophical hermeneutics, as a research approach, places us in the midst of topics and tensions. It asks of us to follow a topic as it unfolds and in its unfolding journey we are placed at risk of losing its threads and ourselves (Davey, 2006). This tension between head and heart needs attention, recognition, care of self and care of the topic. Looking back, I would say, that this position of being amidst is neither an easy venture nor one in which I remained unscathed. A quote from Deleuze and Guattari (1987) reminded me of why: “It is not

easy to see things in the middle, rather than looking down on them from above or up at them from below, or from left to right or right to left. Try it and you will see everything changes” (p. 25). Understanding and change is the reward and the risk of a hermeneutic adventure. I have been moved, marked, and changed by this topic of cancer, death, children, and nurses. My hope is that I have brought this work to a place where it can remain in the midst of further conversation, discussion, and examination - - that the effect of topics such as this, will continue to be in play, to be pushed toward further understandings of its effects on nurses, society, and researchers alike. My hope is that there will always be more questions.

Chapter One: A Topic Calls

An Invitation to the Topic

As a mental health nurse by background some people are surprised to learn I work in cancer care, and yet cancer draws me to it on a personal and a professional level. I come from a large Scandinavian family that has been decimated by cancer. With both of my parents having ten siblings each, the branches of my family that have fallen to cancer continue to grow as it begins to now call for my generation. Six years ago I was approached to become part of the Interprofessional Psychosocial Oncology Distance Education (IPODE) program for healthcare professionals working in cancer care. Knowing how my family relies upon and requires the care of these healthcare professionals through our walk with cancer, I was eager to work with the program. During the first year of my work with IPODE, I co-facilitated a graduate psychosocial oncology course attended by nurses and social workers. Two of the nurses who participated had a pediatric oncology background. While discussing the difficulties and trials of our work during an on-line seminar another oncology nurse asked of the two “how can you work with kids that die?” and then exclaimed, “I could never, not with kids.” Previously, these two nurses had shared how excited they were to be part of a community that understood, that they could be open with, and learn from. They shared that they often felt out of sync within pediatrics as if the death of the children they worked with was contagious. I do not believe the other nurse meant any harm, her question perhaps born from her own curiosity and discomfort. It did however have an effect. Over time in the seminars, the voices of the two pediatric oncology nurses

become smaller, quieter, until at times it appeared they were no longer there. I wondered if they felt out of sync again, as if their hoped for “safe space” had been shattered and they were relegated again to the outside by those of us “who did not get how you can work with kids that die.” I also wondered if there was a safe place to have these conversations for pediatric oncology nurses and how indeed did they navigate these issues.

To Gadamer (1989), “understanding begins when something addresses us” (p. 298). This sense of address, or call of a topic, according to Jardine (2006), can also “strike us, catch our fancy, ... speak to us, call for a response, elicit or provoke something in us, ask something of us, hit us, bowl us over, stop us in our tracks, make us catch our breath” (p. 270). There is an element of surprise, of springing back as if from the force of impact. The death of a child has been described as the kind of experience that can take one’s breath away; like a punch to the stomach, it can drop you to your knees with its intensity (Bearison, 2006). The stories of these nurses continue to bring me back to that breathless experience. Shannon, a participant in this research, carries with her the remembrances of a six-year old Hispanic boy. Worn down, in pain, and suffering he asked for his treatment to stop. He asked for his family and those healthcare professionals working with him to accept this, to be okay with his decision. His greatest worry was not that he would then die but a wondering of “do you think the angels will speak Spanish.” His question resonated and stayed with me as the disorienting magnitude of expression found in the work of these nurses. It took my breath away. These are questions of unfathomability, questions we never want to hear arising from a

six-year old child, and yet they do continue to arise in pediatric oncology. It is for this reason that my work is entitled such that it is. There is a necessity to attend to this “sharp end of the punch” that has taken my breath away and to attend to the work of these nurses that matters. There is a need to remember that the death of children in cancer care remains an irrefutable but contemptible constant in their work - - a constant emphasized when a child tells us what we as a society cannot face, and when a nurse years later recalls his name as tears stream down her cheek.

Background to the Research

We commonly believe that our children should not die before us, yet each year in Canada, approximately 1500 children under the age of 20 will develop cancer. While 5-year survival rates now exceed 80%, cancer remains one of the leading causes of disease related death in children and adolescents (Canadian Cancer Society, 2009). Advances in cancer research and technology over the past 50 years have greatly improved the prognosis of childhood cancers. As a result, there has been a dramatic increase in the survival rates of children with cancer. Some malignancies are now considered curable. Although the advances have been significant, there remains a wide-range of diagnoses and prognoses in childhood cancer (Ellison, Pritwish, Mery, & Grundy, 2009). The International Classification of Childhood Cancers has classified 12 diagnostic groups of childhood cancers (Steliarova-Foucher, Stiller, Lacour, & Kaatsch, 2005). Compared with adults, children have a higher proportion of blood and lymphatic cancers. Leukemia, a cancer of the blood, is the most common childhood malignancy (26%), with lymphomas (17%), and cancers of the central nervous system (16%) the next most

common. Cancer is marginally more prevalent in boys than girls, and the type of cancer diagnosed often varies by age groups (Canadian Cancer Society, 2009). A diagnosis of childhood cancer may be delayed due to the nonspecific nature of signs and symptoms that can also vary by type of cancer and extent of the disease. Compared with adults, tumours in children are more likely to have short latency periods, to grow more rapidly, aggressively, invasively, and to metastasize more frequently (Pizzo & Poplack, 2010). The prognoses of childhood cancer will vary widely depending on the location of the malignancy and its development but 5-year survival rates for all malignancies have improved considerably in Canada to approximately 82 % (Canadian Cancer Society, 2009).

Improvements in childhood cancer survival rates have been attributed to improvements in treatment regimes. Clinical trial protocols, used for many types of childhood cancer, have given a definite survival advantage to children. Almost 80% of children with cancer in Canada are either enrolled in a clinical trial or receiving treatment according to a registered protocol established by a clinical trial (Ellison, Pogany, & Mery, 2007). Once a child has been diagnosed with cancer, there is a range of treatments. Methods of treatment include surgery, radiation, chemotherapy, and bone marrow transplant. Some malignancies will require treatment with a combination, or all of these methods. The length of treatment for childhood cancer is considerably longer than for adults and can range from five months to three years and more (Ellison et al., 2009). Pediatric oncology patients in Canada will be admitted to the hospital 5000 times and

spend approximately 50,000 days in the hospital per year (Scott-Findlay & Chalmers, 2001).

The introduction of increasingly more effective treatments, medications, medical imaging technologies, and surgical procedures has produced significant improvements in prognoses and longer survival times. However, with these advances, medicine has over time become increasingly complex. Despite substantive improvements in life expectancy and prognosis, this greater complexity has led to more uncertain consequences, including the knowledge of when treatment has failed and dying is imminent (Docherty, Miles, & Brandon, 2007). Most children with cancer will die in a hospital setting (Bearison, 2006; Libin, Papadatou, & Wolfe, 2008). It is often during the time surrounding the death of their child that families require the greatest amount of expertise from healthcare professionals (Davies, Steel, Collins, Cook, & Smith, 2004). The memories surrounding the moment of death can have profound impacts on family's grief and bereavement. Bellali and Papadatau (2006) found the memory of events, experiences, and interactions surrounding a child's death had positive or negative effects upon the grieving process of parents for several years after the loss. Nurse presence during the time of a child's death has been seen as a source of great comfort (Heller & Solomon, 2005; MacDonald et al., 2005). A failure to acknowledge emotional needs and nurses' absence during the moment of death has shown to be profoundly distressing for some families. This distress has shown to continue four to nine years after the loss of their child (Kreicbergs et al., 2005).

Healthcare professionals, and nurses in particular, are now more than ever affected by childhood death since an increased number of these children will die in hospital while receiving active cancer treatments (National Cancer Institute, 2009). Caring for a child dying of cancer and a family experiencing immense suffering is challenging complex work. Pediatric oncology nurses are frequently the healthcare professionals bearing witness to this vulnerable and intimate time of profound loss (Olson et al., 1998; Papadatou, 1997). These nurses attend to the physical and the emotional needs of children with cancer and their families during the course of this life limiting illness, at the moment of death, and beyond, however, little is known about how they themselves are affected, and how this ultimately has an impact on the care they are able to give.

Research Purpose and Significance

Research has shown there can be tremendous amounts of suffering in families who have had children die from cancer, and this suffering can continue for years (Bellali & Papadatau, 2006; Heller & Solomen, 2005; MacDonald et al., 2005). It is an obligatory demand of nursing to attend to suffering, to diminish, and hopefully soften suffering's progress whether it is of an emotional, physical, or spiritual nature (Wright, 2005). In the midst of this attendant practice, are pediatric oncology nurses who "with their hands, voices, and hearts" (de Ruiter, 2007, p. 63) witness the unfathomable experience of a child's death. Pediatric oncology nursing is an area that is at once both rewarding and stressful (Clarke et al., 1996; Docherty et al., 2007; Papadatou, Bellali, Papazoglou, & Pertaki, 2002, Papadatou, Martinison, & Chung, 2001). It follows that

professionals who witness the pain and suffering of children and their families may also experience pain and suffering (Papadatou et al., 2002; Rashotte, Fothergill-Bourbannais, & Chamerlain, 1997). However, there is a paucity of literature in this area and relatively little is known about how pediatric oncology nurses are affected by the death of a child in their care. My research focused on how nurses were affected by their day-to-day involvement in the complex navigation of circumstances and relationships surrounding the death of a child from cancer.

This research is timely considering the lack of research found in the literature and the continued call from the pediatric oncology community for support to pediatric oncology nurses. There is a need to uncover this knowledge through the conversation of the nurses who work everyday within this complex area of clinical practice. My intent with this research is that it will serve to add to our understandings of these effects on pediatric oncology nurses and to translate this understanding into ways to support nurses in this inevitable, yet challenging, component of their work. I aimed to explore the manner in which healthcare and society can ultimately assist them to continue to do this important work in ways and means that are helpful and not harmful to them.

Research Question

The research topic I chose to explore was that of the impacts on pediatric oncology nurses of the death of a child in their care. I was curious about the impacts and effects of this complex experience on nurses. In a context where relationships form, and are sustained over time by the very nature of the trajectories of childhood cancer, how do

nurses navigate, live alongside, and experience their own losses when a child with whom they have cared, and perhaps loved, dies?

Chapter Two: Review of the Literature

Dying, Death, and Societal Understandings

Death is the one certainty in life. Yet, western society has often been denoted as a death denying society (Gray, 1988; Kastenbaum, 1995; Kübler-Ross, 1969). Even though death happens all around us every day, “discussions of death are regarded as morbid, impolite, and distressing” (Lee, 2002, p. 92). There exists, instead, a broad range of euphemisms and medical terminology used to avoid speaking of death in conversation (Bearison, 2006; Kastenbaum, 1995). Phillipe Aries’ (1982) book, *In the Hour of Our Death* delineated five epochs of death that have arisen in western society over the past millennium. His final epoch, *invisible death*, reflects the belief “death has been banished, both metaphorically and literally, from the arenas of our lives” (Kamerman, 1988, p. 28).

The complexities and understandings of death and dying are not necessarily personal experiences. Rather, they are determined by cultural expectations, social values, and community practices (Weisman, 1973). “The norms, values and customs of the larger society mediate and make sense of the dying experience so that any understanding of death must encompass the larger sociological perspective” (Retsinas, 1988, p. 209). In an examination of the impacts of a child’s death on pediatric oncology nurses, it is thus essential to trace some of these ancestral and historical perspectives about death in western society.

It has been argued that a “death system” (Kastenbaum, 1995, p. 59) has facilitated the removal of death and dying process from the home and secured its banishment. This death system is an “interpersonal, sociophysical and symbolic network through which an

individuals relationship to mortality is mediated by his or her society” (p. 59). It consists of people, places, times, objects, symbols, and language that encompass medical, legal, philosophical, moral, religious, and economic considerations (Auger, 2000; Eddy & Alles, 1983) which moderate how persons in western society become educated about death.

In the past, education about death and dying took place primarily within the family through individual and family development life experiences. Families were larger, children died as frequently as adults, and few were protected from death and its subsequent rituals. Deaths were expected and the process was integrated into the family life cycle. Less fear and denial were attributed to death (Kastenbaum, 1995; Stroebe, Stroebe, & Hansson, 1998).

The fifth epoch, *invisible death*, corresponds to the later modern era of the 20th century (Aries, 1982). This time period saw dramatic changes in attitudes toward death and mourning. These changes were precipitated by the believed excesses of Victorian period mourning practices, as well as medical and technological advances that countered arguments to the divine mystery of death (Aries, 1982). There have been considerable demographic changes over the last century, including reduced infant mortality rates, increased life expectancy, and lowered birth rates. The majority of deaths now occur in adults. Death has come to be considered a problem of aging. Improvements in medicine including the introduction of antibiotics and childhood inoculations, and hospital births have contributed to a lowered childhood mortality rate. Larger numbers of infants and children live into adulthood. This has contributed to the expectation children will outlive

their parents (Bearison, 2006; Northcott & Wilson, 2008). Additionally, with longer life expectancies, there is also a longer period of lived time to experience and be affected by loss (Bearison, 2006).

Urbanization and increased mobility has contributed to the fragmentation of communities and extended families, reducing the resources available to care for, and memorialize, the dead and dying. The funeral industry began at the end of the American Civil War to meet the need to embalm and preserve the large numbers of bodies shipped home from the battlefields (Aries, 1982). The industry grew rapidly throughout the 20th century, and gradually appropriated the majority of formerly private death rituals (Mitford, 2000; Searl, 2000). The staggering numbers of deaths from World War I and the influenza epidemic in the first decades of the 20th century saturated society with death. This fostered an aversion to thinking about death, and a subsequent diminishment of talking about death in society (Northcott & Wilson, 2008).

Causes of death have changed dramatically during the last century. Previously, infection or parasitic diseases such as tuberculosis, pneumonia, and dysentery caused one in five deaths in Canada (Eddy & Alles, 1983, Northcott & Wilson, 2008). Substantial rapid growth in medicine and technology has occurred since World War II (Connelly 1997/1998; Kastenbaum, 1995). As technology advanced, more illnesses became treatable or even curable. Another practice unique to the 20th century was the institutionalization of ill and dying persons. Prior to this time period, hospitals were often thought of as places of death and were shunned. With advances in medicine and technology, public confidence in hospitals grew. As public confidence grew, so did the

number of hospitals. The care of dying persons began to shift to hospitals (Northcott & Wilson, 2008). By 1954, over three-quarters of all deaths in Canada were recorded as occurring in hospitals (Wilson et al., 2001).

These shifts in medical care also impacted nurses and physicians. To meet public demand for skilled healthcare workers, the numbers of nursing and medical schools grew significantly across Canada (McPherson, 1996). After graduation, nurses typically had worked in private homes where they cared for the chronically ill or dying. Dramatic shifts were seen in the time period from 1890 to 1940 in this practice. Lack of steady employment and poor work conditions caused many nurses to seek more secure work in the growing number of available hospitals (Canadian Nurses Association 1964; McPherson, 1996). During the later half of the 20th century, care of the dying became less significant. Nursing and medicine shifted their focus to the preservation of life. Although dying and death were frequent topics in health literature until the 1940s, little mention of either is noted in the health literature from 1950 to 1990 (Northcott & Wilson, 2008; Wilson et al., 2001).

It has been argued these dramatic changes regarding how, where, and why people die and are buried have contributed to death fear and the denial of death (Aries, 1982; Auger, 2000; Eddy & Alles, 1983). Dying in an institution rather than one's home has resulted in a denial of death as well as distancing individuals and families from the death process. Death has become less public. Rituals and preparation of the dead body have been subsumed by hospitals, morgues, and by the funeral industry rather than as public involvement by family and loved ones. Aries (1982) argued this distanced stance has

also displaced the reality of facing one's own death. According to some, death has been turned over to the experts. These experts inform when and how persons are dying. They have also devised procedures for disposing of dead bodies. Commutatively, this has displaced death as a natural part of life while simultaneously increasing its unknown, fearful, and mysterious nature (Aries, 1982; Kamerman, 1988; Kastenbaum, 1995). Miles (1993) suggested these well-intentioned societal structures or "death system" (Kastenbaum, 1995, p. 59) have also attempted to mitigate loss and the subsequent expressions of grief.

Theoretical Frameworks of Death and Dying Research

Becker (1973) surmised humans are unique in the fear of death because we are the only species with an awareness of time, and the loss of time, through death. To Becker, "death is man's peculiar and greatest anxiety" (p. 70) and our fear of death is tantamount to being human. The universal human concern of death has been a topic of contemplation and examination throughout time and across cultures. The academic pursuit of death studies has crossed multiple disciplines and been examined by clinicians and researchers over the past century amassing a significant body of work (Lamers, 2012).

Discussions of death and dying tend to return to how human beings are affected by loss and death. Given this, a research study examining the impact of death must potentiate discussion of loss, mourning, bereavement, and grief. While reviewing the theoretical literature in this area it became quickly apparent these concepts are joined and

difficult to sever. I thus offer an intertwining of death and its human responses as found in the literature.

Early Psychoanalytic Theories

During the later years of World War I, there were an immense numbers of deaths. Loss was on everyone's mind. With two young sons fighting on the front lines, and anxious for news of their safe return, Sigmund Freud initially expressed his understandings of grief work (Bradbury, 2001) in 1917 through a paper entitled *Mourning and Melancholia* (Freud, 1957). According to Freud, libidinous energy attached to the mental representation of a loved one (cathexis to the object). After the object died, this energy remained attached to memories of the deceased. Libidinous energy, being a finite resource, required cathexis to the lost object to be withdrawn (de-cathexis) so that it could be available as energy for the bereavement process. Freud believed the work of grief consisted of gradually releasing bonds to the deceased through recalling memories and reviewing the past. The process was completed when the energy had been withdrawn from the deceased and transferred to a new object (Freud, 1957). Failure to complete this process was thought to result in "emotional stunting" (Stroebe, Gergen, Gergen, & Stroebe, 1992, p. 1206).

Freud's (1917/1957) psychoanalytic theory has extensively influenced the development of the dominant modernist discourse surrounding grief and bereavement evident throughout the past century. The idea of working through loss was carried forward by subsequent theorists including Lindemann (1944), who stipulated pre-death functioning is returned to after a period of grief. Lindemann believed de-cathexis or

“emancipation from the bondage to the deceased” (1963, p. 11) must be achieved. Grief was described as a syndrome that began with an acute phase of four to six weeks that gradually diminished over time (Lindemann, 1963). Movement through his linear series of stages led to recovery and ultimately the severing of and detachment from the relationship with the deceased. Expressions of grief beyond this timeframe were thought to be a complicated grief reaction (Brabant, 1989/90; Rothaupt & Becker, 2007).

Twentieth century studies on death and dying continued to increase after WWII with the “pervasive death anxiety” (Benoliel, 1982, p. 102) following the bombing of Hiroshima. Haunted by the memories of never before seen casualties, many modern era thinkers returned to considerations of life and death issues. Early seminal work in current era death studies has been attributed to American psychologist Herman Feifel (Lamers, 2012). In 1959, Feifel edited a book entitled *The Meaning of Death* with trans-disciplinary contributions from eminent thinkers including psychiatrist Carl Jung, theologian Paul Tillich, psychologist Robert Kastenbaum, and philosophers Walter Kaufman and Herbert Marcuse (Feifel, 1959). This work challenged the invisible nature of death and encouraged an acknowledgment of mortality as essential for a meaningful life. His efforts broke the entrenched taboo that had previously discouraged research or study of death and dying. The book laid the foundation for the field of death studies that would eventually be known as Thanatology. Thanatology, derived from the Greek *thanatos* meaning death (Hoad, 1996), is a collaboration of numerous fields of study concerned with death and dying, bereavement, grief, and mourning (Lamers, 2012).

Stage and Phase Models

The early psychoanalytic theories of Sigmund Freud (1917/1957), and later Erich Lindemann (1944), gave rise to numerous stage and phase models of grief, which continue to influence understandings, experiences, and responses to loss (Rothaupt & Becker, 2007). Bowlby (1961) enhanced existing understandings of grief through his work on attachment theory. He is credited with moving grief theory from an individual focus to an interpersonal perspective in an attempt to revise psychoanalytic theory (Parkes, 2002; Stroebe et al., 1988). Bowlby viewed grief as a process, resolving equilibrium between the self and the social environment. Normal functioning returned when bonds to the deceased were broken. The severing of attachments to the deceased continued to be required for recovery. Bowlby's attachment model became the foundation for further stage and phase model work by Kübler-Ross (1969), Bowlby and Parkes (1970), Parkes (1972), and Worden (1982). Elisabeth Kübler-Ross described the origin of her work with WWII Polish concentration camp survivors: "I saw dying in its most horrible form, but also living and surviving in its most gracious form" (1978, p. 18). This evidenced human struggle with death, and her work with dying cancer patients, led to her conceptualization of a five-stage adaptation model of dying. She argued movement through the over-lapping linear stages (denial, anger, bargaining, depression, and acceptance) was predictable and consistent across dying individuals. These were not stages moved through systematically, nor in a chronological order, but rather responses to death that may be permanent, temporary, or imperceptible (Kübler-Ross, 1969). Kübler-Ross's work had enormous impact throughout the world. During the 1970s, due to its

easily understandable staged process and recognizable appeal, it was misappropriated into grief counseling by clinicians and the general populace (Retsinas, 1988). This undertaking saw her model applied to a different population from the dying persons she researched, and generalized to account for a variety of losses. The movement to view her model as suitable for a variety of losses was neither negated nor refuted by Kübler-Ross (Koningsberg, 2011). Following her death in 2005, her final book *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss* was published. In it, she claimed the five stages of dying had been misunderstood but were nevertheless useful to those grieving the loss of a loved one (Kübler-Ross & Kessler, 2005).

Bowlby and Parkes (1970) presented a staged model that theorized grief as a biological and psychological process. Progression through the ascribed stages included anger, protest, hope for the loved one's return, despair when hope is futile, and finally recovery and reorganization through breaking the bonds of attachment. Parkes (1972) subsequent solo work focused on grief resolution as a release of old roles and patterns of interactions and the establishment of new ones. Parkes proposed a four-phase theory showing an evolution of the bereaved person's return to feelings of safety and security (homeostasis) as they resolved their grief. According to Parkes, grief work is fundamentally a realization and coming to terms with the reality of the loss.

Worden (1982) identified four central tasks that must be accomplished to resolve grief. He emphasized grief work as a process, not a state, and criticized Parkes' (1972) phases as implying passivity. Worden has revised his task model over time. The initial change included assistance for the bereaved to find place for the deceased in their

emotional lives. In his subsequent 2002 version, Worden constructed the final task as a redefinition, rather than a relinquishment, of the relationship with the deceased (Worden, 2002). This revision reflects the growing movement away from traditional theories of time-limited phases or stages that result in a breaking of bonds with the deceased, and an end to grief (Rothaupt & Becker, 2007).

The early stage and phase models garnered healthcare professionals and general public attention to the topics of death, dying and grief. This work collectively brought about significant changes in the ways in which many people think about dying and grief (Corr, 2007). Numerous theorists, however, have identified a paradigm shift that has been taking place over the past two decades. Within this shift, the traditional theories of grief and bereavement, inherited from Freud, are being reviewed and challenged (Attig, 1996, 2004; Klass, Silverman, & Nickman 1996; Moules, 1998; Neimeyer, 2004; Walter, 1996). In a seminal paper, Wortman and Silver (1989) challenged what they believed were “mistaken assumptions” (p. 349) in dominant bereavement literature and clinical practice. They argued against the necessity to work through stages and debunked recovery and resolution as expected norms. Instead, Wortman and Silver argued for recognition of the variability in response to loss, and that there is no “prescription for how to grieve properly” (1989, p. 355). Stroebe and Schut (1999) suggested that, rather than discrete stages through healing, there is an ongoing oscillation between loss orientation and restoration orientation. Their Dual Process Model of Coping with Bereavement stipulated the bereaved cycle between times of experiencing grief actively and focusing on the loss, and then move into times of restoration orientation through

rebuilding their new life and engaging in new relationships, activities and distractions (Stroebe & Schut, 1999). Other critiques have followed that explored perceived success in grief resolution, and the subsequent pathologizing of experiences not congruent with normative perceptions (Attig, 1996; Klass et al., 1996). These critiques have asserted the narrowly held stance of normative grief work has been harmful to many and led to the defining of abnormal, pathological, unresolved, chronic, morbid, prolonged (Tomita & Kitamura, 2002; Wortman & Silver, 1989); complicated (Enright & Marwit, 2002), dysfunctional (Rancour, 1998); exaggerated (Jacobs, 1993); or traumatic (Jacobs, Mazure, & Prigerson, 2000) grief.

Current Reinterpretations of Loss and Grief Theories

Freud's views of grief work and relinquishing bonds through de-cathexis have been pervasive and long lasting in their influence on dominant grief and bereavement theory (Rothaupt & Becker, 2007), yet, he may well have set the context for some of the current reinterpretations. Freud wrote to a friend who similarly experienced the death of a child:

Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. It is the only way of perpetuating that love which we do not want to relinquish. (Freud, 1961, p. 386)

Freud's words imply a stance more closely aligned with contemporary grief theories that have arisen from a social constructionist understanding of the world. These

understandings assert human beings construct individual meanings in the context of the social environment in which they exist. There are then many or multiple perspectives of a situation. Each truth is created within the context of a particular individual's social and historical milieu, his or her individual and family experiences, and his or her capacity for reflection and insight (Gergen, 2009). Neimeyer (2006) punctuated six required criteria for a theory of grief, situated in social constructionism, to successfully disrupt traditional theories. First, it cannot be assumed any two individuals will follow a preset path of bereavement; rather, there is an acknowledgement of the diversity and variability of grief expressions. This breaks open the stance of an expected normative, or even familiar, expression of grief to include individual experiences and understandings (Holland & Neimeyer, 2010). Second, bereaved persons are active participants, not passive receptors, in facing the challenges evoked from the death (Neimeyer, 2006). This suggests understandings of loss need to be open to the variety of ways in which individuals and collectives anticipate and/or assimilate loss into their personal and shared belief systems. Third, grief theory needs to contain rich descriptions that explore personal meanings of loss. These descriptions cannot however substantiate a pattern of "normal" grieving. Fourth, there is a focus on the meaning and beliefs that shape emotional, behavioral, and somatic responses. Grief is viewed as an adaptation to loss rather than a cathartic process of breaking bonds with the deceased. This untethers grief from its Freudian connections to releasing bonds. A social constructionist position resists the premise that each person experiencing grief will have the same needs (Gillies & Neimeyer, 2006). What is more important, according to Neimeyer (2006), is the

recognition that reconstructing meaning following a loss involves cognitive, emotional, behavioral, and spiritual capacities. Individuals must create and recreate meaning from loss in a way that fits for them. Fifth, is an acknowledgement of the transformative capacity of loss. Recovery and return to a previous functioning is no longer the expectation (Neimeyer, 2006). There is recognition of an adaptation into a changed world while maintaining a sense of continuity and self-knowledge (Attig, 1996, 2002; Moules, Simonson, Prins, Angus, & Bell, 2004). Finally, while highly personal, grief responses are situated in larger social, cultural, and family contexts (Rosenblatt, 2001). Perhaps the two most well known contemporary theories that have arisen from social constructionist tenets are “continuing bonds” (Klass et al., 1996) and “meaning reconstruction” (Neimeyer, 2006).

Continuing bonds theory. Klass et al. (1996) denoted, from their independent research over the course of a decade, that “rather than letting go, they [the bereaved] seemed to be continuing the relationship” (p. xviii). This recognition spurred an awareness of other clinicians and researchers who also viewed similar reactions in bereaved persons. An edited book arose from these discussions. It contained the work of many like-minded scholars, who wished to challenge the belief that the purpose of grief is to sever bonds with the deceased (Klass et al., 1996). Other scholars had also begun to challenge this dominant discourse. White (1989) disrupted the premise that the work of grief entailed a finality of relationship and saying goodbye to a loved one. Instead of saying goodbye, White premised, that what was important was rather “saying hullo again” (p. 29). The relationship continued, albeit differently. Concordantly, the bereaved

do not resolve or get over their loved ones death but rather adapt and change their relationships in a process of accommodation that continually changes over time, but is never complete (Klass et al., 1996; Moules, 1998; White, 1989). Persons grieving construct an inner representation of the deceased that is part of the normal grieving process. Continuing bonds with the deceased can be a healthy part of the survivors ongoing life. Many persons will never reach a time when they finally stop grieving (Klass et al., 1996). Instead, many will continue to experience recurrent feelings of grief throughout their lifetime (Rosenblatt, 1996). Moules (1998) expressed that grief is a “journey of relationship” (p. 161). Instead of something to be gotten over, grief is the “experience of keeping in relationship with the lost person, who physically absent, is still profoundly a member of the family” (1998, p. 148). Attig (1996) similarly described mourning as a transition that moves from loving in presence to loving in absence. It is a practice of relearning and reshaping our relationships with ourselves, with others, and with the deceased.

Meaning reconstruction theory. Meaning reconstruction theory suggests that significant loss disrupts the coherence of meaning by which people construct their lives. The death can confirm or alternatively disconfirm the meaning systems constructed to understand their existence. It can also potentially create new experiences for which the bereaved person has no adaptive constructions (Neimeyer, Baldwin, & Gillies, 2006). Through this process, the person constructs and reconstructs stories of meaning that enable them to move into their new “assumptive worlds” (Parkes 1988, p. 57) despite the physical absence of the person (or entity) who/which was lost. According to Neimeyer,

this process sees the bereaved “search for ways of assimilating the multiple meanings of loss into the overarching story of their lives” (2001, p. 264).

Affirming or reconstructing personal meaning into a world that has been challenged or transformed by loss is seen as a fundamental element of grief (Attig, 1996; Neimeyer et al., 2006). This process includes the related practices of sense making, benefit finding, and progressive identity change (Neimeyer, 2001, 2006). The ability to discover or construct meaning in the presence of loss has been identified with more favorable bereavement outcomes (Neimeyer et al., 2006). According to Neimeyer (2001), meaning making is not a goal to be reached but rather an activity that changes over time. This concurs with Moules’ (1998) assertion that grief is neither an experience that is resolved nor possible to “get over” (p. 143). It is instead preferable to recognize “people do not have to relinquish their grief or escape it... [it] remains with people, though it assumes different influences and has different voices over time” (Moules & Amundson, 1997, p. 384).

Nursing Research on Death and Dying

A pivotal study by Jeanne Quint Benoliel in the 1960s began a resurgence of interest in nursing research about death and dying. As a part of the larger study by Glaser and Strauss (1968), Quint Benoliel examined the preparation and comfort of new graduate nursing students in working with dying patients. Her results suggested students were neither adequately prepared nor were they comfortable in providing care to the dying (Benoliel, 1982). Benoliel’s early work was foundational for the development of education and research into nurses care of dying patients. Other research studies in

medicine and nursing began at the same time with early work by Saunders in the United Kingdom leading to the developments of hospice and palliative care (Benoliel, 1999).

The 1970s saw an increase of research on nurses' attitudes about death, responses of patients to impending death, and family bereavement. Nurse researchers at this time were also developing conceptual and operational definitions for factors related to death and dying such as death attitude and death anxiety (Benoliel, 1988; Kurlychek, 1978; Taylor, 1983).

A subsequent focus turned to the interaction of nurses and understanding their encounters with death. Working with terminally ill and dying patients has been found to be emotionally draining and challenging (Clarke et al., 1996; de Carvalho, Muller, de Carvalho, & Melo, 2005; Kaplan, 2000; Rashotte et al., 1997; Saunders & Valente, 1994). Oncology nursing has often been described as among the most stressful specialty areas (Emery, 1993; Fitch, Matyas, & Robinette, 2006; Gray-Toft, 1980; Kash, Holland, & Breitbart, 2000; Lederberg, 1998; Papadatou, 2000; Vachon, 1987). Due to the length of many treatment protocols, oncology nurses and their patients enter into distinctive relationships characterized by their closeness, intensity, and duration of time, often extending from many months to years (Bearison, 2006; Feldstein & Gemma, 1995; Zander & Hutton, 2009). A major source of occupational stress among pediatric oncology nurses has been found to be their concern with the death and dying process of their young patients (Emery, 1993; Kushnir, Rabin, & Azulai, 1997; Hinds, Quargnenti, Hickey, & Magnum, 1994; Spinetta et al., 2000; Woolley, Stein, Forrest & Baum, 1989). Such losses, while working with children who have a potentially life limiting illnesses

such as cancer, are inevitable and perhaps even expected. Yet, according to Lasagna (1970), this “‘premature death’ will often be considered “more tragic” than the death of an adult patient as it represents “an example of unfulfilled promise” (p. 83). Papadatou (2000) suggested:

It is not uncommon for health care workers to perceive the death of a child as a “triple” failure: first, because they did not have the means, skills, or abilities to a save a life; second, because in their social role as adults, they were unable to protect the child from harm; and, third, because they “betrayed” parents who trusted them with the most valuable being in their life. (p. 576)

Working in an environment where the death of a child stands in contrast to expected normative beliefs, and is considered a failure, can leave pediatric oncology nurses vulnerable to high levels of personal stress (Hinds, 2000; Gray-Toft, 1980; Vachon, 1998), burnout (Koocher, 1979), and grief (Clarke et al., 1996; Papadatou, 2000; Woolley et al., 1989).

Stress, Burnout, and Nurses

Beginning in the late 1980s and 1990s, research began to focus on the levels of stress experienced by nurses who provided care to dying persons. There was indication from this research that nurses who were frequently exposed to the dying process and death of their adult patients experienced significantly higher levels of stress and burnout (Chiriboga, Jenkins, & Bailey, 1983; Jenkins & Osthega, 1986). However, nurses who worked in hospice or palliative care settings experienced significantly lower levels of burnout. Researchers attributed this difference to better training and more effective

support in hospice and palliative care settings (Bram & Katz, 1989; Foxall, Zimmerman, Standley, & Bebe, 1990; Gray-Toft & Anderson, 1981). While no literature within the pediatric realm was identified, it can be surmised that similarities might be found. To attend to the discrepancies found within these practice areas, I have chosen as much as possible to review literature within oncology and specifically pediatric oncology.

Pediatric oncology nurses have been recognized as a particularly stressed specialty group due to their prolonged exposure to the suffering of patients and their family members. This is an exposure exacerbated by the typically close attachments over long treatment periods formed between nurses and their patients (Hinds et al., 1998; Lederberg, 1998). Individuals who experience persistent stress report symptoms of depression, anxiety, guilt, anger, and apathy (Cullen, 1995; Koocher, 1979, Zander, Hutton, & King, 2010). In addition, the “intense and ongoing losses experienced in oncology care make oncology nurses particularly vulnerable to the ‘burnout syndrome’” (Lewis, 1999, p. 1065). Burnout represents a set of symptoms associated with a prolonged process of attempting to cope with demanding stressors that culminate in the exhaustion of personal resources. It has been defined as a combination of physical fatigue, emotional exhaustion, depersonalization, and cognitive lethargy as a result of exposure to intense stress over time (Maslach, Schaufeli, & Leiter, 2001).

Nurses who are burned-out are at a high risk for becoming “abrasive, bitter, and cynical” (Cullen, 1995, p. 24). Burnout has been related consistently and negatively to work performance, job satisfaction, quality of life, and psychological wellbeing (Ergün, Oran, & Bender, 2005). Increased sick time and substance abuse are prevalent.

Emotional withdrawal from patients and fellow staff members, and a lack of focus, may have detrimental effects on patient safety, increase errors in judgment, or lead to an inability to provide a secure and supportive environment for patients and families (Cullen, 1995; Zander et al., 2010). Lowered patient outcomes have been identified in patients who have been cared for by nurses who suffered from burnout (Vahey, Aiken, Sloane, Clarke, & Vargas, 2004). Burnout has also been related to high staff turnover. It has often been cited as the reason nurses give for leaving their current positions (Hinds, Quargneti et al., 1994; Zander et al., 2010). Feldstein and Gemma (1995) concluded that leaving the specialty of oncology did not resolve the despair or burnout of nurses. This continues to be reflected at systems and professional levels, wherein nurses who are burned-out are not only leaving their current positions; they are leaving the nursing profession. This creates additional strain on the nurses that remain, as well as compounding the current issues of nursing recruitment and retention (Hinds, Pritchard, & Harper, 2004; Papadatou, 2009).

Pediatric oncology nurses are exposed to a wide variety of stressors in their work, including those having to do with the frequent and out of sync nature of their young patients' deaths (Bond, 1994; Emery, 1993; Olson et al., 1998). While there is a wealth of literature focusing on the issue of burnout in nurses, the majority of the research has been in the adult population (Zander et al., 2010). Limited research has occurred in pediatric or pediatric oncology nursing (Hinds et al., 1990). Hinds and colleagues have been one such group to attend to this area. Their program of research at St. Jude

Children's Hospital has been pivotal in pediatric psychosocial and the larger scope of pediatric cancer care since the mid-1980s.

Among their multi-dimensional research program, Hinds and colleagues have undertaken a series of studies of pediatric oncology nurses responses to the stressors of working with children with cancer (Hinds et al., 1990; Hinds, Puckett et al., 1994; Hinds, Quargnenti et al., 1994; Hinds et al., 1998; Hinds et al., 2003; Olson et al., 1998; Sanders 1994). I am providing a brief overview of their decades of research. The theoretical framework used to guide these research endeavors has been the Stress-Response Sequence (SRS) model (Hinds et al., 1990). The SRS instrument was developed to determine relationships between role-related stress, coping, and work consequences in pediatric oncology nurses. The challenge, according to the research group, was to distinguish factors that maximized stress diminishment from those that contributed to, or created, stress. Since 1990, a series of studies using the SRS have attempted to identify role-related stressors and sources of role-related meaning for nurses (Bond, 1994; Clarke-Steffen, 2000; Hinds et al., 1990; Hinds et al., 1998; Hinds, Quargnenti et al., 1994; Kushnir et al., 1997; Olson et al., 1998; Sanders 1994). In addition, the process and outcomes of intervention strategies designed to reduce role-related stress have been reported (Hinds, Puckett et al., 1994). The results from these studies of the SRS model yielded inconclusive and disappointing outcomes. Two further studies, which additionally sought nurses' experience with role-related stress and role dissatisfaction through the use of open-ended interview questions, yielded inconclusive findings (Hinds,

2000; Hinds et al., 1998). The totality of these findings prompted a modification of the original model to include the variable “role-related meaning” (Hinds et al., 2003, p. 214).

The revised instrument, the Role-Related Meaning scale, once again found the stress and coping components of the model did not predict role consequence. In contrast, descriptive findings revealed the nurses were moderately to highly stressed, frequently and effectively used coping strategies, had high levels of job satisfaction, organizational commitment, and group cohesion. The nurse participants also indicated low intent to leave their current organization. These conflicting outcomes suggested to the research team, that despite revision, a new model was required to predict role consequences in pediatric oncology nurses (Hinds et al., 2003).

The SRS model has received critique that it has failed to account for the unavailability of stress in pediatric oncology nursing practice. This practice specialty has high patient acuity, limited human resources that lead to high patient-nurse ratios, and the added dimension of watching the long-term suffering of children and their families. The question asked of the SRS model and its developers has become: if stress cannot be alleviated altogether, how do or can nurses influence factors in their work in such a way that do not become burned-out or affected by alternate negative reactions? (Forte, 2000). Indeed while speaking about the failure of the original and the revised forms of the SRS model to predict role-related consequences for pediatric oncology nurses, the research team concluded perhaps a remarkably different approach to target role-related stress was required (Hinds et al., 2003).

Recent attention has been given to the premise that oncology nurses may suffer from posttraumatic stress, secondary trauma, vicarious traumatization, or compassion fatigue as a result of working with terminally ill and dying patients (Meadors & Lamson, 2008). A correlation between exposure to a high volume of stressors and the development of these conditions has been found in the literature (Figley, 1995; Lewis, 1999; Maslach et al., 2001; Muscatello et al., 2006; Papadatou, Anagnostopoulous, & Monos, 1994; Sinclair & Hamill, 2006). Individuals with a tendency for empathetic interactions with patients, including oncology nurses, have been found to be at higher risk (Meadors & Lamson, 2008). These conditions have been found to be a strong contributor to resignations, staff turnover, increased sick time, lowered productivity, and a threat to the ability to provide effective care (Meadors & Lamson, 2008; Pfifferling & Gilley, 2000). These terms have often been used interchangeably within the literature. There has been a movement to consider these as separate and distinct concepts (Cunningham, 2003; Maslach et al., 2001; Sinclair & Hamill, 2006). Regardless, all of these conditions arise from exposure to a trauma (Figley, 1995). Traumatic exposure has been described as a “person experiencing, witnessing or confronted with an event or events that involved the actual or threatened death or serious injury, or a threat to the physical integrity of self or others” (American Psychiatric Association, 2000, p. 467). However, there has been a correspondently recent shift, from the study of stress and its correlation to burnout and related conditions, to understanding the stress of nurses as a response to loss and grief (Papadatou, 2009).

Loss, Grief, and Nurses

Rando (1984) described the concept of loss as including everyday losses, not just those that might be considered traumatic: “Loss is a natural part of existence” (p.16). It may be physical (tangible), such as through the death or loss of a beloved possession, or symbolic (psychosocial) such as getting divorced or demoted at work. Perhaps the most commonly recognizable loss faced by nurses is the loss of a patient through death. The death of a patient has been identified as major stressor for nurses (Emery, 1993; Clarke et al., 1996; Hinds, Quargnenti et al., 1994; Kushnir et al., 1997; Spinetta et al., 2000; Woolley et al., 1989). The death of a child is often considered the most difficult loss to endure. It is out of sync with the perceived natural life order, and thus deemed unfair and incomprehensible. Healthcare professionals stand alongside family members in the struggle to understand or find meaning in the death of a child (Kaplan, 2000; Papadatou et al., 2001; Woolley et al., 1989). While research in this area has been denoted as extremely limited, nurse’s grief, in response to the death of a patient, has become recognized (Hinds et al., 2004; Papadatou, 2009).

Saunders and Valente (1994) investigated nurses’ bereavement. Their data analysis yielded four themes, which they proposed as tasks, experienced by nurses following the death of a patient: 1) finding meaning, 2) restoring or maintaining a sense of personal integrity and self-esteem, 3) responding and managing personal feelings, and 4) realigning relationships. They recommended nurses’ need to establish a balance that allows expression of their grief while maintaining the ability to fulfill professional role

obligations. Being able to process and successfully cope with grief assists nurses in avoiding burnout in their careers (Saunders & Valente, 1994).

In a concept analysis of grief, Cowles and Rodgers (1991) described factors important to the grieving: 1) the nature of the loss, 2) the relationship to the lost, 3) the presence of support, and 4) the individual's previous experience with loss. This concurs with findings from Saunders and Valente (2002) who stipulated developmental age, exposure to death, deceased's age at death, nature of death, and relationship to deceased were factors that may positively or negatively influence grief. Increased experience, older age, and an increased exposure to death were found to mitigate the veracity of stress. Less experienced, and younger nurses however had greater stress responses; while nurses who had more distant relationships with patients were found to have less stress responses (Cowles & Rodger, 1991; Saunders & Valente, 2002).

Hinds and colleagues, in response to nurses' grief, offered a grief workshop as an intervention to determine its impact on the nurse participants (Hinds, Puckett et al., 1994). Nurses positively evaluated the workshop but no decrease in their grief symptoms or perceived stress was found. Interestingly, the workshop increased stress levels of the more experienced nurse participants as compared to the less experienced nurses. The researchers speculated the workshop may have highlighted the more experienced nurses' sensitivity to loss and grief from which they had been previously successful in defending themselves against (Hinds, Puckett et al., 1994).

Saunders and Valente's (1994) themes were echoed in a grounded theory study of Canadian pediatric nurses who cared for dying children (Clarke et al., 1996). The nurse

participants described a sense of struggle in dealing with the death of children. Two core themes were identified from the data: the experience of grief distress, and the experience of moral distress. Nurses were found to cope more effectively when they acknowledged and expressed their emotions over the dying or death of a patient, yet, moral distress arose as nurses described facing the dilemma between “obligation” (Clarke et al., p. 505) to follow physician’s orders and duty to provide a comfortable death. Davies and colleagues identified a number of facilitative coping strategies nurses used to manage distress. These included acknowledgment of their grief responses, attribution of meaning, search for support among family, friends, and colleagues, and maintaining control over situations (Clarke et al., 1996). Peer support and a sense of being valued were identified as particular conditions that enhanced nurses’ coping. Conversely, certain personal or work-related expectations did not allow the expression of grief and constrained nurses’ coping with patient loss. Nurses believed expressions of grief were contrary to expected standards of professional behavior that taught them to not show emotion or become emotionally attached to their patients. Grief became “compounded by a workplace ethic that did not generally acknowledge the profound effect on nurses caring for chronically ill children in the terminal phase” (Clarke et al., 1996, p. 502). Nurses believed “managing death” was an expectation and that, “by virtue of being nurses, they were supposed to know how to cope” (1996, p. 502). An inability to express grief or have it “managed properly” (1996, p. 503) led to negative consequences for nurses including, “lack of energy for others, avoidance of similar situations, lack of

confidence, harboring regrets, and an unwillingness to take care of dying children in the future” (1996, p. 503).

The need to maintain professional boundaries and controlled expressions of grief was supported by Kaplan (1997, 2000). In her doctoral work and subsequent publication, Kaplan used a qualitative descriptive format to explore the grief reactions of pediatric nurses caring for dying children. She found the pediatric nurses in her study experienced both physical and emotional manifestations of grief. They also struggled with balancing the intensity of emotions that arose when caring for dying children, with their need to be seen as competent care healthcare providers. Kaplan’s work corroborated the findings of Saunders and Valente (2002) and Cowles and Rodgers (1991) that the type of relationship with the child and the events surrounding the child’s death affected the emotional response. Kaplan’s results indicated nurses’ experienced “emotional tension” which they denoted was a “grief-like reaction” (1997, p. 175). Nurses shared they could not, nor should they ever, become accustomed or habituated to working with dying and death, however, given the confines of institutional and cultural norms, they learned to hide their emotional experiences. Kaplan described nurses’ stories of being forced to hide in the washroom to express their pain and then quickly return to the care of a newly diagnosed child within minutes of the first child’s death. They also, however, asserted the need to maintain an emotional distance so as to not become overwhelmed by their work, and described feelings as a hindrance to care. These findings led Kaplan to develop a model of caregiver grief. Her model was composed of tasks that saw nurses moving through emotional tension as regulated by influencing factors (type of

relationship with the child), in connection with their management style (coping behaviors), that ultimately mediated their symptoms (emotional and physical expressions of grief). For Kaplan, nurses who became burned-out were those who had become stuck in their ability to process and work through these fluctuating tasked components of grief.

Papadatou (2000) similarly proposed a model of grief for healthcare professionals, and in particular pediatric oncology nurses who have been her target population of research interest. Her model included employment or professional influences such as a care unit's goals, value assumptions about care in illness, dying, and death, rules regarding professional conduct, as well as, nurses personal influences such as beliefs, values, assumptions about self, others, life, loss, and death. These details influenced how nurses were affected by loss and how they expressed their grief. She described her model as being situated in the theoretical framework of the Dual Process Model of Coping with Bereavement of Stroebe and Schut (1999). It expressed similar fluctuations between times of active grieving and times of moving away from and avoiding grief.

Papadatou and her colleagues in Greece represent the core of the small body of research on nurse's grief in pediatric oncology. According to Papadatou (2009), coping with death originates from our personal experiences with loss, but is also mediated by cultural, institutional, and work-related factors. The research from this team has attempted to elucidate how some of these factors impact nurses and other healthcare professionals in pediatric oncology.

Papadatou, Martinson, and Chung (2001) conducted a transcultural, descriptive study investigating the grief experiences of pediatric oncology and critical care nurses in Greece and Hong Kong. Different ways to elicit meaning from the deaths of their patients were found between the two cultural locations. Greek nurses found reward and meaning in being able to assist children at the end of life. Despite this, they viewed the deaths with some anger and questioning. The Chinese nurses, in contrast, were more accepting of the children's deaths. It was hypothesized this may be due to differences in religious beliefs of the two countries. The pediatric oncology nurses were found to grieve more than critical care nurses over the loss of the personal relationship with the child. Papadatou et al.'s (2001) findings revealed, regardless of work or cultural setting, nurses experienced a grieving process characterized by a fluctuation between two psychic processes. The first involved experiencing and expressions of grief. The second component was an avoidance or repression of grief by moving away from the loss experience. Similar to the Dual Process Model of Coping with Bereavement (Stroebe & Schut, 1999) in which Papadatou's model is based, this fluctuation is seen as normal, healthy, and adaptive. The continued fluctuation allows nurses to grieve without being overwhelmed by the loss experience (Papadatou, 2000).

In a mixed methodology exploratory study, Papadatou, Bellali, Papazoglou, and Pertaki, (2002) explored the stress and grief responses of Greek physicians and nurses to pediatric oncology patient deaths. The researchers were interested in answering the following questions: what motivates professionals to work with seriously ill children?; what challenges do they encounter while caring for dying children?; how are they

affected by children's death?; and what are some of the contributing factors? In the qualitative part of the study, the researchers used semi-structured interviews with a grounded theory analysis to explore concepts related to caring for dying pediatric patients. The interviews were directed toward discussing the difficulties, stressors, and rewards of providing care, as well as, the healthcare professional's response to the experience. A researcher-developed rating scale was used to explore relationships between the level of stress and elements of care of dying patients (Papadatou et al., 2002). Unfortunately, no reliability or validity testing was reported for the measure.

Nurses and physicians reported the highest stress from painful deaths and unrelieved pain. Differences, however, were observed in terms of the way these two groups (a) perceived the loss of the child, and (b) expressed or avoided their grief. Long-term relationships with patients were found to be more stressful for nurses than for physicians. Physicians reported symptom control and a peaceful death were the greatest rewards whereas, nurses reported contribution to care, close relationships, and recognition from the family were the greatest sources of reward. Nurses felt being present at the death was a part of their role and responsibility in care (Papadatou et al., 2002). Physicians believed their own presence at time of death was beyond their call of duty. The researchers saw a healthy grief response as dependent on whether or not the participant had a balanced "fluctuation" between "experiencing and avoiding" grief (Papadatou et al., 2002, p. 351). Little demonstrated fluctuation led to a pathological response and greater burnout. The majority of nurses in the study indicated they would rather stay in their current position despite its demands. In contrast, the majority of

physicians reported, if given the choice, they would rather leave. Nurses attributed their desire to stay to the contributions of their work and to the relationships formed with their patients. Physicians attributed their negative response to their lack of supportive relationships with other medical colleagues (Papadatou et al., 2002).

Working in the midst of often terminally ill and dying children profoundly implicates professionals on a personal level. According to Papadatou (2009), “it is a work that is extremely personal in nature, and as such it demands that we be aware of what we bring into our relationships with others and how we are affected in return” (p. 108). Responses to loss are affected by the culmination of personal attributes we bring to the relationship, along with mitigating work-related, situational, institutional, and sociocultural variables (Papadatou, 2001). Together, these “variables can contribute to the disenfranchisement of our grief and lead to shame, loneliness, and alienation, or they can facilitate loss integration and personal growth” (Papadatou, 2009, p. 119).

The majority of research found within the pediatric nursing literature focused on the negative aspects of nurses’ experiences of grief. Grief was most often described as an unavoidable distressing consequence of caring for dying people (Papadatou, 2009), however, Papadatou, in her most recent work, touched upon the transformative and meaning-making capacities of grief. One other notable exception was the work of Judy Rashotte. Similar to newer social constructionist understandings of grief, Rashotte (2005) wrote of both the positive and negative effects of grief. Her study, a hermeneutic phenomenological inquiry into the grief experiences of pediatric intensive care unit (PICU) nurses, revealed even though they experienced pain over the death of a patient,

they felt that they were able to have meaningful interactions. Each encounter with a patient death allowed the nurses to enter into a “process of self-discovery, professional validation, and change” (Rashotte, 2005, p. 185). Other sources in the literature have suggested there can be both positive and negative effects of grieving (Barnard, Street & Love, 2006; Moules, 1998; Moules et al., 2004; Rashotte et al., 1997). Barnard (1995) noted the risks and opportunities of grief. While the risks included “the undoing of the professional, the fear of being overwhelmed by the patient’s suffering, agony and chaos” (Barnard, 1995, p. 23), the rewards offered “opportunities for personal growth and enrichment” (1995, p. 24). The experience of grief brings suffering and sorrow, but it also brings comfort, in the memories of the deceased person that it represents. When viewed in this manner, “grief becomes a permanent, enduring, sometimes relenting, sometimes poignant, but always present part of the life of a person who has lost” (Moules, 1998, p. 148).

Summary of Literature

There has been an identified lack of research literature related to pediatric oncology nurses and their experiences of having a child die in their care (Clarke et al., 1996; Hinds et al., 2004; Kaplan, 2000; Papadatou, 2001, 2009). This area of practice has been singled out as a particularly high stress area of clinical practice, given among other factors, the distinctive long-standing relationships formed between nurses and their young patients. The death of a child has been found to be a source of high stress. An increased number of children with cancer die in the hospital, often after extensive clinical protocols and treatment efforts have been undertaken to save their lives. Thus, pediatric

oncology nurses are increasingly directly confronted and affected by childhood death. Research has identified pediatric oncology nurses are at an increased risk for stress, burnout, and related sequelae (Hinds, Quargneti et al., 1994; Zander et al., 2010). There is beginning recognition, over the past two decades, that nurses experience grief when faced with loss in their clinical practice (Kaplan, 1997, 2000; Papadatou, 2009; Papadatou et al., 2002). Pediatric oncology nurses have been identified as the disenfranchised yet grieving survivors of oncology patients (Doka, 1989; Papadatou, 2009). It has become apparent nurses who witness the pain and suffering of children and their families also experience pain and suffering themselves (Kaplan, 1997, 2000; Papadatou et al., 2002; Rashotte et al., 1997).

Long-term outcomes of these cumulative experiences are not known, suggesting research into these areas is critical. Clinicians and researchers identified throughout this literature search have consistently called for making support for pediatric oncology nurses a priority in research and practice (Hinds et al., 2004; Spinetta et al., 2000). There is a growing need for research that extends our understandings of how nurses experience the death of their patients. How do they cope, integrate these losses, and how do they find the energy to reinvest in relationships with other children, some of whom will also die while in their care? The healthcare system needs to begin to better understand pediatric oncology nurses experiences amidst work conditions in which patient death is an integral and ongoing reality.

Chapter Three: Philosophical Hermeneutics and Research

Gadamer (1989) reminded us of our connection to history - our past, our inheritance, and the traditions that collectively become us. We, in essence, “cannot step over our shadows” (Moules, 2002. p. 2). Part of the hermeneutic consciousness is an awareness of and appreciation for history; we are situated in our own history and are also shaped or rather effected by history (Gadamer, 1989). Discussions of research grounded in philosophical hermeneutics must therefore acknowledge its history and tradition, as well as, the history and situatedness of the topic to be explored.

In this chapter, I attend to the historical, philosophical, and methodological underpinnings of the ways I understand philosophical hermeneutics in relation to my doctoral research. I also address the fit of philosophical hermeneutics as a research approach to explore my topic of the affects of a child’s death on nurses in pediatric oncology.

Historical Underpinnings

Philosophical hermeneutics is not a traditional theory of interpretation. It does not seek to establish a generally acceptable method for the reading of obscure and difficult texts. Philosophical hermeneutics is, much rather, an interpretation of interpretation, a prolonged meditation upon what “happens” to us within “hermeneutic experience” when we are challenged by texts and artworks, ancient and modern. (Davey, 2006, p. 1)

Hermeneutics is the theory and practice of interpretation. The name originates from the Greek messenger god Hermes who carried messages of knowledge and

understanding between the gods and mortal humans. Hermeneutic origins are steeped in the interpretation of biblical texts and the development of frameworks to guide these exegetical practices (Moules, 2002). Schleiermacher, acknowledged as the founder of modern hermeneutics, advanced a stream of hermeneutics that encompassed a theory of broader textual interpretation. In so far as hermeneutics was asserted by biblical scholars to be the proper method for the recovery of meaning, he developed a framework of rules for sound interpretive practice for all subject material (Grondin, 2003). Schleiermacher emphasized the creativity of interpretation, the pivotal role of language, and the circular interplay between the parts and the whole of an interpretation (Gadamer, 2001). Dilthey, a student of Schleiermacher, has been credited with grounding hermeneutics in a general theory of human life and existence. His work paved the way for what we have later come to recognize as the turn to ontology (Moules, 2002). Dilthey viewed interpretation as always occurring with reference to a personal, shared, and historical situatedness. Interpretation was therefore neither fixed nor absolute. Hermeneutics, for Schleiermacher and Dilthey, remained a methodological concern of how to ground interpretation within the human sciences as properly “scientific” (Grondin, 2003).

Husserl’s phenomenology broke from these concerns of methodology with a critique of the scientific claim to the superiority of objective observation. His work on intentionality was premised as a move away from the Cartesian thought of reality being completely separate from the individual and “out there” (Gadamer, 2001). To Husserl, we are already implicated in the world through our consciousness (Gadamer, 1989). Husserl viewed phenomenology as a means of reaching the essence or true meaning of a

phenomena through bracketing, or setting aside, our own prior knowledge of the phenomena and the opening up and peeling away of the layers that constitute reality (Gadamer, 2004). His goal was to create a philosophy that was presuppositionless (Gadamer, 1989).

Already prepared with a depth of understanding of the historical progression of hermeneutic thought, with close attention to Husserl's development of phenomenology, Heidegger's contribution interwove phenomenology and hermeneutics through the question of "being" (Ricoeur, 1998). Husserl focused on understanding through the act of being in the world through the phenomena of the complexities of human experience. Heidegger's concern for human being gave way to the conceptualization of, "Dasein" which he described as a way of being, being-in-the-world, being-there, or there to be (Gadamer, 1994). Dasein refers to that entity or aspect of our humanness which is capable of wondering about its own existence and inquiring into its own Being (Dreyfus, 1991). The being of an entity, has to do with its awareness of its existence and with the capacity for self-reflection whereas "big B" Being is the sum total of who we are at any moment in time given our history, culture, education, future, and how we are situated in our ontological stance (Heidegger, 1962).

Heidegger also transformed an understanding of the "hermeneutic circle." Viewed as central to all hermeneutic work, the hermeneutic circle is used to describe the interpretive movement from the part (text) with its interpretative interdependence with the whole of, or context of, the text. The hermeneutic circle became a way to understand the experience of the individual (part) within the context of

the many who share an experience (Gadamer, 1994, 2001). In this work, the role of the interpreter is one of proximity, where we acknowledge that all understanding is “always already” understood by my being with those we wish to understand. It makes explicit that we cannot, nor should we try, to remove ourselves from the phenomena of interest, but rather, we must already find ourselves “in” the world “along with” that which is to be understood. Hermeneutics, seeks understanding of something - a topic, an event - that is based in its prior ontological understanding or rather a prior hermeneutical situatedness. For Heidegger, this meant to be-in-the-world is already to be committed to understanding. Heidegger’s intention was to emphasize the ontological relevance and significance of the hermeneutic circle, how it serves to gain enhanced understanding of experience. This was not a prescriptive purpose toward the pragmatics of understanding, but rather a description of the way interpretative understanding is achieved. This kind of understanding is not concerned with the comprehension of a fact but in comprehending a possibility of being through human experience (Gadamer, 1994, 2001). As such, all being is interpreted and described through our experiences of something. Human beings live with and through their experiences and evolve and transform through the sharing of each other’s experiences (Gadamer, 1994, 2001).

Gadamer, academically trained in neo-Kantian philosophy and in classical philology, was also divergently influenced by the work of Heidegger. With these influences, Gadamer advanced a radicalized philosophical version of hermeneutics (Davey, 2006). His hermeneutics forwarded an account of the nature of understanding in its universality. This encompassed both the ontologically fundamental orientation of the

hermeneutic situation, as well as, the broad nature of hermeneutic practice. In doing so, he also critiqued prior hermeneutic preoccupation with the problem of method (Grondin, 2003). Gadamer's work represented a reworking of hermeneutic thought that broke with prior hermeneutic tradition yet simultaneously reflected back on that tradition (Gadamer, 2001).

Gadamer (2001) spoke to three movements of hermeneutic understanding. The first movement began with Luther's grounding of biblical interpretation in Aristotelian rhetorical principles. This punctuated the knowledge from hermeneutic humanistic reading of texts in understanding. The second movement was Schleiermacher and contemporaries who premised all understanding is always already interpretation, and the universal role of language inherent in this. Gadamer (2001) proposed that the third movement was Heidegger's assertion that self-understanding, or rather application, is part of the interpretive process. Gadamer took up these three movements, in particular Heidegger's third movement, to demonstrate the limits of the scientific concept of method. Understanding, for Gadamer, involved not only the moment of understanding and of interpretation but also that the moment of application, or understanding oneself, was also part of the process (Gadamer, 2001). Gadamer developed a philosophical hermeneutics that provided an account of the proper ground for understanding, while nevertheless rejecting the natural sciences claim that understanding rests solely in a method or set of rules (Gadamer, 1989). This was not a rejection of the importance of methodological concerns, but rather a cautionary insistent focus on what the objectivist or

scientific method neglects - - that of the priority of understanding as a dialogic, practical, situated activity steeped in experience and learning (Davey, 2006).

Philosophical Underpinnings

The movements of hermeneutic understanding in Gadamer's work are fundamental to my understanding of philosophical hermeneutics. They are a tangible means of grasping the basic assumptions of the breadth of his work and how they are then utilized in my approach to research.

Philosophical hermeneutics is philosophical in that it strives to discern objectivities within the subjective voice. It reflects on the historical and cultural preconditions of individual hermeneutic experience and seeks to discern in it something of the predicament, character, and mode of being of those who "undergo" such experience. And yet the philosophical within philosophical hermeneutics remains hermeneutical for it is not concerned with the abstract nature of such objectivities but with how they manifest themselves and are concerned within the particularities of experience and their ramifications.

(Davey, 2006, p. 1)

Philosophical hermeneutics is concerned with understanding what the understanding of an experience is. Through the researchers' experiences and pre-understandings, they begin to look for commonalities within shared experiences that, although shared, are always told slightly different. This speaks to philosophical hermeneutics being an interpretation of an interpretation to broaden our understanding of a topic (Davey, 2006; Grondin, 2003). There is an understanding that each voice within a

topic, including my own, arrive with an historical situatedness that is contextually and ontologically driven. Philosophical hermeneutics remains connected to hermeneutics as it is concerned with how these experiences play out and become manifested in the lives of the participants - - in other words, how the participants live with what these experiences have created in their life circumstances (Davey, 2006). Philosophical hermeneutics, as a reflective practice, is oriented not towards reading and analyzing texts solely but is a means “of bringing something unexpected about, a way of inducing interpretative interactions that not only expose us to the unusual and unanticipated but which also place the assumptions of our customary horizons at risk” (Davey, 2006, p. 4). When operated as a means to stretch us beyond the taken for granted in our own horizons of understanding, new and different potentialities can be explicated that offer valuable insights for nursing research and practice.

To understand (*verstehen*) signifies that one generally “gets something” or that the something has become clearer. There is also an ability to integrate this particular meaning into a larger frame of meaning. This was the dominant notion of understanding found in hermeneutic theory of the 19th century (Gadamer, 2004; Grondin, 2003).

Heidegger transformed the epistemological cognitive oriented framework of understanding dominant in the 19th century towards a more practical notion of understanding. He premised understanding as an ability, a know-how, a capacity, or a possibility of our existence (Heidegger, 2001). This delineated not a specific theoretical knowledge but rather that one was capable of something in a practical sense (*sich auf etwas verstehen*). This sense of “to understand” implies an element of self understanding

(Grondin, 2003). For instance, if I know how to swim, there is always a possibility of my self played-out in this understanding; I am the one who knows how to swim, who is capable of the task. The self is implicated. This form of understanding Heidegger regarded as interpretation. The focus of his hermeneutics was thus the sorting out of the possibilities of human understanding, what it means to be (Gadamer, 2004).

While resting on Heidegger's version of understanding, Gadamer veered away from this hermeneutics of existence. Gadamer continued to assert, as in the work of Heidegger, that to understand is to be concerned, that is to be able to apply a certain meaning to a situation. To understand thus forwards a sense of application. It is always a possibility of my understanding that is played out when I understand a text (Grondin, 2003).

Gadamer, however, added another movement of understanding to the epistemological understanding of traditional hermeneutics and the practical understanding of Heidegger. In the German language, the word to understand can also signify to concur, to agree, or to come to an agreement. He used this definition to reflect that speakers in a conversation come to a basic agreement on the subject or topic matter. They understand each other (Gadamer, 2001). This delineation was important to Gadamer for two reasons. Firstly, he wished to disrupt the premise that understanding involved the objective reconstruction of the author's original intent of the textual meaning. According to Gadamer, this notion negated that the interpreter was also very much concerned with the topic under consideration. This is not an objective recording of the author's intent but rather the interpreter shares in and has put into play his/her prior

understanding of the topic. This prior understanding of the subject matter is inherent to every understanding, such that understanding can be said to be guided foremost by the topic. The interpretation that is arrived at is neither solely that of the participants nor that of the researcher but together they accomplish a different understanding (Davey, 2006; Grondin, 2003).

Secondly, Gadamer wished to punctuate the importance of language in how we gain an understanding of something (Grondin, 2003). Humans experience the world and communicate it through language. It is the fundamental mode of human interaction of expressing the meaning of our being-in-the world, and how we understand ourselves as being in a linguistically mediated, historical situatedness. The possibility of agreement can only occur through language. To understand is thus to interpret or articulate something into words as a participation in a co-creation of meaning. As an historical event in our life, everything that happens to us becomes embedded in language. Human understanding is thus always made possible through interpretation (Gadamer, 1989, 2001).

According to Gadamer (2001), understanding presupposes cognitive, practical, and linguistic elements. These three elements culminate in application. This does not indicate a freedom to garner any interpretation the interpreter wishes (Grondin, 2003). Gadamer's form of application is akin to translation. In other words, what I wish to understand (translate) is always something at first foreign to me but also requisite for my interpretation of the topic and my understanding of it (Davey, 2006). In wishing to seek an understanding of the impacts of a child's death on pediatric oncology nurses, I cannot

say whatever I want. The topic arrives with its own historical situatedness. The topic, the participants, and me with my own prior understandings move and transform our understandings in a manner that I can attempt to follow and articulate. This is not a one-way process but rather a shifting of perspectives that might negate, overturn, and disrupt prior understandings. Application is always present in the form of a vaguely common topic that hopes to be understood (Grondin, 2003). Interpretation from my perspective as nurse and researcher becomes my common ground to hear and learn from others. In this context as a researcher, I acknowledge that understanding can only be tentative and provisional as I attempt to create an understanding of another's experience. At a later time, I might find myself returning to these texts to find other interpretations and findings, however, for now, this is my attempt to grasp what needs to be understood while aware it can never be finalized.

Prejudices are vital conditions and prerequisites of understanding. Prejudices are formed through all of our life experiences, relationships, and history. They refer to the fore-structures or prior understandings that allow the topic to be understood in a preliminary interpretation (Davey, 2006). Gadamer argued understanding occurs as a requisite of our prejudices (Grondin, 2003). When our prejudices are challenged we become opened to the possibilities of other understandings in which both the participant and the researcher are transformed (Davey, 2006; Gadamer, 2001).

Understanding is always subject to revision when confronted with more convincing evidence or interpretations. The hermeneutic circle illuminates the tentative, speculative, and provisional nature of understanding. Vague anticipations of the whole

are revised the more the text, or rather the subject matter itself, is engaged (Gadamer, 2001). Gadamer (1989) argued most experience that delivers insight is negative. It has the potential to disrupt previous held understandings, yet opens space for unexpected alternatives, and to understand more or differently (Davey, 2006). It is thus not the open space that Gadamer points to but what its openness allows to happen, for understanding to become something more than it is now. “It prompts us to think differently about ourselves” (Davey, 2006, p. 26).

These three movements of understanding culminating in application highlighted the circularity of interpretation that I have previously introduced as the hermeneutic circle. This premise originating in ancient rhetoric, and extended in the work of Heidegger, as a general principle of composition forwards that a text must articulate the parts with the intent of the whole. It was used to describe the to-and-fro nature of understanding from the whole and from the whole back to the parts. This is a continuous process that amends understanding in the anticipation of a more cogent articulate understanding of the whole (Gadamer, 1989, 2001, 2004). All understanding works towards a universal context in which we are always already a part of and implicated. Reaching an agreement between two differently situated consciousness occurs by means of the fusion of their horizons. The fusion of horizons highlights that we live neither within closed horizons, nor within one unique horizon. Understanding constitutes itself provisionally through the fusion of horizons. It is from this creation of a new horizon that we are able to make a comment, or rather an interpretation of this shared experience (Gadamer, 2004).

Methodological Underpinnings

Philosophical hermeneutics, as a research method, is complicated from the outset by Gadamer's critique of the word method. Gadamer took a critical stance toward the assumptive truth of method as solely scientific - a set of fixed, repeatable procedures for amassing verifiable, reproducible, and quantifiable knowledge (Gadamer, 1989). Instead, the intent of philosophical hermeneutics is to value experiences of truth through a means of investigation into the nature of understanding and how these events of experience are situated in history, dialogue, and language (Jardine, 1992). Gadamer argued against the premise that understanding and interpretation is the sole domain of the sciences. For Gadamer, understanding and interpretation belong to all humanity, and experiences outside of the realm of the scientific method must be retrieved and legitimized (Gadamer, 1989). Additionally, Gadamer leveled critique against those who classified his work as a hermeneutic method. In both of these instances, the scientific method and that of a traditional hermeneutic method, two other factors prevail: those of sameness and closure. By this, I refer to the premise of each version to follow a set of rules to achieve a similar or equivalent final result. In the scientific method, this is reproducibility. In traditional hermeneutics, one follows criteria to reproduce an interpretation that not only holds the author's original meaning, but that would also be a similar interpretation produced by another (Gadamer, 2004). Gadamer's underlying assumption is not based on reproducing or maintaining sameness but rather on opening understanding, expanding, overturning, and transforming it through an encounter with differentiation or difference. In other words, revelatory expansions of understanding happen when the other does not think the

same as I do, or when I no longer think the same about a person, idea, or text (Davey, 2006). This is the transformative quality of philosophical hermeneutics that is garnered through experience.

Experience in philosophical hermeneutics asks of those who choose to take it up to become disciplined, judicious, insightful, and knowledgeable in how to proceed rather than outlining a set of rules (Davey, 2006). Philosophical hermeneutics, given these criteria, has been called a philosophical practice versus a philosophical method, wherein the differentiation of a method is how to engage in an activity, while practice denotes the act of engaging in an activity. The sound practice of hermeneutics requires the acquisition or cultivation of a guiding sense for what is more appropriate given a particular judgment. This is a form of knowing versus the application of a prescribed set of rules often found in a method. Active engagement in the exploration and explication of a topic of interest is the hallmark of philosophical hermeneutics as a practice (Davey, 2006; Jardine, 2006). This is a dynamic manner of research that has no prescriptive resolution to a set of problems that can be followed to a reproducible end result. Philosophical hermeneutics, grounded in the work of Gadamer, nonetheless provides a way forward in research that is disciplined, situated deeply in philosophy, and recognizable on its own merit for its capacity to create meaningful and useful findings for practice oriented disciplines such as nursing (Moules, Laing, McCaffrey, Tapp, & Strother, 2012). Gadamer, however, did not leave us on our own and throughout his work one can see markings of “critical procedures” with their own “clear style and a discernible signature” (Davey, 2006, p. 18). Gadamer (2001) discussed the implications

for social sciences and humanistic research, grounded in his work, in an interview with philosopher Carsten Dutt. Throughout the series of questions and answers Gadamer (2001) attended to these critical procedures that include the call or address of a topic, data collection or generation, and data analysis or interpretation (Moules, 2002).

According to Gadamer, research begins with the address of a topic:

How do we come to our questions? When we pose them, how do we go about answering them? No problem just falls from heaven. Something awakens our interest - that is really what comes first! At the beginning of every effort to understand is a concern about something: confronted by a question one is to answer, one's knowledge of what one is interpreting is thrown into uncertainty, and this causes one to search for an answer. (Gadamer, 2001, p. 50)

Difference awakens us to the possibility of some new answer. To Gadamer, the address of the topic and its awakening into our awareness happens first. It may cause negation of, or a challenge to, our held beliefs about a topic. It may also invoke curiosity to know more. In all accounts we begin to look for answers and begin an engagement with the topic (Gadamer, 1989, 2001). This engagement, as Gadamer offered, includes beginning to ask questions and collecting data:

In order to come up with an answer, the person begins asking questions. But no - one asks questions *von sich aus* (just from oneself) - apropos of nothing. To think otherwise is simply to fall into scientific ideology. No, understanding is not something that takes place at the end of humanistic research about an object, it

stands at the beginning and governs the whole process of questioning, step by step. (Gadamer, 2001, p. 50)

Understanding provides possibilities and avenues of choice as one engages with the topic. This process of understanding is found in Gadamer's modalities of understanding - the cognitive, the practical, the linguistic, and culminates in application. We are addressed by a topic because something of it calls to us. We wish to understand it; yet given our historical situatedness we "already always" have a beginning, base provisional understanding of this thing (Gadamer, 1989, 2001). In order to understand:

Heidegger took up the issue of the hermeneutic circle which was already addressed in Plato's Phaedrus. If I want to understand, then I must project something, and one must return to the project again and again. This is the first element...but now to the second element: this is the one I emphasized. Hence my notion of play. One participates in play as a partner. (Gadamer, 2001, p. 52)

As linguistically, historically consciously bound finite humans we are tethered to our horizon of understanding. However, with openness to the other and recognition of the difference that disrupts our previously held understandings we are moved and our awareness is transformed. We are also implicated in this event of understanding. We keep in play - participate as an active proponent of that which we seek to understand.

Horizons are not rigid but mobile; they are in motion because our prejudgements are constantly put to the test. This happens in every encounter with what has come down to us... Being of history one is dealing with. In the end it comes to the fusion of horizons. (Gadamer, 2001, p. 48-49)

Our prior understandings are constantly challenged by what happens to us through our engagement with a topic. Interpretation is therefore tentative, provisional, and ongoing as our horizons continually change and shift. All of these acts of interpretation culminate in the fusion of horizons that yields a momentary glimpse of an understanding (Gadamer, 1989, 2001).

Understanding and interpretation are always intertwined with each other.

Explication in language brings understanding to explicitness; it makes concrete the meaning that comes to be understood in the encounter with what has been handed down to us...what has been handed down to us, is never a mere repetition of its words but rather a new creation of the understanding that achieves determinate expression in the words that interpret it. (Gadamer, 2001, p. 52)

Gadamer (1989) reminded us that to understand something is to bring it into language and to find words to express the experience. The researcher's task is to take the participants multiple contexts and expressions of the topic (data) and interpret them into a meaningful cohesive perspective applicable to his/her research domain. Placing the interpretation into writing locates it contextually in order to answer the research topic. This interpretation of an interpretation is fundamental in research informed by Gadamer.

Being experienced does not mean that one now knows something once and for all and becomes rigid in this knowledge; rather, one becomes more open to new experiences. A person who is experienced is undogmatic. Experience has the effect of freeing one to be open to experience. (Gadamer, 2001, p. 53)

This is not a finite resolvable task. It requires the researcher to be flexible, and open to new perspectives that arrive from the research data. As a researcher becomes more knowledgeable of the topic area and the tenets of philosophical hermeneutics he/she become, in Gadamer's (2001) words, more experienced. This is a generative practice in which researchers extend and expands their scholarship.

Fit of the Topic

Our lives are not lived according to scientifically guaranteed programs and secure from crises; rather we have to undergo our experiences ourselves...In our experience we bring nothing to a close; we are constantly learning new things from our experience. (Gadamer, 2001, p. 52)

Death has been deemed the defining aspect of the universe in which we live (Heidegger, 1962). The death of a child from cancer is an incomprehensible experience, a crisis that marks all those involved (de Ruiter, 2007). We commonly believe that our children should not die before us; it is an event out of sync, and contrary to what we perceive the natural order of things should be (Papadatou, 1997). According to Gadamer, the "attempt to grasp the unpredictable character of the spiritual and mental life of human beings is the task of the art of understanding which we call hermeneutics" (Gadamer, 1996, p. 165). In the context of this research study, philosophical hermeneutics grounded in the work of Gadamer was chosen because it specifically looks to uncover and extend our understandings of the often forgotten, unexplainable, and incomprehensible finitude of the human experience (Gadamer, 1996).

This is not an experience that can be measured and quantified with scientific knowledge. The type of knowledge garnered from scientific premises is inadequate to address these significant and inescapable existential issues regarding death and loss (Gadamer, 2001). Heidegger wrote that we are not able to study death, enter it, look around, quantify the experience, and return. We can only examine the impact it has on those who are left behind (Heidegger, 1962). The word impact is from the Latin *impactus*, meaning to press closely, push into, or strike forcefully against something (Hoad, 1996). There is a carried sense or effect of coming into contact with a thing or person and being transformed by our association with it. Gadamer (2001) cited the *pathei-mathos* maxim of Aeschylus in describing the position of undergoing an experience in philosophical hermeneutics. The *pathei-mathos* maxim - through suffering learn wisdom - highlights this is not a distanced approach in which through being injured, we gain intelligence. Aeschylus in deference is showing us that in undergoing an experience, in suffering, we run up against what it means to be human (Gadamer, 2001). This shift of perception is fraught with a disquieting realization that death is in actuality a part of living and living is finite (Dreyfus, 1991).

This use of self-knowledge and application in undergoing an experience is one of the “fits” of philosophical hermeneutics as an interpretive research method to my topic. The other inherent fit is the transformative nature of understanding that I have chosen to highlight. A research topic, which attempts to explicate the impacts of death and dying on nurses is not one with which I can take a distanced impartial stance. There is an

inherent sense of obligation and responsibility to the topic as it presents itself that fits with hermeneutic as a research method.

Chapter Four: The Research Process

Participant Recruitment

Hermeneutic inquiry cannot be measured or predicted by a number, therefore there is no appropriate sample size calculation. My supervisor and I estimated that six to ten participants would need to be interviewed to provide the needed richness of data required for this particular topic at this level of PhD study and analysis.

The participants for this research inquiry were garnered through a purposive selection to provide a detailed rich encounter of their experiences with patients' deaths. Inclusion extended to any nurse registered with the College and Association of Registered Nurses of Alberta (CARNA) who has worked or was presently working in hematology/oncology/bone marrow transplantation specialization areas at the Alberta Children's Hospital.

Recruitment. Recruitment occurred by email and poster presentation. The study was introduced and participation invited by sending out an email with my research poster attached, introducing and outlining the details of the study and providing my contact information to key informants, patient care manager, and clinic directors of the hematology/oncology/bone marrow transplantation areas situated at the Alberta Children's Hospital with the intent the research email would then be sent out to all staff. This email also requested permission to place the study recruitment poster in staff areas of the units. Within one week, through word of mouth from this initial email, I was contacted by over twenty staff within the hematology/oncology/bone marrow transplantation program indicating their interest in participating in the research project.

Given this overwhelming initial response and the parameters of six to ten participants for a doctoral level philosophical hermeneutic research study it was decided, in consultation with the study supervisor, to cap recruitment at this point. The recruitment poster was therefore never placed in staff areas of the hospital nor were the proposed further recruitment strategies utilized. The recruitment poster is included as Appendix A.

Introducing the participants. Fifteen registered nurses agreed to participate in this research study, met the inclusion criteria, and were interviewed. The community of pediatric oncology is small, and to heighten confidentiality only a brief snapshot of the participant group is offered. All fifteen were registered baccalaureate prepared nurses who received their training in Canada. The length of their nursing practice varied from two to thirty years, with an average of seven years. Two of the participants, Ursula and Paige came from other specialty areas prior to working in pediatric oncology; the remainder had worked in pediatric oncology since the completion of their undergraduate degrees. At present, four of the participants Kate, Maeve, Amy, and Shannon have left oncology for other areas of pediatric practice. The remaining participants work in a range of pediatric oncology positions including the in-patient unit, out-patient clinics, education, academia, and management. All participants were women. Their ages range from mid-twenties to mid-fifties, with varied cultural, familial, spiritual backgrounds, and beliefs. For purposes of this research, the pseudonyms Amy, Anna, Erica, Heather, Jamie, Jill, Kate, Leah, Maeve, Michelle, Paige, Sara, Shannon, Sue, and Ursula were used.

Data Generation

A philosophical hermeneutic inquiry generates data through engaging in conversation with participants. The intention of conversation is to bring the topic forward, to enliven it, and extend our understanding of it (Moules, 2002). Philosophical hermeneutics is concerned with interviewing those individuals who are best able to speak to the topic and enrich understanding of it (Jardine, 1992). Thus, I selected and interviewed participants who, as pediatric oncology nurses, were knowledgeable and able to speak to the experience of having cared for children who died from cancer.

Conversation in philosophical hermeneutics opens and maintains space for the topic to be engaged (Gadamer, 1989). The interplay of question and answer in conversation is negotiated between researcher and participants in a responsive recursive manner to allow meaning to be co-created. According to Gadamer, “to reach an understanding in dialogue is not merely a matter of putting oneself forward and successfully asserting one’s point of view, but being transformed into a communion in which we do not remain what we were” (Gadamer, 1989, p. 379). It was not my point of view as a researcher or as a nurse as “expert” that was important, but rather an awareness of my pre-understandings, those known and unknown to me, that come from these positions, and their possible influences on my understanding of the topic (Gadamer, 1989).

Research interviews. The research interviews occurred one-on-one with individual participants and myself in a mutually agreed upon time and location. The interviews averaged between 1 to 1 ½ hours, which allowed for adequate time to establish

an environment conducive to the sharing of experiences. The interviews were audio-recorded and then transcribed verbatim into written text. The written text allowed for a revisit of the interviews on repeated occasions.

Through the use of a semi-structured interview, I explored what it meant for pediatric oncology nurses to experience the death of a child. What did it mean for them to have been present or even absent at the deaths? How were they able to do this? Did the stance of being a witness to families suffering disrupt their previous held version of themselves? How did it manifest, influence, and affect them as nurses and as people? A list of guiding questions was generated from my own curiosity regarding the topic, as well as, those from the study supervisor Dr. Moules (Appendix B). They were used as needed throughout the interview. Probing, clarifying, and uncovering further utilized difference or behavioral effect questions to delineate meaning and deeper understandings (Wright & Leahey, 2009). Basic demographic data of the participants was obtained. Field notes were written following each interview to record contextual details and beginning interpretations to accompany the transcribed interviews.

Data Analysis

Interpretation in philosophical hermeneutics begins when the topic addresses the researcher. My task in this analysis was to explore and consider alternative perspectives of the topic (Gadamer, 1989). To Gadamer, the basic modality leading to understanding is conversation. Conversation always takes place in language and language is the vehicle for expression, interpretation, and understanding to occur. In order for interpretation to occur, there must exist some textual representation of the topic (Ricouer, 1998). The text

in this research was derived from the participant research interviews. Understanding began as an engagement between the research participants and myself through conversation. This engagement continued with the interpretation of the textual data such that the process of understanding can be seen as coming to a new or different understanding about the topic at hand (Gadamer, 1989).

As discussed previously, the fusion of horizons provides a description of how understanding is extended from the multiplicity of perspectives about the topic. The art of interpretation is to take the individual accounts of an experience and to interpret them into commonalities among the experiences to create a new understanding. The fusion of horizons involves the formation of a new context of meaning that enables integration of what might be unfamiliar, strange, or even anomalous. In this respect, all understanding involves a process of mediation and conversation between what is familiar and what is foreign in which neither remains unaffected and both are transformed (Gadamer, 1989). This interaction with text constitutes a new conversation in which the participants voice is replaced by text and brought back into the world through interpretation (Gadamer, 1989; Ricouer, 1998). The participant narratives were honored yet detached for new relationships to develop. This process of engagement of horizons is an ongoing one with no final completion or complete elucidation. In philosophical hermeneutic research, there will never be a finitude or scientific reproducible truth; understandings are thus always provisional and open to alternate possibilities (Gadamer, 1989).

The pragmatics of data analysis. Data analysis in hermeneutics is synonymous with interpretation and is already in play at the time of the research interview (Moules,

2002). This process was continued through the transcription process, reading and re-reading of the transcripts, reflection on the interviews writing and review of field notes and interpretive memos, generation of interpretations, and interpretive writing.

This process from a transcribed interview to an interpretation of value and resonance that can extend or overturn understanding of the topic, that is *true of something*, is challenging on a pragmatic level to describe. The metaphor of the fusion of horizons can be of assistance in looking between the whole and the parts. It invites a consideration of the particulars of my topic in the context of the familiar, while also attending to the familiar in the context of the particulars (Gadamer, 1989; Grondin, 2003; Moules, 2002). This means, on a pragmatic level, that certain findings were then further developed, through a reading and re-reading of the transcripts, to identify other data that spoke to and engaged the topic. This movement in and out of the data allowed for consideration of avenues that might not have been initially visible, and enhanced understanding of the topic.

Relevant literature from multiple sources, including but not limited to nursing, other professional domains, philosophy, and non-academic literary works were returned to as a means to explore, understand, and find meaning in the history, context, and language of the topic. Rather than being a source of validation or confirmation that the interpretation was the right, or correct one, literature expanded and extended resonance with the topic (Jardine, 2006). The culmination of this endeavor is intended to be a work that extends, disrupts, and transforms the theoretical and practical understandings of this topic as it is situated within the broader domain of nursing.

Trustworthiness of the Research

Understanding and engagement of the philosophical premises underlying Gadamer's work and its applicability to research should not be taken lightly. This work requires the researcher to proceed with caution, maturity, and to become experienced (Jardine, 2006, 2008).

Philosophy is NOT, as one often hears, the professional art of splitting hairs, the search for artificial precise definitions - one who attempts to philosophize must first of all have an attentive ear for the language in which the thinking experiences of many generations has been sedimented, long before we begin to attempt our own thinking. (Gadamer, 1992, p.181)

This work called for me to become experienced with the long history and tradition of philosophical hermeneutics, and also to search the literature, to familiarize myself with the landscape, history, and ancestors of my topic (Jardine, 2006).

There has been considerable debate regarding suitable terminology for criteria that establish the quality of qualitative research (Emden & Sandelowski, 1998). Thorne positioned disciplinary relevance and contextual awareness were appropriate accountability criteria (Emden & Sandelowski, 1998). Madison articulated the rigour of interpretive research should be judged on its coherence, comprehensiveness, appropriateness, and potential (Madison, 1988). Morse, Barrett, Mayan, Olson, and Spiers (2002) concurred and articulated rigour needs to be considered in the planning and execution of research rather than an add-on in the evaluation process. They proposed verification strategies to reposition validity and reliability as appropriate criteria through

the use of methodological coherence, appropriate sampling, and thinking theoretically (Morse et al., 2002). Taking up the principles established by Madison (1988) and Morse et al. (2002) required me to carefully and methodically maintain coherence between the tenets of hermeneutics, the manner of participant selection and interviews, and the subsequent interpretive analysis. The “how” of my work was detailed in the form of an audit trail, journaling, and interpretive memos. In addition, my supervisor who is experienced with the topic of pediatric oncology and hermeneutics reviewed my ongoing interpretive work. This ensured I had feedback regarding the quality of the work and its appropriateness to the research topic. Finally, those who read my research work will ultimately speak to whether or not it is coherent, useful, and provides new understandings of the topic.

Ethical Considerations

This research project was submitted to the University of Calgary Conjoint Health Research Ethics Board for approval. Principles of ethical research were addressed through an ethics review board examination of informed consent of participants, privacy and confidentiality, conflict of interest, and inclusion in research. The consent form (Appendix C) and consent process included an overview of the inquiry, a statement of commitment to participate in a research interview, an explanation of the voluntary nature of participation and ability to withdraw consent at any time, and a description of how confidentiality was addressed throughout the research process.

Consent and confidentiality. At the time of meeting with potential participants, informed consent was obtained. This included consent for audiotaping the interviews, as

well as for publication and presentation of the research findings (Appendix C). I transcribed the research interviews myself without the use of a transcriptionist. The study supervisor was the only other person who had access to the complete data; members of the supervisory team had access to select aspects of data analysis. Consent forms were kept in a locked drawer in the office of the student researcher, and were the only items containing participant names or study ID numbers. Transcripts, documentation, and field notes related to the research were kept in a locked filing cabinet. All electronic versions of data were maintained on a password-protected computer.

Participants' names were replaced with pseudonyms in the transcripts. The use of pseudonyms will also be maintained for any future writing or publications regarding the research. Any direct quotes from transcripts used for publication will be further screened to limit identifying information that could lend to the participants' identification. It is possible despite every effort, the participants and others may recognize the participant's story if they were to read it. Participants were made aware of this risk.

If during the interview, a participant decided to withdraw from the study, the interview would not have been transcribed, and citations not used in the research. However, due to the nature of this type of research, it is not possible to ensure the interview will not have some influence on the analysis and interpretations. This did not happen and all participant interviews were utilized in the analysis and interpretations.

Potential harm. While no harm was expected from this research study, measures were taken to prepare for the eventuality should it arise. Attention to protecting confidentiality was taken while assuring safety and mitigation of harm. Should a

potential for harm to self or others be revealed, the participants were informed in the consent form, that legal authorities would need to be informed. If during or following the interviews, a participant indicated they were in need of further counseling support, they would have been referred to the Grief Support Program of Alberta Health Services. It is important to discuss this, as entering into conversations regarding issues surrounding the death of a child might have proven emotionally distressing. This might be particularly so if the participant had found the experiences painful or the suffering of the patient and/ or family overwhelming. The review of these experiences might have brought forward strong and perhaps even uncomfortable emotions. It was necessary to be cognizant of this potential risk. However, previous research has revealed participants have found the opportunity to discuss these experiences, particularly related to loss and grief, beneficial, helpful, and even cathartic in dealing with the emotional sequelae (Cutcliffe & Ramcharan, 2002; Moules et al., 2012; Thomas & Pollio, 2002). None of the participants indicated, during or following the interviews, that they were distressed therefore no further follow-up counseling support was required. Several participants specified that the opportunity to share their experiences was helpful in reviewing their values and beliefs regarding their work in pediatric oncology.

There is a burgeoning field of inquiry detailing that qualitative researchers who explore sensitive topics may place themselves at risk of emotional distress (Dickson-Swift, James, Kippen, & Liamputtong, 2006; Woodby, Williams, Wittich, & Burgio, 2011). Researchers venturing into these sensitive topics of inquiry are challenged with maintaining and containing “emotional equilibrium” during the research process

(Jackson, Backett-Milburn, & Newell, 2013, p. 3). There is, however, limited literature as to how this required process of self-care and self-awareness might be achieved. Given this knowledge, yet limited accessible resources, it was necessary for me to outline and position protective safety mechanisms for myself. These self-care processes included conversations and “emotional check-ins” with my supervisor, family, and friends. I maintained a journal throughout my work in which I could detail and recount the emotive entanglements and tensions as they arose. At times it was necessary to distance myself from the analysis and interpretive writing to give myself space and time to regain equilibrium.

Moving Forward

An academic work, situated in applied philosophical hermeneutics, consists in many ways of two distinct portions with their own rhythm, tone, and form. The chapters that have gone before are for lack of a better word “academic,” they have attempted to explicate the previous knowledge of this topic, argued the gaps and need for this research, explained the historical, philosophical, methodological tenets of philosophical hermeneutics and outlined procedural and ethical details. At this juncture, philosophical hermeneutics should uphold and support but give way to the voice of the topic. What follows ventures into the world of nurses in their entwinement with children and families struggling, living, and dying amidst childhood cancer. This is a venture that necessitates a change of rhythm, tone, and form that matches these experiences.

Each of the four main interpretive chapters that follow explores an individual and discrete interpretive finding that may be read as standing alone in its own right and

context. It is my intent that each of these chapters conveys a separate finding that informs our understanding of pediatric oncology nurses experiences of childhood death. In the hermeneutic interpretive tradition, we do not intend to set out to have interpretations build upon one another in a sequentially oriented manner or that provide scaffolding for a complete picture or story with a beginning, middle, and end. Rather, the intent is that these interpretive findings inform, change, shift, and expand our understanding of the topic of interest. It is in this address and exploration of the topic that these interpretive findings have something to say to each other and thus become intertwined. There is a movement in hermeneutics between these parts of an experience, seen in the individual and discrete interpretations and the whole of the experience one is researching that will lead to new and/or different understandings.

Given that this work has twelve chapters I thought it helpful to give an outline of the landscape of the chapters that follow as a guide. Chapter five introduces the setting and the core of the research endeavour. Chapters six through nine contain the major interpretive findings. Chapter six explores the ideals and realities of nurses entering into pediatric oncology practice. Chapter seven articulates the struggles in negotiating boundaries and maintaining balance between the personal and the professional in practice. Chapter eight moves beyond individual nursing practice to explore the societal and healthcare norms and expectations that have shaped the experience of death in pediatric oncology. Chapter nine troubles the expressions, manifestations, and consequences of facing childhood death in oncology. It is in this chapter that the findings begin to speak more clearly to one another and to the whole. Chapter ten situates the

research, education, and practice implications of the research. Chapter eleven articulates the topic through my perspectives and personal involvement. Finally, Chapter twelve explores the provisional nature of philosophical hermeneutics in the entrances and exits of the topic.

Chapter Five: Lego House of Love

Death does happen. There is, there is sadness, and there are things that will affect you. If someone entering the field wants any kind of longevity they have to figure out really quickly how they are going to stand in the middle of that. (Anna)

During the 2014 Caring for Kids radiothon radio personality Hot Rod Harriet described the Alberta Children's hospital as the "Lego house of love staffed by angels on earth" (Corus Radio, February 7, 2014, 8:13). Opened in 2006, the new Alberta Children's Hospital is the first free-standing pediatric facility built in Canada in more than twenty years. It has changed the landscape of the city it is situated in and the landscape of pediatric care in Canada. A building of bright primary colours, the hospital was designed in consultation with children, families, and healthcare workers and based on the popular building blocks. The defining vision of the hospital was to create an environment that would reduce stress and promote healing, and to be a state of the art healthcare facility with an at home feel (Alberta Children's Hospital, 2011). It has alternatively been described as the "most beautiful place you could ever hope to never have the misfortune to visit" (Picard, 2006, para 1).

The Hematology/Oncology/Bone Marrow Transplant Program situated within the Alberta Children's Hospital is a specialty referral program for children in southern Alberta, southwestern British Columbia, and western Saskatchewan. Considered a medium size pediatric cancer care program, a broad spectrum of hematological and oncological disorders are seen and treated through its inpatient unit and outpatient clinics (Alberta Children's Hospital, 2014). The nurses who participated in my research are

unequivocal in their praise for the hospital and the oncology program. Two declared it to be the best place in the world to work and, should they not work in oncology, they most likely would no longer be nurses. Walking onto the inpatient unit, “Unit 1,” I am always continually struck by the activity; there is a buzz of laughter, joy, and camaraderie; the *“walls are overflowing with love”* (Heather). Parents, children, and the staff all seem to know each other, marked by being in the community of childhood cancer. World-class care is given. *“It is a good place to be”* (Heather). There are bright colours, laughter, perhaps a birthday cake or two as celebrations are marked often and cheerfully with toys and music. The unit is full of children and full of life. Sometimes though, death hides amongst the toys, lingers in the laughter, and trails off into tears. In whispers or in torrents, beds are moved down the hallway to the palliative room and each nurse who enters the *“best place you never want to be”* (Sara) has to find their own way of standing in the middle. This research reaches down into that place of childhood death, of the unfathomable as happened, and how that plays out in the day-to-day lives of nurses.

Standing in the Midst of Death and Sadness

Learning how to stand in the midst of death and sadness is at the core of my topic. A child diagnosed with cancer is a shared journey into the unfathomable. For a child to suffer and die is a parent’s worst nightmare (Moules, 2009). It is out of sync with what we believe to be the natural order of the world. Children hold our legacy and to face their loss is to see our own life and future cut short with a heart battered and torn. To situate ones self in the midst of this suffering, and to assist in meaningful and helpful ways, are

the tasks of pediatric oncology nurses. Their role is to help carry the burden when the parents and families cannot.

Families allowed me the privilege of travelling with them. I think what they allow me in that time is not facilitation as much as it is almost the job of a Sherpa. I get to carry some stuff because they can't carry it all. And so sometimes it is holding up instrumental things, sometimes holding up emotional things, sometimes it is holding a family member when another member can't deal with them. Because when you are given that weight, in that time, you can't travel alone. You need help. You need sometimes a guide; sometimes it is a guide through a terrain they have not travelled before. But most of the time it is about carrying the weight that they cannot carry. (Ursula)

Ursula described her work with children and families, as akin to being a Sherpa. Originating from the mountainous region of Nepal, Sherpas were immeasurably valuable as guides to the early explorers of the region. Today, Sherpas are most renowned for their hardiness, expertise, and experience in high altitude work alongside climbers and mountaineers in the Himalaya regions (Handwerk, 2000). Sherpas have built the “yellow brick road to the summit” (Schaffer, 2013, para 4) of the world’s highest mountain Everest. The yellow brick road refers to miles of ropes and ladder lines annually set along the South Col route. Due to its thin air and treacherous conditions, this area above 26,000 feet has been deemed the death zone. While fixing lines, shuttling supplies, and escorting clients to the summit of Himalayan peaks, Sherpas are exposed to rock fall, crevasses, frostbite, exhaustion and, due to the blood-thickening effects of altitude - -

clots, strokes, and death. There is no other industry in the world that so frequently injures and kills its workers. While training is significant, no amount of practice inoculates Sherpas from the increased exposure to risk they are asked to take on in the Himalayas. Walking through the Khumbu Icefall is considered so dangerous that many outfitting companies acclimatize their clients on neighbouring peaks to avoid traveling through it. In a typical climbing season, a Sherpa might make a dozen round-trips through this area while guides and clients make between two and four (Schaffer, 2013).

Nurses working with dying children are faced with “relentless prolonged horrors” (Sack, Fritz, Krener, & Sprunger, 1984, p. 678) similar to traversing the Khumba Icefall on Everest. They are the guides who have gone before, who are presumed to know the path, are able to shoulder heavy burden, and through their experience can assist families. Unlike Sherpas who are guiding clients to a known summit, nurses in these situations are guiding children and their families towards death. Children, families, and nurses are walking towards a destination and end that no one ultimately knows. Death, for all our technology and medical skill, remains a mystery fraught with pain and peril (Kastenbaum, 1995). The path, while worn from others footsteps, is particular in its unfolding curves, writhe with ambiguity, unpredictability, and uncertainty each time, for each child, family, and nurse. While guiding families through this journey, the nurses in my research were themselves wrestling with these realities, uncertainties, and learning how to be in the midst of cancer and death.

The Language of Metaphor

The use of metaphors frequently arose in the language of the nurses interviewed. The most prominent metaphor used being that of journey or the cancer journey. Increasingly evident in cancer care over the past decade, the metaphor of journey encompasses and articulates the nature and spectrum of the cancer experience from diagnosis through to remission or bereavement and beyond. It is pervasive in all modalities of cancer care. Used by families, patients, healthcare organizations, and foundations, it represents the current thinking and language of cancer care in North America.

In the form of words, expressions, idioms, or allegories, metaphors such as the cancer journey, replace one object or idea with another. Metaphors reframe complex issues and help to provide meaning (Lakoff & Johnson, 2003; Penson, Schapira, Daniels, Chabner, & Lynch, 2004). According to Ricoeur, they are a “means by which our deepest insights into reality can and must be expressed” (1977, p. 35). This ontological significance of metaphor is relevant in moments of crisis and suffering as people struggle to find words to express a reality that seems to evade more literal language (Moules et al., 2004; Teucher, 2003). Metaphors, according to Moules et al. (2004), “offer something to grasp, something that can be pictured and understood as a place to rest the mystery of the profound, wordless, faceless experience of suffering” (p. 105). Metaphors thus offer a place of safety and rest (Moules et al., 2004). They also provide a means of distancing from a distressing experience, perhaps dampening the magnitude of the unknown somewhat. It has been postulated that the use of metaphor is a fundamental human response to crisis and suffering (Olney, 1972). Given this, it is not surprising that the

language of pediatric cancer care abounds with metaphors. Pediatric cancer and the death of a child represent the most terrifying embodiments of the unknown: it is disruptive, messy, heart wrenching, unpredictable, and resists our attempts to impose certainty or comfort (Teucher, 2003).

Throughout this work the language of metaphor appears in the words of the nurses interviewed. These metaphors are evident as well in my own writing. Some of the metaphors were taken up, extended, and played with, while others were challenged and placed in position to be queried.

Opening the Well Lid

The chapters that follow explore my research into the experience of pediatric oncology nurses and childhood death. Fifteen pediatric nurses contacted me within the first few days of participant recruitment and were interviewed for this research. I mention this for two reasons. Firstly, this number represents roughly one quarter of the nursing core of the pediatric oncology program. There was seemingly immense interest in this topic and how it weaves into the day-to-day fabric of their work. Secondly, this number of interviews produced over a thousand pages of transcripts. In following the topic, certain interpretations were garnered while many more leads, avenues, and trails were then covered over. Gadamer (1989) affirmed hermeneutics as the practice of *aletheia*, a Greek word referring to the “the event of concealment and unconcealment” (Caputo, 1987, p. 115). Moules (2002) offered the metaphor of opening the lid of a well, “flipping the lid open and letting it rest, allowing one to look into what lies beneath it” (p. 6). However every opening and resting of the lid means “there is [another] closure and

some things are necessarily left behind” (Moules, 2002, p. 6). My task is thus not to discover how things “really are” but to engage in the “dance between revealing and concealing, between opening and closing off” (Jardine, 2006, p. 15), to engage with the truth of this topic as *aletheia*.

Chapter Six: The Ideals and The Realities

I've experienced many, many, many deaths. You're involved in the actual caring of that family and child when they were admitted, you were giving a lot of different treatments, and you were there for really vulnerable moments, and you were even often there for the death. I would say I remember every child that's died. I remember moments with that child.

I think the first year or two were really difficult because I didn't know how to navigate that and I was so new. I had no kids of my own. I was in my 20s. Initially I wasn't sure what I was getting into in pediatric oncology. I didn't really have any thought of "well of course it's going to be...there's going to be death." I hadn't really thought about it. I was just trying to give chemo and blood, and I was just making sure I got through my day. I wasn't really thinking about how that impacted me, but I think that it was very, very powerful. I don't know, powerful is not very explicit, but I found it more difficult to deal with. Even now, I have many kids I looked after that would give me Christmas ornaments. I still decorate my tree with all of them. Every time I hang a Christmas decoration from these kids, and there's quite a few of them, I see their face. That's like twelve years ago, ten years ago, and I just remember their journeys, and most of those journeys ended in death. So I just find it powerful. (Sue)

Sue is reflecting back on the ideals and realities of work in pediatric oncology. She is taken back to remembering herself as a young twenty year-old nurse attempting to get through her first few days of practice. In these first days of practice she was

confronted with the reality that she would be navigating relationships with patients and families, she would be walking beside them giving often painful treatments, witnessing vulnerable moments, and confronted with death. These children, known over the years, have not left her. They remain in her memory, their faces reflected in the twinkling of ornaments on her Christmas tree. This is not an image of nursing as technical, or scientific, or biomedical although it is all of these as well, this is an image of nursing as relational, as emotive, intimate, and affective. Sue shared with me that she decorates the Christmas tree with her own children, recalling aloud each child as the ornaments are hung. To her it is a remembrance of the children who have died and a blessing for the life she is privileged to have with her own children. It is this portion of her work as a nurse in pediatric oncology that is powerful to her, these often difficult, yet real moments of nursing that have stayed with her and shaped who she has become as a nurse. To me this emulates the idealized version many of us arrived with in nursing school and as new graduates, held in the realms of society and echoed in the words, “*angels on earth*” working in a “*lego house of love*” with the realities, the pain, and learning that arrives in practice. It reminds me to confront who we are as nurses, in the midst of reacting and negotiating what comes towards us in our day-to-day work. This often happens in renegotiating what we believed nursing work to be, where we began as nurses entering practice environments, with how the road along the way has changed us.

What Have I Gotten Myself Into?

I really didn't know what I was getting myself into. It was interesting, and the idea of working with a balance of acute and chronic illness kind of all in one

appealed to me. But to be honest I think I was completely naive to it. I think both from a medical and an emotional perspective what all is involved in pediatric oncology nursing. I think I certainly did not think through how involved and how much it affects you as a person to work somewhere like this. (Jill)

Jill believed she did not know what she was getting herself into stepping into the world of pediatric oncology. For her, it is an area of nursing practice that involved and affected her as a person. There is, it appears, an element of the personal involved and implicated in her words. This suggests a not knowing, of feeling overwhelmed, at the realities encountered and how they will affect and even perhaps change you as a person and as a nurse. Much has been written recently about the emotional complexities of cancer care and of the distress faced by patients and family. Distress is now considered the sixth vital sign in the adult cancer care system. There is an increasing realization that an illness such as cancer affects more than the physicality of the person. The effects are multi-dimensional and far-reaching (Accreditation Canada, 2008; Bultz & Carlson, 2006). These effects could also be reflected in and upon those who work in these areas as well. In pediatric oncology, long relationships are typified between families and healthcare professionals, particularly nurses (Papadatou, 2009). Not only are nurses immersed in the family's cancer experience, they are immersed for long amounts of time. Being naive or naiveté indicates a lack of experience, judgment, or information (Merriam-Webster Dictionary, 2014). There seems to be little awareness of how much working in this area could affect Jill as a person, or how it would come home with her. Naiveté is also suggestive of a lack of formal training or technique that one enters into an

arena unaffected by the past. It indicates a lack of worldly experience, understanding, and sophistication, or one who is guileless, unsuspecting, unaffected or unguarded and susceptible to influence. There is a sense of being inexperienced and malleable (Merriam-Webster Dictionary, 2014).

I think because every young bright-eyed nursing student comes in with that, I care for people, and I want to help people, and I'm going to make people better. The reality is that they don't always get better. (Shannon)

The reality is that children do not always get better. Nurses working in pediatric oncology do and will continue to face the death of their young patients until a cure for cancer is found. Papadatou (2009) discerned that nurses often find themselves in a position where they must handle the tension between the ideals and the realities of work. Sue, Jill, and Shannon seem to indicate nurses are exposed to closeness with patients they are not prepared for, and which takes a personal toll. Naiveté, or the innocence of one who has not been there before, are also reflected in Shannon's choice of words bright-eyed. The complete expression is "*bright-eyed and bushy tailed.*" It indicates someone full of enthusiasm, eagerness, energy, and confidence, and up with the dawn to take on a new adventure (Dictionary.com, 2014). In Kate's estimation, this naiveté changes as nurses are involved and immersed in practice. There is also a sense that becoming a nurse is working through the realization that things are different than expected.

I think a lot of the brand new nurses into oncology come in with a bit of the attitude of I'm in this position, I am going to be helpful. They have this altruistic notion of what nursing it is going to be, what kind of person they are going to be,

and how they are going to connect with people. It is going to be different and I do find after your first few years it's not as you thought. It is not this glamorous world. (Kate)

The phrase “reality shock” has long been used to describe the response of new nurses to the mismatch found in practice between their idealized version of nursing and the realities encountered (Kramer, 1974). Coined in 1974 in Kramer’s classic study, “reality shock” occurs as nurses transition from educational environments into practice settings that forward different priorities and pressures than previously experienced. There is, according to Kramer, a need for nurses to learn to balance the needs of individual patients within the constraints of the healthcare setting. This process of integrating the ideals and the realities of practice is most prevalent in the first eighteen months of work as nurses move through four phases of adaptation: honeymoon, the shock, the recovery, and the resolution. A similar adaptation and learning process was detailed by Patricia Benner in her 1984 work on the transition of nurses from novice to expert. Moving through the five phases requires experiential learning and development over time. This model is founded on the Dreyfus Model of Skill Acquisition that contended expertise is based on experiential learning (reflective practice) and situation-based learning. Learning through the context of being in actual situations is deemed essential for progressing from a novice to an expert (Benner, 1984).

Reality shock or role transition has long been held as an inevitable, albeit difficult process, as nurses move into practice environments (Boychuk Duchsher, 2012; Dyess & Sherman, 2009). Throughout the years there have been numerous critiques of both

Kramer and Benner's work. The major argument of these is often centred on the premise that both models in their discrete movements from novice to expert or honeymoon to resolution are far too simplistic to account for the complexities of phenomena at play in these transitions (Field, 2004; Gobet & Chassy, 2008; Paley, 1996). I would concur with this articulation, and while it is not within the confines of this research, nor is it my intention to advocate for, or provide, a comprehensive critique of these models, I preface that, for the nurses in this research something else is going on that effects and impacts their work in pediatric oncology. Pediatric oncology nursing has often been recognized as among the most stressful specialty areas (Emery, 1993; Fitch, Matyas, & Robinette, 2006; Gray-Toft, 1980; Kash, Holland, & Breitbart, 2000; Lederberg, 1998; Papadatou, 2000; Vachon, 1987). The challenges of this area of practice are highlighted on the Journal of Pediatric Oncology Nursing website:

Caring for children with cancer is one of the most technically and emotionally difficult areas in nursing. Not only are you dealing with children and adolescents who hurt, you must reassure and educate families, balance a multitude of other health care professionals, and keep up with ever-changing nursing practice and care. (Journal of Pediatric Oncology Nursing, 2014, para 1)

Technically and emotionally difficult, this area of nursing traverses both of these distinctive yet interconnected roles. There is another reality, however, that sets this world apart from other areas of nursing practice and this engagement with cancer care as a new nurse. To get a glimpse into this other reality I return to the words of Sue, remembering the faces and the names of the children she has worked with that have died. Her words

indicate to me that something else is going on that is affecting, influencing, and shaping nurses work in pediatric oncology. There are other powerful forces at play beyond, or perhaps more precisely in addition to, those influencing the majority of new nurses moving into and adjusting to the realities of practicing as a nurse.

Stepping Into the World of Pediatric Oncology

There is a culture that is separate of pediatric oncology. It is separate. It is different. (Ursula)

According to Ursula, pediatric oncology stands as separate, in many ways, within healthcare, nursing practice, and society. Stepping into the particularity of pediatric oncology, is stepping into a world that is already formed and held in society's consciousness.

I think that they internalize it like "oh my god kids die?" I mean no one wants to hear about kids dying, the reality of that. I mean everyone's fantasy is to have a baby, have them grow up, get married and graduate, do all this stuff. So when that's kind of turned around they're stopped in their tracks. They are like "oh my gosh, how can you do that? How can you work there? Like that's so sad."

(Amy)

Despite significant advancements in treatment success rates and research developments there is an image held of children with cancer. This is not an image of medical and research success, but rather a popularist image of bald headed children, ravaged by cancer, children who ultimately die. We see their faces and make assumptions. These assumptions are carried over in our fears and in our curiosity about cancer, children, and

the work that nurses do amidst these facets. In many ways, the nurses who choose to work in pediatric oncology are marked by entering into this world, a separate and different world that stands in opposition to society's belief that children do not die.

Each nurse I spoke with shared how this separateness influenced the way they speak about where they work and the work they do in pediatric oncology. This difference is shown in the curiosity about and yet aversion to the death of children.

People ask me where I work I only say the children's hospital. Because as soon as you say pediatric oncology you can tell they want to ask all these questions. Other nurses are like that too, the first thing they ask is like "how do you do it, isn't it sad, and don't they always die?"

I mean okay you tell anyone that you're a pediatric oncology nurse they're like "oh my god! How do you do it?" (Leah)

Amy shared that she has *learned to just not really tell people* where she works. Not telling people or a reluctance to fully share that they work in pediatric oncology was an experience shared by many of the nurses with whom I spoke. It seemed to be a point at which the receiver upon hearing they worked in pediatric oncology was upset and emotional. I sense that these nurses wished to avoid these emotive encounters to protect themselves and others. For Sara, her reluctance to tell people where she worked hinged on feeling judged and needing to defend her choice of work. In turn, she felt as if she needed to defend the type of person and nurse she viewed herself to be.

It's a weird thing when you think about it. If I go somewhere where I don't know people and they ask "oh what do you do?" I generally just say "nurse." If

people want to ask further, if they say “where do you work?” I’ll say “oh I’m a pediatric nurse.” And they’ll say “oh! Wow and what part of pediatrics do you work?” But as soon, as soon as I say I’m an oncology nurse people are upset and they say “oh my gosh, oh I could never do that, I could never work there, I’m too soft.” I always have to say “I’m very soft, I just think it’s just where I’m supposed to work.” You’re kind of defending it, like people think you have to be a jerk to be around families with kids who are dying. (Sara)

Believing that this is where you are supposed to work and having it stand in contrast to what society wants to think about or deemed acceptable was challenging for these nurses. It proffered a different reality and implication onto them as they strove to work through the process of becoming pediatric oncology nurses.

Each nurse I spoke with described pediatric oncology as a distinctive area of nursing practice. They believed that this distinction was characterized by its diverse and changing treatment protocols requiring specialized knowledge and training, discrete patient and family care needs that balance acute, chronic, and palliative dimensions, and the relational and emotional aspects. These features influenced not only nurses’ reactions to their own roles but also how they viewed themselves and their work in relation to other practice settings within the institution, and in relation to the broader society. Stepping into the world of pediatric oncology brought many of these nurses face to face with society and their own fears of death and dying.

What If They Died on My Shift?

A lot of nurses are scared. I was too at the very beginning. I didn't want any patient that was dying because what if they died on my shift. (Leah)

The fear of death and dying encounters in pediatric oncology shaped many of the initial tensions and struggles for new nurses. As Anna discerned, “*it is one thing to know yes there will be death and it is another thing to have to go through that.*” Working through the realities of the death and dying of children was challenging for all the nurses I interviewed. When I asked the nurses in this study to recount a story of when a child's death affected them or stayed with them, the responses I received inevitably spoke of their first experiences with childhood death. These children's dying and death, and their part as nurses in that journey, stayed with them and lingered. These stories and the children and families they encountered have never left, although many times in dark nights I would imagine they hope they might. For many of the nurses, this first encounter with childhood death centered on their inability to know what to do, where, or how to be. In many ways, they spoke of their naiveté and discomfort in facing this unexpected newness of their nursing practice.

I was probably only a few months out of orientation...I remember being assigned to the patient and going in and out of the room and hoping no one would ask me any questions, and that he wouldn't die in that time I was in the room because I had no idea what to do. There have been situations since then that have been more sad for me, for lack of a better word, but that was the most, like it sticks with me the most, because I was so uncomfortable and so out of my element. (Jill)

These moments of the discomfort of not knowing what to do in the room with her young patient who was dying have stuck with Jill. In her words, they have stuck with her because she was uncomfortable, and out of her element. We have all experienced the sensation of not knowing what to do, or the discomfort of newness and the unknown. Being out of your element denotes a feeling of unease. To be out of your element is often considered to be uncomfortable with the environment you find yourself in (IdiomQuest, 2014). People often do not perform well when they are out of their element. A person may also be considered out of their element when they are trying to do something that they are not good at doing, or have not done before, or are somewhere they have not been before. In contrast, to be in your element often refers to the basic building blocks of where we feel comfortable, at ease, and at home. It indicates being in an environment naturally suited to, or associated with, doing what one enjoys. This term alludes to one's natural abode, as does the antonym, out of one's element (IdiomQuest, 2014). It also predicates that if one is out of their element, there is the capability, hope, or reality of being in one's element, of feeling comfortable, at home, and unaware of feeling distressed.

Jill was distressed in this first exposure to a child dying. The emotional upheaval can be heard in her words that she hoped he would not die while she was in the room. As Jill continued to speak, her sense of being uncomfortable and out of her element focused on her belief that she was not a good nurse, and that she did not know what to do in the face of her patient's dying.

I didn't know what to do, and I just felt like I was doing the family such a disservice by being their nurse at this time when they needed this great nurse. I just wasn't this great nurse yet. He did not pass away on my shift, but it certainly was the active phase of dying when I was looking after him. I just remember 12 hours at a time being absolutely terrified that I would do something wrong or say something wrong. (Jill)

Twelve hours of going in and out of a room while being terrified of doing or saying something wrong cannot have been a pleasant or easy experience for Jill to endure. It is an experience that she expressed has stuck with her and perhaps marked her. This is compounded by her sense that she was not assisting the child or family in the manner they required or deserved. In her words, she was providing them a disservice, which stands in direct contrast to the fundamentals of nursing to provide service to those in need. Jill's story is a stark reminder of the terrifying experience it can be for new nurses and the reality of attempting to navigate these first entrances into rooms with dying children and their families. This is an entrance into a means of being a nurse that exposes the relational and emotional components of nursing. This is where nursing theory collides with practice and with persons who are distraught and in need of our care as nurses.

Nursing is more than the physical tasks and skills learned in formal nursing education. Jill appears to have an already formed understanding of what makes a great nurse. This understanding is guiding her statements of what she believes she should be doing or not doing. We are en-cultured into a way of being as nurses that is beyond who

we are as individuals. We inherit a history of what it means to be a nurse, and what it means to be a good and competent nurse. This understanding is instilled in us through our education and punctuated in our code of ethics. We learn what a nurse should be in how we are evaluated in school, how we interact with one another, other disciplines and our patients. Even how we dress becomes part of our professional identity. These threads form not only our personal identity as a nurse but our collective image. They hold the public's expectations of the role of nurse, what they can count on a nurse to know, do, and be (Gordon & Nelson, 2005; O'Brien, 2001). Nurses and patients, alike, have targeted similar characteristics that identify a good nurse. These include both personal and professional characteristics, skills, and knowledge. Great nurses are considered to be knowledgeable, skillful, and capable of integrating their skills while fostering personal relationships with their patients (Rchaida, Dierckx de Casterle, De Blaeser, & Gastmans, 2009). These common understandings of what a great nurse is stood out in sharp contrast to how Jill viewed her relational skills and behavior while working with this family. These factors caused Jill to feel out of her element and uncomfortable to the point of not being able to engage with the child and family. What stands out for me is Jill's use of the word "yet." Yet is a small word. It, however, encapsulates all of Jill's potential and possibilities to become the type of nurse that she believes matches her patient's need. Yet, means "up to now," but also indicates an eventuality or a change at a future point in time (Merriam-Webster Dictionary, 2014). In this one small word can be heard Jill's anguish of going in and out of a room, being

terrified of causing harm, but also hoping that one day that she might be able to assist this family in the manner she believed they deserved.

Reconciling the Awkwardness of Not Knowing What to Do

Sara struggled too, with this feeling of being out of her comfort zone, and thus not knowing what to do in a situation she had not encountered before.

He was in the hospital probably from September on until he passed away, and it was just very small changes. We had him so often you just watched as he got closer and closer to his death...I helped his nurse that day, I helped her prepare him after he passed away. But I didn't say anything to his mom. I was so awkward that even though, I think she probably expected because I had had them quite often, I totally avoided her. I pretty much would run if I saw her in the hallway. I would just go the other way, because I didn't, I really didn't know what to say. I didn't know how to deal. I didn't know what to do, I didn't know, should I cry? I mean I was at work, and had to continue at work for the rest of the day, and so I didn't. I didn't know what to say to her if I was to start talking to her and she was talking. I didn't know how would I comfort her. What would I say to her? What would anything I had to say be of value to her in that moment? I had seen adults pass away, but never, that was the first child that I had ever seen pass away. So I felt like I was so inexperienced in that moment that the best thing for me, and I don't even know if I could have controlled it, it was just I knew that I could not speak to her in that moment and I had to remove myself. You know, actually it haunted me a little bit that I hadn't. (Sara)

Sara wrestled with not knowing how to be, what to do, or say in the midst of this young child dying and her encounters with his mother. She struggled in that moment with what could be possibly of value to this mother. Along with this discernment of value, was her own struggle to maintain her presence in the face of this child's dying, the first child she had seen die. She somehow sensed that she could not stop herself from fleeing the room. This need to flee overtook any other, and she realized she needed to remove herself from the situation and could not speak to the mother. She was in her words too awkward to do anything else. Awkward originally referred to moving in the wrong direction. It is connected to being tactless, embarrassment, and to being thrown into doubt (Merriam-Webster Dictionary, 2014). Sara, in feeling awkward, quite literally ran in the opposite direction when faced with the child's mother and her own discomfort. In running up against her own discomfort of not knowing, who she was as a nurse was challenged and in need of re-evaluation and reconciliation. She recognized her own frailty, saw that she was not yet ready to be the nurse who walked comfortably into these situations or had a sense of ease or knowing what to do. She recognized a need to protect herself.

Sara: After that when I got more experience parents would say "it meant so much when a nurse we had had quite often just acknowledged that our child had passed away." So I actually, it was about a year after he had passed away, I sent an email through his social worker to the mom, because I felt like I needed to reconcile the fact that he had passed away and I hadn't acknowledged with her. I felt very strongly that I would think about it probably forever if I didn't.

ACM: You used that word haunting, how did it help with the haunting?

Sara: I felt that I had acknowledged it with the family. If I did run into her in the community, I wouldn't feel like oh, if I never said anything and I would then continue to have to avoid her...It meant something to her and it just made me feel much less, I mean I wasn't actively stressed all of the time, but any time he came up I would feel this almost dread, that I should have said something.

Sara was returning to and dwelling in her sense of dread rooted in her inaction with this mother. She was haunted by things left undone, unsaid, and her sense of awkwardness that saw her running away from the situation. Her ability to acknowledge this situation quieted the haunting and allowed her to move forward. It entertains an ability to move toward, rather than run in the opposite direction of awkwardness. This move toward also indicates a willingness of self-exposure. Sara was moving towards being able to stand amidst the uncomfortable feelings that death brought, while reconciling that her work encompassed both life and death. She needed to bring together the discordant events of how she had acted in that moment, what she had learned, and who she wished to be as a nurse. In running away in her awkwardness, she felt stuck or continued to relive this moment of awkwardness. She had been reliving the moment, stuck in its haunting of what she had and what she had not done as a new nurse with this mother and child. In order to reconcile and bring them together she needed to acknowledge them, her own dread, and in doing so was able to move beyond her awkwardness. This allowed the haunting to quiet and for her to make peace with what

had happened. She was not forgetting the experience but rather was able to move forward with who she was becoming as a nurse.

I think probably for my whole first year of nursing in oncology, it was all based on skills. I couldn't really step outside of learning how to give chemo or learning how to take care of central lines, very basic nursing items. Once I was comfortable with the job, once I was comfortable and confident in my skills then I felt like I very much was able to open up to...bring a more emotional part into.

(Sara)

Many of the nurses I spoke with recounted their first year of practice as a time of focusing on “*basic nursing items*.” Like Sara stipulated, there was a sense of needing to learn what the “job” was and to be comfortable before they could extend themselves into relationships with families and attend to emotional care. This was marked by strong emotions related to what they attributed as a “steep learning curve” within pediatric oncology and their learning needs as new nurses in practice.

For Sara, this learning to be a nurse was described as an opening up and a means of becoming comfortable. To me, this indicates a move towards her patients in relationship, and an awareness of another level of engagement and entwinement. Nurses provide comfort measures in many modalities. Comfort is an important component of nursing care. Patients that are comfortable heal more quickly, cope better, can be rehabilitated more thoroughly, and die more peacefully than those who are uncomfortable (Kolcaba & Wykle, 1997). Comfort is a “stage of physical and material well-being with freedom from pain and trouble and satisfaction of bodily needs; relief or support in

mental distress or affliction; consolation, solace, soothing” (Oxford Dictionaries Online, 2014). Comfort, however, also denotes a position of strength, from the Latin *fortis* it means a fort, fortress, or stronghold (Online Etymology Dictionary, 2014). A fortress protects but, in doing so, also cuts off from being open to another person or disruptive experience. Striving for comfort, in ourselves as nurses and in our patients, necessitates awareness that, as we are touching and affecting our patients, so too are they touching and affecting us. It necessitates moving away from the comfort found in a position of strength or fortitude and moving toward opening oneself up to the risks of being affected by encounters with our patients. For Sara, this indicated an appreciation that she could now open herself up and bring a more emotional component to her work.

This kind of opening up occurs when we as nurses feel comfortable, at ease, or are walking towards our patients rather than running away or being terrified. It signifies, as well, that there is a willingness or capability of increased exposure. There is a risk to increase one’s exposure, to take on and bear, in the form of compassion within the therapeutic relationship. Prior to this point, Sara and Jill were caught up in acquiring the skills, tasks, and routines of pediatric oncology, with little room or capability to look beyond and enter into the relational space of being with patients and families.

Experience appears to be equated with an acquisition of comfort, of settling into a practice environment, and doing what one encounters in it. It positions us to challenge what we know, believe, think, or feel against what we are faced with in practice. This process of growth, transition, and positioning the ideals and the realities of nursing practice is not accomplished alone others are looked to for guidance.

I Looked to My Peers

I walked in at seven in the morning. The patient I was assigned to died at seven thirty. I dealt with everything you had to do with respect to supporting that family, and preparing the body, and then taking the child down to the morgue, and doing all the paperwork. I came back up from the morgue, and then this is just the way it is, they said well there is a new patient coming in. So I went right into the same room, new diagnosis, three year old.

This didn't always happen but I think over time, as a pediatric oncology nurse, whether you're on the unit and/or in the clinic, you just have to do what is presented to you. And yes, you can have a response and a reaction, but part of where I've learned some of this, is just being in it. Being slammed with lots of different things and being surrounded by a lot of nurses that do the same thing. In the midst of that experience it was really really hard as a new staff nurse. I felt that I was way over my head, and I was sad, and I didn't know how to deal with it. Looking back at where I am now and where I come from, in a way I believe it's really helped me create a situation where I can still be in this profession, surrounded by death all the time. (Sue)

Sue recounted, that as a new nurse, she was often thrown into and was “slammed” by situations that she did not know how to deal with. In the midst of these difficult and sad encounters, other nurses doing the same work surrounded Sue. There was a sense that they were with her providing mentorship, guidance, and support. Anna

recalled that upon her first patient death she also looked to her peers for how to handle the situation.

I remember the very first death. The little girl was in the hospital for it and I had just come on after [she died]. I knew it was coming, it wasn't unexpected but I don't really know how I felt. I looked to my peers. I did not do this consciously but looking back on it, I can see that I kind of looked around to see - - How do people handle this? What do you do? (Anna)

Anna and Sue attributed their ability to formulate what to do when faced with children dying with being able to observe their peers. It was in watching their more experienced colleagues that they discovered how others handled death and, in turn, began to figure out what and how they could navigate these experiences. Anna denoted that it was not perhaps a conscious decision to look to peers for assistance but something that happened due to their presence. Her ability to observe what they did showed her avenues of what she could or should possibly do.

Luckily I Could Swim Most of the Time

When Leah first started on the unit there were more experienced nurses on the floor that helped her and provided guidance.

I think it's really important to have older mentors on the unit. I think that really helped. I had a line when I first started and there was a couple of them that had been there for a long time and they kind of helped me. (Leah)

Having more experienced nurses working alongside, was for Leah, a beneficial resource. It seemed for her to provide a cushion of support that is now lacking on the unit. Leah

recounted these few experienced mentors moved into other positions within the program shortly after she began. This left her and the other “younger” or less experienced nurses to, as she shared, “*sink or swim.*”

That’s the hardest part about having such a young unit, is you kind of have to sink or swim. Luckily I could swim most of the time but, yeah, it’s tough. It’s, it’s it’s really hard. I think as a new grad there I think it’s really tough. (Leah)

Being thrown into situations and figuring out as you go along seems to be a frightening dimension of a lack of mentorship on the unit. Leah described her ability to persevere as being lucky enough to “*swim most of the time.*” She was able to through these experiences stay above water. While being thrown into situations and being overwhelmed, is a reality for many nurses as a component of transition into practice, having few mentors added another dimension in navigating through difficult and emotive encounters with children who are dying.

The mentorship of strong senior nurses was pointed out by many of the nurses with whom I spoke. They spoke of their own training and worried for the newer staff working on the unit that no longer had the benefit of learning from mentors. While they believed they learned from experience and “*being slammed*” by things, they had the ability to look to strong senior nurses for assistance and guidance.

Strong senior nurses that actually did the same thing. They would show you how.

“Yep this is what we gotta do.” “And no you can’t go home, you have to keep going.” “And you have to come in tomorrow.” Like if you had three shifts, it’s not like you could say, “Well, I had a death yesterday; can I have a day off?”

There are no days off. So I just, I think you sort of get tough. You're in it. It's what you've chosen as your career. (Sue)

Sue described being shown how to work through difficult experiences in practice by other nurses. It was through their guidance that she was able to “*get tough*,” or in other words get through these experiences and learn from them. This getting tough is also reflected in the words of Anna that you have to “*keep it together*,” and “*you have to keep going*.” The ability to watch, learn, and model other nurses successful navigation of emotive and difficult experiences was attributed by both Sue and Anna as a reason for their long careers in pediatric oncology. Experience, in the words of Anna, Sue, and Leah does not appear to be mutually congruent with years of work in pediatric oncology. The experience I believe they are referring to is that of being placed in situations of navigating loss and dying in practice. While this could also indicate that a nurse with more of this exposure to the dying and death of young patients has been a nurse for more years than another “less experienced” nurse, this is not necessarily the case. Anna believes that younger and newer nurses today struggle because they are missing these role models.

They don't have role models. That would not have happened in my day because they were they were so much older, and so much more seasoned, and they knew how to experience things. Whereas on the floor now the vast vast majority of them are so young, and they don't have that experience. They don't have the role models to show them this is how you deal with this. You have to keep it together, you have to nurse other kids, you have to keep going. (Anna)

A lack of life and nursing experience compounded by a lack of mentorship is believed by Sue and Anna to make learning how to navigate working in pediatric oncology more arduous. Without this mentorship, newer nurses are left to “parent” themselves.

I just really think there is something to be said about that lack of mentorship and role modeling. It is kind of like a parent child thing, not like these older nurses are doing it intentionally and it is not like the younger ones are looking for it intentionally but you can't but help it. (Anna)

This is not a view of parenting as a disciplinarian or authoritarian but as a teacher, guide, and protector. A parent has the role and responsibility of keeping children safe while exposing, teaching, and preparing them for navigating life. One cannot help but wonder what happens in the day-to-day work life of these nurses without the benefit of role models and mentors working beside them, doing the same work. What difficulties and challenges do they encounter that could have been mitigated, diffused, or prevented. New nurses sinking or swimming together also has a component of needing to relearn what has already come before versus having those stepping stones of knowledge of what has helped and sheltered children, families, and nurses before. There is also something in less experienced nurses working together with those more experienced that challenges and fosters both that is now lacking. This is a component of their practice that for both more experienced and less experienced nurses that does not come naturally.

It Does Not Come Naturally

Putting yourself in uncomfortable situations and from those situations, in the beginning the first couple of patients I looked after that were dying, starting to recognize that it is not easily comfortable for people. The nurses that were good in those situations did not come by it naturally, probably some maybe a little bit easier than others, but it wasn't a situation that anybody walked into the first time and had all the answers...Later, I was more able to embrace those families and those patients when I did have them rather than just putting my head down and getting through my 12 hours and getting out. (Jill)

Working amid ill and dying children is not easily comfortable. It is not something that you can typically walk into the first time knowing how to be, what to do, or have the answers. It is a process of placing yourself in uncomfortable situations, and discovering with the assistance of others, what you are capable of, what you can and cannot do. It is, according to Jill however, these encounters of embracing and moving towards families in an acknowledgement of where they are at, that matters.

There are parts of nursing for everybody and there are different areas for different people. I think there's something so beautiful about our practice and our ability to care for people that are going through, what from the outside, is the worst thing that they are ever going to have to deal with. Being able to be the person that steps into that and can guide families, in a way that suits them, is the best thing that I do. (Jill)

Stepping into pediatric oncology and being faced with the realities of children dying is not an easy or comfortable process. For nurses such as Jill, this is however the best part of what she does as a nurse: for her it matters. To enter into these encounters with patients and families, rather than running away, requires these nurses to be open to the discomfort of their not knowing what to do in the face of death and to submit to the fact that learning happens in the exposure of their doing. For many of the nurses I spoke with, it was their first encounter with childhood death that stuck with them: it shattered their innocence and naiveté of being the nurse and person who has not witnessed the death of a child. The process indicates a new awareness that they would not just be working within the realm of delivering cancer therapies to restore children to health. They would also be bedside, working with children in the midst of their dying and death. There is a realization they could not rely solely on the learning from formal nursing education, but must be open to the learning found in difficult and uncomfortable situations in practice. There is a flexibility and responsiveness that is becoming in their work and in their identity as nurses.

Reflections on a Christmas Tree

Sue's reflections of trying to get through her first days of practice intertwined with the ornaments she has hung on each year's Christmas tree culminate for me the tensions of entering into and becoming a pediatric oncology nurse. This is an entrance into a world that stands apart, separated by society's fear and aversion to children dying. It requires a willingness to thus enter into and then to stay in an area where nurses must learn to navigate emotive and challenging encounters with dying and sit with the rawness,

vulnerability, and exposure this provokes. This is not a natural or comfortable process. Nurses require the assistance of others to guide and mentor them to a position of safety and protection, to teach them how to “*get tough,*” and “*keep going.*” There is also an awareness, that in the struggles to enter or stay in rooms where children are dying, where families need help and comfort, that they will also be affected and marked. This cannot be explained solely as the typical tension between the ideals of nursing education and the subsequent realities of the transition to practice experienced by the majority of nurses. While pediatric oncology nurses struggle with getting through their first days of practice, as all new nurses have, there is also an awareness that it is no longer possible for them to return to the naiveté and not knowing innocence of the time before they witnessed the last breath of a child. This is an appreciation that, for some, the faces and names of the children who have died will be reflected in ornaments on their tree, in their life, and in their nursing practice.

Chapter Seven: A Fine Balance

The death of a child is like a stone cast into the stillness of a quiet pool;
the concentric ripples of despair sweep out in all directions
affecting many, many people.

(Defrain, Ernst, Jakub, & Taylor, 1991, p. 10)

These words evoke a shared collective sense of loss. This is a loss that encircles and transforms all those in its wake. This is an idea perhaps expressed in the oft spoken adage *it is our loss too*. Nurses, such as Sara, spoke of being drawn in, off balance, thrown-a-kilter, and of their struggles to regain their footing and find their line of safety and purpose amidst the concentric ripples of despair.

I've had really great relationships with families that have meant a lot to me.

When their child has passed away it has really hurt, and it's made me very sad. I think it's a protective mechanism, as well for me, that in order to work in oncology and to go through the emotional stuff, I need to have my own life that's not connected. I think sometimes you see people who aren't as successful because their whole being is at work, and it's all intertwined, and so it's hard to leave it.

(Sara)

Pediatric oncology is an area where long relationships are formed. It is a place that evokes strong and difficult emotions. Sara delineated a need to protect herself, to disconnect her life away from her work so that it does involve her whole being. This intertwining and shared sense of loss can seemingly blur the lines that demarcate what is personal and professional.

As nurses, we know lines. We are situated at the frontline of healthcare, we work a designated line, lines run our medications, and show up in our charting. Lines feature in the stories we tell, and in those we cannot bring ourselves to speak. We see lines in the furrowed brow of a distressed patient and in the rivulets of tears on a family member's grief stricken face. The language of lines showed up in many ways, by many of the nurses I spoke with, in how they were marked, delineated, traced, and bounded by these impacts. It is these lines and how they manifested that is of interest to me. Like the circles of loss and affect, we are drawn into the "concentric ripples of despair" (Defrain et al., 1991, p. 10) from the dying and death of children in pediatric oncology. They curve around us, affecting what we do, where we go, and how at the end of the day we are affected by the work of which we find ourselves in the midst.

Being Drawn In

In 2006, the Canadian Association of Nurses in Oncology (CANO) (2006) developed new standards that defined the scope, process, and structure of practice within oncology nursing. *Standard 6* detailed the expected parameters for the therapeutic relationship between nurses and patients. Persons with cancer and their family are entitled to supportive, knowledgeable, caring and therapeutic relationships with healthcare professionals throughout their cancer experience. The nursing role for *Standard 6* follows. I have added italics for emphasis.

The nurse is willing to engage in the cancer journey with the individual and family. This relationship is built on trust and mutual respect. The nurse negotiates with the individual the boundaries of the relationship. The nurse

recognizes the longevity and chronicity of the journey. *The nurse is willing to enter into and share with the individual and family as they experience vulnerability, hope and despair. The nurse is willing to take risks, be vulnerable and make changes. The nurse must understand and know her/himself and be willing to engage in a therapeutic patient-nurse relationship.* (CANO, 2006, para 13)

This practice standard calls for nurses to be open, vulnerable, and to take risks within the therapeutic relationship. I wonder, however, how nurses learn to find the boundaries of these risks and where the lines of vulnerability as a person and vulnerability as a nurse are marked. Who pencils in these lines, and at the end of the day who or what are they judged by? As Shannon remarked below, in building relationships in pediatric oncology, ones that are often long and intense, it is not difficult to cross lines and be drawn into something other than commonly perceived ideas of professionalism.

I've seen nurses in my career that definitely crossed those professional boundaries. It's not hard to do in our line of work. Because these patients, these families draw you in. And you feel like you're a member of their family. And it's really hard to remember that I'm a medical professional, and I am kind of a member of their hospital family, but I'm not a part of that family. (Shannon)

The language of being drawn in struck me as I read it. I can visualize a nurse becoming drawn into a family portrait. Sketched into the fabric of the family's experience of being in hospital and amidst crises, it is easy to colour yourself outside of the lines of being a professional and see yourself as a member of the family. It seems,

therefore, important for nurses to discern how they are drawn in a family's portrait. Are they penciled in, helping and holding the family, or have they indelibly inked themselves permanently into the picture? The nurse, as a part of the hospital family is a temporary role; the closeness and connection with and to the family is fragile. Nurses share in these moments measured in days, months, or years the possibility of loss. It is through the possibility of loss that a different family picture may emerge changing both the colour and the constitution of the image and the relationship. The boundaries of this picture are sometimes difficult to discern, demarcate, and draw. As Paige described, it is about distinguishing the lines between patient and family and how we recognize our place in the bigger picture.

Recognizing at the end of the day that this is not your child, this is not your brother, this is not your sister, this is not your niece. This is a patient. (Paige)

There is a difference between being family and being like family. This is a difference between opening oneself up and risking in terms of moving towards being with a family through moments of intense crises or “being there” in a personal capacity as family. The means to navigate these differences are not outlined by CANO, and it would appear that the skill of knowing how and when to be vulnerable and how or what to risk is open to individual nurses to determine on their own accord. Nurses dealing with this tension between wanting to be open and risk for their relationships with patients and the need to protect themselves from sharing in loss, again, and again are seemingly left to figure it out on their own accord.

Walking a Tightrope

Michelle described her encounters with the tensions inherent in relational encounters with her patients and their families as one of walking a tightrope.

I think it's kind of like you are walking a tightrope. On one side you are over involved and on one side you're under involved. You're always trying to be professional. I really truly believe that on the extreme, over involvement doesn't allow you to properly help people because you need to be able to have a certain amount of perspective to be able to help them and to be able to see... That balance of figuring out what part of how you separate, how you tease out the personal parts and the professional parts is really a hard thing. I think you learn that as you go. (Michelle)

Figuring out how to separate the personal and professional is akin to walking a tightrope. Nurses, such as Michelle, must find ways to balance their involvement with patients, with being able to see personal and professional risks and peril. Walking this fine line is by all accounts not an easy task, there is danger present in each step taken.

Nik Wallenda is a seventh generation tightrope walker who gained fame by successfully crossing Niagara Falls in 2012. Wallenda considered tightrope walking to be less a feat of mystery than that of a physical and psychological challenge requiring significant training to learn (Wallenda, 2013). Suspended high above Niagara Falls, he was vulnerable to the elements, battered by exposure, wind, rain, and temperature changes he also had to mitigate his own fears. This required practice, experience, and skill. Michelle can be seen as needing to make discernments in the continual navigation

of what lies on either side of this tightrope. This involves a balance of involvement, openness, and exposure with protection. The tightrope also offers a perspective on the perils and pitfalls missed at ground level. Perhaps the metaphor of the tightrope walk illustrates the necessity of professional boundaries viewed from different perspectives with distinctive challenges. There is a need to have enough distance to acknowledge and appreciate the risks involved and the inherent dangers below without getting too close to become unhinged with fear. The successful navigation of these shifting demands of personal professional connection and protection was challenging for many of the nurses with whom I spoke.

Personally boundaries, has been I would say, of all the things to work on that's been my greatest challenge. Is yeah navigating boundaries to where you still feel connected but you're not pathologically connected. (Paige)

There is a difference between being connected with a family and pathologically connected, a connection I would delineate as one that does not harm either the nurse, or family, and child involved. Creating and then navigating healthy boundaries, however, can be a difficult task. It often constitutes a risk of entering into a relationship and the discernment of knowing when a relationship is too close or too distant.

The tough part is, as much as nursing is a group thing, it is also your own individual practice. As much as we have our professional boundaries and we learn all this in school, I think pediatric oncology is almost an exception in the way there is really no other unit, well I guess I shouldn't say that, but it's really

hard to not go beyond these boundaries, right? I think nurses have a lot of figuring out how to deal with these things. (Leah)

This delineation is often a nurse-by-nurse, patient-by-patient scenario in which broad rules and regulations do not capture the subtle minutia experienced. Individual nurses are then often left to discover and work out in moments of emotion and discomfort what is appropriate and beneficial for all involved. The closeness of these encounters, and the immediacy of them can distort and blur lines. A certain amount of distance is thus needed to see and have perspective. Being too close distorts this perspective; what is required is a discernment and risk that is wise. While full of danger the tightrope also affords a different and often broader perspective to the ground below and what lies to either side. It shifts and extends our horizon of vision in the process. An experienced or practiced person is one with a broad horizon, who has “integrated various perspectives, and knows how to leave things in the open” (Grondin, 2011, p. 13).

I Am Not Their Sister or Their Best Friend

According to Anna, there is a fine line of discernment that needs to be maintained.

I think that there is a fine line we need to walk between of course you are allowed to feel it and be vulnerable and to be unsure of yourself. For me it has always been very important to walk that line of I am still a professional here, I am not their sister, or their best friend. (Anna)

I am neither their sister nor their best friend, although perhaps in differing circumstances this might be the case. Walking a line between the professional and the personal was

important and yet challenging for these nurses. There are long-term relationships, emotions, and, according to Maeve, there is at times love also involved.

You do, you live with some families, you really make a connection with some.

Connecting with some families and not with others as close. But that's because there's just those families that you just love, you can't help but love them, they're fantastic people in a very bad situation. (Maeve)

When nurses open themselves up and care for these children and families the tension is obvious, the line tenuous and often blurred. They are joined in an experience that is situated outside what the rest of society can bear or wish to hear about. Families, children, nurses, and other professionals reside in this separate realm, situated apart. It cannot help them differentiate and navigate these boundaries, particularly when they live with and love the child and the family involved.

I think that there's probably nobody that does this line of work who can do that 100% of the time. Ultimately there are families and patients that you connect with on a personal level. Whether it is right or wrong, it is a lot harder to completely separate that kind of work relationship and personal relationship when you really do genuinely like people. (Jill)

What do nurses do when they love a family that they are working with, when they recognize in them something that draws them closer on a personal and a professional level? Ultimately, as Jill noted, it is not a clearly delineated and defined separation. It involves walking between shifting priorities and connections. This type of discerning separation was detailed in Henderson's (2001) description of the successful navigation of

the emotional demands of nursing work. Henderson (2001) premised nurses as walking a continuum between the fluctuating dynamics of engagement and detachment.

Engagement is one's emotional attachment and connection to a patient. Detachment is seen as a distancing objectivity required to effectively function in certain aspects of nursing work. Becoming too emotionally attached or too close renders the nurse ineffective and incapable of doing his or her job. Whereas, if a nurse is too detached, there is no point of connection with patients, dehumanization can result, and care suffers. To be successful in this tightrope-walking endeavor, a nurse needs to continually shift between these two dimensions (Henderson, 2001). Henderson (2001) spoke of the recursive nature of the nurse-patient relationship, and of the inherent risks and rewards to both professional and personal self of this occupation of care. The therapeutic relationship was described as containing intrinsic tensions, pitfalls, and risks that were left to the individual nurse to mediate.

The connection referred to is illuminated in the CANO standards through reference to nurses being required to be open, vulnerable, and take risks (CANO, 2006). Nurses learned how to mediate the needed distance of protection and entered into therapeutic relationships by being in the midst of practicing and experiencing where that line was for them.

I actually think it's just experiential. I think part of it is just being in, in it and living it to be honest. I think that barriers not the right word. But people say "how can you do that?" And I'm thinking, "I don't know that's a really good question." I have never really not been able to do it. There are times when I feel

more vulnerable and there are times when I say take it home...But I'm somehow able to keep some kind of line between what's here and what's at home. I think I'm better at it now than I was initially and I bet part of it is related to experiencing it so many times. I mean I have no idea how many deaths I have experienced for a child anywhere between the ages of zero and eighteen, but it's well into the seventies or eighties or even more...At the end of the day, that affects you...it's influencing and colouring how future things are I think. (Sue)

Experiences with dying children and their death has coloured and influenced Sue. It has shaped her nursing practice, and who she is as a nurse. She has, however, found a way to draw a line between her home life and her work life. This line fluctuates and is not permanent, there are times when she feels more vulnerable and exposed. Vulnerability has been referred to as the most elemental fact of living systems. The ways in which living creatures open themselves up to others is the source of their own becoming and the manner by which they are able to affect others (Heidegger, 1962). Vulnerability is often perceived in western thought as a frailty, a fatal flaw, or weakness. It is related to the Latin *vulnerabilis*, meaning to wound or open (Online Etymology Dictionary, 2014). This sense of vulnerability, however, does not point to frailty, dependence, or loss of social autonomy. It is, rather, connected to recognition of the suffering of another. It signifies an openness and availability for another. Many of the nurses I spoke with were aware they had been affected by their immersion in relationships with children and families. They required caution and awareness of the dangers that could befall them as they walked the tightrope.

Sue has been coloured and affected by experiencing the deaths of many children. She has been marked and at certain times felt vulnerable. She has, however, been able to, through these experiences, establish and recognize her boundary line between work and home. Experience has also given her a tacit knowledge or tact of how to react next time. This sense of where the line is between self and other, as a nurse in a therapeutic relationship, is difficult to discern. It is difficult to establish the line between connection and over connection. Becoming experienced in practice, however, afforded Sue the ability to begin to colour in the line of what was significant and relevant to her work in pediatric oncology. Practice revealed itself through colour and discloses the ways in which she has been affected. Colouring differentiated the line and she could begin to more clearly establish home from work.

Distinguishing the Personal and the Professional

For Michelle, colouring lines afforded the ability to begin to distinguish needed boundaries and thus balance between the personal and the professional.

The boundaries, the idea of boundaries and the idea of balance you know? The personal versus the professional and I think that has a big role to play in how people manage. (Michelle)

Walking the fine line, the tightrope, as Michelle indicated, requires balance or equilibrium. Equilibrium is a condition of experienced weightlessness in which different forces balance each other harmoniously. The loss of equilibrium is only reestablished by a counterbalance; however, with every attempt towards equilibrium, there is a threat of going too far in the opposite direction. Gadamer (1996) outlined this playing out in his

description of an acrobatic event akin to walking a tightrope. The wobble that occurs as the person lurches on the left foot, immediately requires force on the right side to avoid toppling off of the thin wire onto the ground. Without a counterforce to balance, or when forward motion stops, the walker is in peril of wobbling uncontrollably. Gadamer illustrated this discernment and movement as one found in the metaphors used for play. For Gadamer, what is required in this balancing act is an awareness of the *spielraum* or play (Gadamer, 1996; Miller, 1996).

The original meaning of *spiel* is to dance or to have movement (Vilhauer, 2010), this is like the dance involved with walking and maintaining balance on a tightrope. The type of *spiel* Gadamer referred to is equated to this movement or space required to be properly balanced. The point is to have some leeway, some play, a little space and some distance is required to function optimally. According to Gadamer, equilibrium is not only a “medical-biological state of affairs, but also a life-historical and social process” (1996, p. 42) a balancing that encompasses the whole of the person. This balancing encompasses who we are professionally and personally.

Like walking a tightrope, entering into relationships with patients and families requires a fine balance. Risk is inherent in all of these attempts at intervention. There is always the threat of becoming overly attached or overly disconnected.

Whether you are at that point where you can establish those boundaries and you can be that support person and that, go-to person and meet the needs for families without kind of crossing that line and without it being too hard for you. (Jill)

The attachment of the nurses to the children and families they work with affects them.

While being a support, it is easy to walk over the line and be in a position where “*you’re taking it home with you every day*” and “*you’re not going to last long*” (Maeve).

Negotiating this balance seems to be key in staying healthy in practice.

Even if I really care about a family they’re not my family. I know that’s something you have to have that balance because you do see some nurses, they’re so emotionally shaken that they either have to go home or they’re attached to every single family in a very - not aggressive way, but that’s kind of sometimes how I think of it. Like they have those inappropriate relationships. (Sara)

Having an aggressive relationship appears to Sara, to be one that is uni-directional, indicating movement from the nurse towards the child and family in an unhealthy or harmful manner. There is a sense from her as to what entails an appropriate versus an inappropriate relationship that is reflected from nursing literature. “The healthcare system in particular has been long intolerant of professionals who become ‘too involved’ with their patients and ‘too upset’ at their death” (Kastenbaum, 1995, p. 340). Many nurses received training that eschewed any display of emotion, even when deemed societally appropriate, as frowned upon (Kaplan, 1997; Papadatou, 2009). Becoming emotionally overwhelmed was viewed as a weakness, frailty, and not professional (Henderson, 2001; Papadatou, 2009). The nursing profession, healthcare organizations, and society has “perpetuated traditional images of nursing as self sacrificing, devotional, altruistic, anonymous and silent workers” (Gordon & Nelson, 2005, p. 63). Inherited from Nightingale, these images have persisted, often running pervasively below our

conscious awareness (Gordon & Nelson, 2005). The culture of nursing has predicated a belief, as well, about the right amount of emotional involvement, with detached empathy and conscious rational detachment (Henderson, 2001; Kaplan, 2000).

Sue indicated that some of her colleagues have an ability to maintain this fine balance between involvement and detachment with great skill and awareness.

Some of the senior colleagues that I have worked with for many, many years have an impressive ability to do this. They still cry. They still have their moments. They write a card to the family afterward. They are present with them, but part of their ability to come in the next day is they were there every step of the way, but they were there in a very professional therapeutic relationship. I think some of the nurses now, especially young nurses hitting Unit 1 struggle with what do you say on this journey. I don't know what to say? I don't know how to do? I'm not saying this for everybody, but I think it's the tricky part so I feel more comfortable having a personal relationship, personal conversations versus therapeutic, and I think that is a huge. And then if you have this personal one happening before death, isn't it more personal than professional? And I think there's something there that's different. (Sue)

Straddling the tightrope between the personal and the professional, according to Sue, plays out in the response to death. There is a difference between a personal relationship and a professional therapeutic relationship even when you love the family. For Sue, the ability to negotiate these boundaries is situated in the difference between a therapeutic conversation and one that is personal in nature. It is in this tendency to

gravitate toward the personal in moments of discomfort that Sue believes are evidenced in the often strongly emotive responses upon a child's death. For her, the key to a sustained practice in pediatric oncology is being aware each "*step of the way*" that nurses are walking with the family in a professional therapeutic capacity. This, however, is a perpetual play of movement through shifting and negotiation. As Leah indicated, this requires a process of learning about yourself as a nurse amidst being in relationships with families.

I've learned to really try to leave work at work because I think it can really bring you down. I think you really need to learn to try and separate yourself a bit, and try to put boundaries, and try to let it just be work but still be able to build that rapport with the families while you take care of them through their journey.

(Leah)

Leaving it at work and taking care of families in a professional capacity is, according to Sue and Leah, in many ways protecting and taking care of the individual nurse involved. It seems to be in these moments of connection that they should be focused on therapeutics - - on what is helpful and not harmful to both parties involved. This is a continual process that must be renegotiated with each new child and family encountered. With each new day "we place ourselves at risk and allow the other to make an impact on us, to teach us, to challenge our preconceptions and habitual ways of being, to change us for their sake, even to disappoint and reject us" (Davey, 2006, p. 266). Nurses need to be aware that in this risk, change, and openness they are also in need of protection, support, and distance.

A Line of Protection

‘You see, we cannot draw lines and compartments and refuse to budge beyond them. Sometimes you have to use your failures as stepping-stones to success. You have to maintain a fine balance.’ He paused, considering what he had just said. ‘Yes’, he repeated. ‘In the end, it’s all a question of balance.’ (Mistry, 1997, p. 443)

Joan Halifax Roshi (2008) has often spoken about the comportment desirable in working with dying persons as one requiring a strong back and a soft front. To me, this is reminiscent of Sara stating earlier that she was a “*soft*” person, and Sue stating that she needed to “*get tough*” to work in pediatric oncology. Dr. Halifax’s work, originating from the palliative care and oncology fields, allows both to co-exist. A strong back provides structure and support in order to bear another’s burden, to carry patients, families, and themselves. A soft front is needed to be vulnerable, open, facing the other in their time of crisis while not being overcome and over wrought. This requires a balance of strength and protection with vulnerability and openness.

I think the hardest part is you don’t know your boundaries. You see families and I mean those families view you as family because you’re their constant right. Which I, I get, but I think a lot of nurses have a really hard time drawing the line. I was that nurse for like a year. But I really learned you can’t always be having this on your back. It’s a lot. (Leah)

Carrying the weight of a family’s journey had worn through Leah’s protection. The weight of bearing another’s suffering was too much and she had become worn down.

For many nurses, the load taxed their limits and boundaries and depleted their strength, and resilience. Their ability to bounce back had worn thin. This speaks to the possible wearing down of nurses who experience the dying and death again and again, without a new or different way to understand and develop their professional experiences. They can become worn down and distressed from a lack of understanding or awareness of the context of the very nature of who they are as nurses and persons. There is a need to be cognizant and vigilant of the affect that repeated deaths of the children in their care could have on their life.

The nurses I spoke with had circumstances in their work and home life that caused the line between their personal and their professional lives to wear thin.

How you deal with it next time how you anticipate stuff, potentially that kind of line and I don't think that line is always the same. I think there are things that make that kind of thinner, recently for example if I've had deaths in my personal life... I'm comfortable with feeling sad, quite often, it doesn't shock me that I'm crying or it doesn't shock me that I'm sad so I don't get too...I don't know how to describe it but personal. Anxiety, or stress, or age of kids, or experiences personally, or other deaths definitely thin the line that helps me keep it separate, for sure. (Sue)

Sue had become aware of the ways in which she had interwoven death from her personal life into her work. She searched for a means to provide some distance between personal loss and professional work experiences. She was able to negotiate her line of vulnerability and protection in a way that was helpful to her. Experiences in her personal

life were spilling over into her work. She struggled to keep them separate. The protection she had evolved was thinned and bare. The thinning of the line afforded less space and distance to escape the sadness and loss faced both at home and work. There was no distance or space. Death and dying were interwoven in all aspects of her life with no escape or refuge. There was a need for a better distance.

I Would Have Kept a Better Distance

It would have been helpful to know that for every ten kids that you look after, six of them are going to die. Just to even wrap your head around it, or even to protect myself so maybe I wouldn't have gotten so involved, or would have kept a better distance. Maybe I would have survived longer. Part of the reason I liked working there was because of that. So it is hard to know where that line is. It would have been nice to know what type of an impact it would have on me emotionally; that I would be losing these kids, and I am going to be berated by questions by these adults, that put all of their emotions and feelings on you for their situation, and how to deal with a parent that is in your face asking you questions wondering why their kid is dying, and you have nothing to tell them. I mean what are you going to say? (Kate)

I wondered as I heard Kate's words how it was possible that she could not have known. The survival rates for children in pediatric oncology have significantly improved, but a cure remains elusive and children do continue to die. Unfortunately, the survival rates for nurses who work in pediatric oncology have not made this same progress. Attrition rates in pediatric oncology are some of the highest found within

nursing practice (Fitch et al., 2006; Papadatou, 2009). If Kate, and other nurses working in pediatric oncology, arrive and are unaware of the dangers to themselves of working amid children dying, I cannot help but wonder what is at play here that this could be the case. How is it that these nurses could not have known, and what responsibility does healthcare education and a society hold? Kate felt unprepared and then was quickly worn down by the realities she encountered in her day-to-day work. In this space of not knowing, Kate answered the call of the other and left herself open to becoming overcome by the experiences. She was without the needed protection. Kate stated that had she known she could have protected herself. Instead, she had left herself open and vulnerable to being wounded. The experience for Kate was too close, raw, and negated her attempts to negotiate boundaries and establish a safe distance in her relationships.

In Emerg I'm not connected with the parents. I'm not connected with the kid. I don't know the kid. And you know on Unit 1 I knew them for six months. I got to know them, I got to know their siblings, and their grandparents, and the pet dog. But in Emerg you just see them so briefly that I think that disconnect is quite beneficial. (Amy)

Amy spared herself the pain and exposure of relational encounters by moving to an area of practice that facilitated a safer distance. She left pediatric oncology, however, for another area of practice that also has a high rate of childhood death. Unlike pediatric oncology, the relationships in emergency are shorter and typically do not foster a close connection with families. The relational distance and disconnect provided Amy with a needed buffer. She had been worn thin by the intense involvement with families in

pediatric oncology. The constant exposure of long term and intense relationships, that are an inherent component of pediatric oncology, made it difficult for her to navigate her needed boundary lines.

I am reminded here again of the often forgotten work of Sherpas in getting others safely to the summits of the worlds highest mountains. The Sherpas, in their day-to-day work, traverse through the death zone on Everest at a rate of twenty-to-one over their clients (Schaffer, 2013). While some might argue Sherpas chose this work, as could be argued for nurses in pediatric oncology, this does not negate the risks on survival of too prolonged exposure in the death zone. With each traverse the risk increases exponentially. In many ways, this is a similar experience to nurses who have assisted many families and children through their dying time. The difference between Kate and Amy's experience of death is in the exposure, the duration of burden being carried, and the relational proximity to children and families. While both nurses experience death, Amy does not develop long-term relationships with children and families and is thus afforded some protection. This points to the heavy burden, carried over a long periods of time, with exposure to the relational, that is found in pediatric oncology. All of these nurses experienced the death of children in their practice; it was in the duration of care and the relationships that were fostered with the subsequent exposure to the other that made the experiences different.

I Am Not in Oncology With My Child

You're in it. It's what you've chosen as your career. I think that's why it's different because I think a lot of the people are outside and they ask the question,

like “how can you do this?” I’m not in pediatric oncology with my own kid and that’s, I think it’s really different. (Sue)

There is a needed sense of separation from the nurses I spoke with between work and home. This was spoken most poignantly by Sue who shared she was not going through the experience of cancer with her own child. There was a difference that was perhaps not appreciated by those situated on the outside of cancer care. A difference that for her, and many of the other nurses, assisted in their being able to work in this area and not be overcome or over wrought. There was a difference in perspective between the personal and the professional that offered them some protection. While this line may be beneficial and attainable for some nurses, it is difficult to achieve.

Leah recounted a story that has marked her nursing career, a story that she tells often of when she felt judged by other nurses for her lack of response and when she wondered how other nurses were managing their balance and boundaries. It can be a difficult road to navigate.

This little girl, she wasn’t a year old went to the ICU and she ended up dying that night. Our oncologist came in and took all of the nurses to debrief them, but someone had to stay on the floor, so that someone was me. I had the busiest patient anyways, and I was I was fine with it. The next morning this nurse looked at me as she was sitting in tears and she was like “I can’t believe that you’re not crying,” she was like “that is heartless.” I looked at her and said “just because I’m not crying doesn’t mean it hasn’t affected me at all.” She was like, “that was,

that was like my kid, that was like my daughter that died in there.” She was, she was pretty wrecked up.

I think it really affected me, I tell that story a lot. I tell it to new nurses, I tell it to students. (Leah)

There is a difference between believing that “*my kid*” died and recognition of a patient who died. For Leah, this discernment was punctuated in an uncomfortable encounter with another nurse, who perhaps believed differently or held different boundaries than she did. Leah felt judged for her lack of outward response and her ability to keep the line in check. It is also a reminder that nurses will have different responses and hold different beliefs about children, and their involvement with families. To Leah, however, this was a reminder that when “*you make it personal*,” pediatric oncology can be a difficult place to work and navigate lines and boundaries. Leah recognized this thinning of lines in a response from a mother that caused her to reflect on her own mother.

Leah: She was slamming her fists on doors, on the floor just screaming and yelling. At the funeral she was in a wheelchair, she was in her thirties but she couldn’t even walk she was like debilitated from this. It was really sad. I think what I did at that moment is I thought about my mom and then just lost it. When you make it personal, and that’s what I think in pediatric oncology you have to try not to do, if you start making it personal it gets really tough.

ACM: The personal meaning you see is?

Leah: You bring it into you, you see it as your mom, or your brother. I see that in some nurses. I see how they over years still can’t deal with it because they still

personalize it like you know, that was my daughter. They have a really hard time letting go.

Bringing it into you, making it personal, seeing the face of your daughter, or mother can make it treacherous for nurses to navigate the tightrope. It can become too much and Leah required a better distance and space that this relational involvement did not afford. It was Leah, and many of the other nurses I spoke with, a needed reminder that “*bringing it into you,*” seeing your family reflected in your patient and/or families can make pediatric oncology a difficult place to work.

Bearing Children: Bearing Others

I went for the diagnosis meeting, and there would be a ten-month old neuroblastoma, given maybe ten months to live. All I could see in the room was the face of my child. I couldn't bear anymore the pain these parents must be feeling. I couldn't bear it because it felt too acute for me. I was probably in a really good place at the time when I did it. I had the capacity in my life to bear that, without bearing the weight of coming home. I think I could come home, and I felt good about my work, and they needed me that day. I don't think it did after my son was born. I just felt I would just come home, and just weep looking at him in the crib, thinking how could anybody hold this, how can anyone bear this. The unbearability of it. (Ursula)

Bearing the weight of another family's journey had become too much for Ursula after the birth of her child. The line between self and other's pain was too close to home thin, raw, and exposed. All she could see was the face of her own child. She could no

longer bear the unfathomable as reality in witnessing other parents experiencing the diagnosis, dying, and death of their child. It brought reality a little too close. In seeing her own child's eyes, her ability to hold and carry the weight of other parent's emotional pain and instrumental needs lessened. Her ability to bear witness to assist another played out in the etymological meaning of witness, as that of martyr or constant sufferer (Online Etymology Dictionary, 2014). To be in this place, with these parents, brought too much suffering. The buffer that had previously absorbed the blows of pain was no longer able to withstand the forces wrought in the eyes of her child. There is a connection here between bearing another's burden and baring oneself in the vulnerability of exposure to another. There is also a sense that, in bearing her own child, her capacity for bearing another's burden had become frayed and thinned. Bearing is related to energy and strength, but also to shelter and protection (Online Etymology Dictionary, 2014). It is the action of providing a person with the necessities of life (Merriam-Webster Dictionary, 2014). Assisting families through their journey with cancer diminished when bearing another took on alternate meaning of to bear. This form is related to the Latin *effete* meaning exhausted, unproductive, worn out, or past bearing. In a literal sense, it indicates one that has given birth. It also indicates a state of being exhausted intellectually or morally from carrying a burden (Online Etymology Dictionary, 2014). Ursula's ability and endurance had waned and thinned. In bearing her own child, she was no longer able to sustain bearing another's reality played out in front of her.

Since the birth of her son, Maeve moved from pediatric oncology. She found she was not able as easily to separate her work and home life and thus made the choice to leave.

Oh it's so hard! Um, I'm not as dedicated to it anymore. And you know it's, it's hard to see kids that are the same age as him or families in a bad situation. I do find I separate myself too when I go to work. (Maeve)

Michelle struggled with this separation as well and shared “it’s more difficult for me to work here having children.” Upon reflection of this difference, she found after having her children the pain of watching other parent’s was one of being struck in the heart with pain.

I’ve only had children for a couple of years so I’m sort of coming to new understandings. Whereas before I felt very empathetically for people but I couldn’t, in my heart I really didn’t understand. And now I sit in a diagnosis meeting, and I look at those parents, and I think oh my god, if I was sitting here, I don’t know how you’re still sitting you know? So I think it gives me a lot more emotion you know, whereas before, it didn’t strike me as hard maybe in the heart. Where as now it does. (Michelle)

Being struck indicates the physical embodiment of witnessing another’s pain brought too close to your own life. Having their own children, for many of the participants, moved the line of too much exposure and increased their vulnerability to the work they were encountering. For some, this meant moving away from inpatient care and the relentless nature of the dying and death of children, to more distant education, outpatient, or clinic

roles. The distance provided a greater buffer and a thicker line of protection from the long-term immersion and involvement with families typical in inpatient care. For others like Maeve, they could no longer bear the unfathomability of the pain in parents' eyes and left pediatric oncology for other areas of practice. Those who remained built protective barriers around themselves, and perhaps their children, to shield them from the pain in other parents' eyes reflecting too harshly onto or into their own reality. The other became one's own and brought it too close to the nightmare. These nurses, somehow instinctually or knowingly, had to distance themselves from the intimacy of sitting beside a child actively dying. They sought a balance where they could remain in pediatric oncology while realizing their capacity to bear another's burden had been depleted.

Boundaries and Balance

Our personal existence is clearly something which is everywhere denied and yet it is also something which is always involved in the attempt to regain that balance which we need for ourselves, for our lived environment and for the feeling of being at home in the world. It extends far beyond the sphere of medical responsibility and includes the integration of individuals into their family, social and professional lives. This does not seem to me to be an abstract task, but rather something concrete which permanently confronts us. The challenge is the continual one of sustaining our own internal balance within a larger social whole. (Gadamer, 1996, p. 81)

The intersection of the personal with the professional, and being able to successfully balance and position boundaries of connection and protection are situated at the core of being a pediatric oncology nurse. Being a nurse in pediatric oncology, being intimately involved in the dying and death of children and the pain of families is more than what happens in the hours of a work shift, and more than the professional obligations of care outlined in a document from CANO. This is not an abstract theoretical concept, but rather something that arises and confronts nurses in their day-to-day interactions with children and families. This also positions that who we are is influenced by our connection with others, with society, and with our professional obligations. We learn the boundaries and the balance of these reaches through experiences that assist in demarcating where our lines of vulnerability and protection are situated. Opening ourselves up towards another is not a single or one time consideration. It is a continual process in which we are also implicated and affected. The manner in which we open ourselves up and bear the weight for someone also exposes our soft front and increases our risk of exposure and harm in the process. It influences the extent to which we can become worn out as nurses.

Bearing the weight of children and families through their cancer journey called nurses to continually confront, balance, and interweave their story with the story of others. Out of expectations, beliefs, and fears, they began to develop a version of themselves as positioned with others. They defended and buffered their positions in times of strife, confusion, or threat. This continual shifting of lines and positions called for them to maintain a fine balance. This is a part of being human, caring, and

compassionate. This ontological struggle is not absolute; rather, it is premised on a shifting continuum based on a complexity of personal and professional beliefs, experiences, and expectations. Lines are navigated, drawn, filled in, erased, and shift with each encounter. It is a reminder that we are never too far from being called back into the world of relationships where we are implicated and involved.

Chapter Eight: Meditations on Elephants

Of all the footprints, that of the elephant is supreme.

Of all of the meditations, that on death is supreme.

(Halifax, 2008, p. 48)

Spoken by the Buddha centuries ago, these words remind us death is intertwined with our existence in this world. In speaking of death, His Holiness the 14th Dalai Lama has said we can either choose to ignore death or we can confront it like the elephant in the room, think clearly about it, and try to minimize the suffering it brings. We can, however, in neither case overcome death (Dalai Lama, 2012).

If you're working at Flames House I think death is a smaller elephant, it's probably not even an elephant over there. Whereas I think in pediatric oncology - you know one of our doc's has a lanyard that says "Failure is not an option" - I think when we work in oncology with cures at like 82% or whatever it is now is pretty darn amazing. I think we think we can cheat death, and we think we can cure cancer. So I think death is failure in oncology. I think that is why we don't want to talk about it, because it makes us feel badly that we haven't fixed the problem. We failed to cure and so therefore they are dying. And I think that's part of a lot of the problems here, the way we look at it, just the idea of it, you almost want to brush it under the rug, you don't want to talk about it. If somebody's dying on the unit they go down that hallway, there's a specific hallway they go and the doors get closed. It is a beautiful palliative room but it's away from other patients. You want to protect everybody else from it, because

maybe we're scared that they'll think that there's no hope right. So, I think here I think death is a really big elephant in pediatric oncology even though it's very present. (Michelle)

The quote above from Michelle forms the basis of interpretation that is threaded throughout this chapter. Her words elucidate many of the societal and cultural norms surrounding death that have impinged upon and shaped pediatric oncology and in turn the work of nurses therein. I will continue to return to the words and metaphors she has introduced. The presence and power of what she had to say I believe needs to be heard in its entirety before I attend to specific portions.

Failure is Not an Option

Words on a lanyard, worn around a physician's neck, offer a glimpse into how death is perceived in cancer care and in our larger society. In Michelle's words, the lanyard represents our belief that we can cheat death and cure cancer. These words of "failure is not an option" have a lengthy history and have a heavy hold on our beliefs. In 1971, President Nixon declared war on cancer by signing the National Cancer Act in the United States (American Cancer Society, 2011). Two years prior, Neil Armstrong had become the first man to walk on the moon (NASA, 2013). The following space mission Apollo 13 in 1970 was a "routine space flight" that became a "desperate battle to survive" (Kranz, 2000, p. 6). Flight crew director Gene Kranz was credited with stating, "failure is not an option" in bringing safely home the three astronauts (p. 7). When he did so, against great odds, the world's imagination was ignited. There seemingly was no scientific goal that was not achievable. During this time, cancer activist Mary Lasker

published a full-page advertisement in The New York Times entitled “*Mr. Nixon: You Can Cure Cancer.*” In this advertisement, she quoted past president of the American Cancer Society, Dr. Sidney Farber, as stating “we are so close to a cure for cancer. We lack only the will and the kind of money and comprehensive planning that went into putting a man on the moon” (US National Library of Medicine, 2013, para 7). Since that time, governments worldwide have spent billions on this endeavor and the battle metaphor has become a universal in cancer care.

Battle and warfare are pervasive in all avenues of cancer care. The Canadian Cancer Society advertises it has been fighting cancer since 1938 (Canadian Cancer Society, 2014). Those diagnosed with cancer are said to be “battling” cancer. Family members often report their hospitalized loved one is a “fighter” who “will never give up” or surrender. Obituaries often denote the deceased has died after a “long and valiant battle” against cancer. These images and words have found their way into pediatric oncology revealing our wish to combat a disease that harms our children.

Children are small, little, and you protect them and you don't want harm to come to them. For a disease to come and take them just seems so unfair. Because children don't die of diseases anymore, they get immunized, they don't die of measles in childhood and so if something comes to take them then it's a vicious terrible thing that's doing this to them. So we want to fight it. Cancer is a fight it's a battle for life. But we are not going to talk about the alternative. (Michelle)

Cancer evokes a battle for life. Victory is the defeat of cancer and the survival and protection of children against this “vicious terrible thing.” Death is thus often

perceived of as a failure to protect children and a failure to win the battle (Papadatou, 2009). This failure to achieve the directive to cure cancer and save our children is often associated with shifts in our sense of power, control, or meaning of work (Bearison, 2006; Hinds, Puckett et al., 1994). Working in an environment where the death of a child stands in contrast to these normative beliefs can leave pediatric oncology nurses and other healthcare professionals vulnerable and in need of protection from the perceived failure in the pursuit of goals of care (Bearison, 2006; Papadatou, 2009).

Because it's almost like that's a failure if you have patients who die, that's a failure in a lot of ways. I don't think that, but that's I think the impression that I get, that when you get to that point, people feel like they failed. (Sara)

The death of a child lies in direct contrast to the premise that failure is not an option and that we can safely bring everyone home. Papadatou (1997) indicated the death of a child is often viewed as a “triple failure” (p. 576); healthcare professionals did not have the skills to save the child’s life, to save the child from suffering, and additionally betrayed the parent’s and society’s trust. Concurrently, there seems to be also a belief and societal reward for maintaining life, as “children dying on a daily basis is not one that the general public is truly able or ready to accept” (Kaplan, 1997, p. 196). Despite what individual nurses, such as Sara, might think or believe they work within a culture and a society that positions failure as not an option, and death as failure. It cannot help but shape the context of how they work. It cannot help but influence how they are able to respond to death and to the children and families involved.

The battle metaphor is understandable given western medicine's premise that illness, injury, and death are problems to be solved and enemies to be overcome. The image also appeals to the North American adage that if we work hard enough and strive valiantly we will prevail, no matter the odds against us. Thus, those diagnosed with cancer vow to fight envisioning they will ultimately triumph. According to Michelle, there is always something more healthcare can offer in this battle, offering second, third, and fourth line cancer therapies. Those who work in cancer care equally take up this metaphor and continue to fight.

We're always fighting for second line, third line, fourth line, therapy there's always something we can offer right? (Michelle)

I cannot help but wonder if this is tied into Michelle's stated belief that we can cheat death. There is always another card to be dealt, or a gamble to be taken, another bluff to be had as we work towards a cure and bet on life, cure, and winning. Despite, however, our seemingly unshakeable belief in the power of science and our increasing understandings of the disease process a cure for cancer remains elusive. According to Dr. Gary Abrass "we are so smart, but it seems that the cancer cell is smarter. It bobs and weaves, slips our punches, and when we back it into a corner, it defends itself in remarkable ways borne of millions of years of evolutionary acumen much of it hidden in the dark matter of our genome" (2013, para 16). Cancer, despite our best efforts, continues to be the cause of childhood death. In our quest for preserving life and finding a cure for cancer, death is no longer regarded as a great teacher but rather a "looming

biological failure” to be denied and avoided (Halifax, 2008, p. 48). Erica and Michelle seem to speak society’s, and in turn healthcare’s collective view, of this situation:

That’s unacceptable, a kid can’t die of cancer, that’s unacceptable. (Erica)

We used to be okay to talk about death. It’s that whole idea too about the death of children. I think we’re just not okay with that anymore it used to be commonplace and now it’s totally not acceptable. (Michelle)

In the unacceptable nature of this scenario played out in front of us, society no longer holds a “collective view of death as redemptive or liberating but sees it as an enemy to be beaten or, at best, a bad situation to be endured” (Halifax, 2008, p. 49). Death does not factor into the story we tell of our life and so has nothing to offer us and is feared or ignored. “When we distance ourselves from death in this unnatural way it would seem that the only solution to the problem of dying is to avoid it at all costs” (Halifax, 2008, p. 49). The death of children is compounded in this rewritten history, factored in as “totally not acceptable.” Death has become, in the words of Jill, something to avoid and no longer talk about.

In general in our society it’s a negative word. Death is almost seen as such a negative and terrible thing. I think that it just becomes natural that we don’t want to talk. We don’t want to talk about the things that are bad. (Jill)

Death is viewed as a disturbing and negative topic. It is a topic our society does not wish to talk about, it is one of those “bad things.” We have normalized not talking about death and, while hidden in plain sight, it is not looked at nor talked about. Each culture and society has norms that frame and regulate our understandings of death and

dying (Brabant, 2002; Doka, 1989). Norms establish guidelines for human behavior, thoughts, or feelings in a particular context and situation. They also regulate our expectations for the responses of others. They are part of our cultural and social context that establishes normative order. Norms are not simply external guidelines they become part of self-identity through socialization. Internalized, they become considered the normal or expected way of behaving, thinking, and feeling. An individual nurse does not on her/his own accord have the capacity to discard norms or change them as they belong to the group, community, population, or culture (Brabant, 2002). According to Jill, society has naturalized or normalized not talking about death. This, in many ways, has effectively tranquilized death (Heidegger, 1962). It has been banished to a quiet realm in the corner in our quest for maintaining and revering scientific means of ending illness and preserving life (Bearison, 2006; Kastenbaum, 1995). “Death is the self-evident counterpart to life” (Gadamer, 1996, p. 155), yet in our quest to wage war on cancer we avoid death and the evidence of our failure at all costs.

The Elephant in the Room

Wars are fought on many levels and battles played out in many venues in the quest to cure cancer. For those families and children living and dying now with cancer, this battle takes on another more immediate and frightful dimension. The outcome of this battle for them is either the life or death of their child. In this realm, however, we do not wish to talk about death. According to Jill and spoken in the quote earlier by Michelle, death and the word death has become a position of discomfort, it has become our elephant in the room.

It's the elephant, and the word almost more than anything, is the elephant in the room. They know the child is dying, or they know the child has cancer, and so it's okay for you to use those words. But I think we are more uncomfortable with it a lot of times than families. (Jill)

The elephant in the room is an idiom used to express the presence of an obvious question, problem, solution, or controversial issue that is either being ignored or going unaddressed. The idiom is based on the premise that an elephant in a room would be impossible to overlook; therefore people in the room are either pretending the elephant is not there or have chosen to avoid dealing with the looming large issue. The idiom can imply a value judgment that the issue ought to be discussed openly, or it can simply be an acknowledgment that the issue is there and will not go away on its own accord. The phrase is often used to describe an issue that if discussed would cause embarrassment, discomfort, trigger arguments or involves a social taboo (IdiomQuest, 2014). The subject being ignored is often of an emotionally charged nature such as dying and death and a decision either conscious or otherwise has been made to avoid engaging with it. Death makes us, as healthcare professionals, uncomfortable; it stares us in the face, mocking our inability to succeed, or in other words presents us with our failures and fallibilities.

Death is a delicate word... We are more uncomfortable with it than families are. We can have a child that comes in for palliative chemo everyday, but nobody nobody says the word that they are dying. (Jill)

Death is a delicate word that cannot be spoken due to our discomfort. To have a child on palliative chemotherapy everyday and no one acknowledges this connection

indicates our aversion and wish to turn away from any sight or hint of death. We, however, know on some level that death is a possibility.

ACM: In the very essence that we call it a battle or that there is a struggle means that death is an option.

Michelle: Yeah, very much so. The fact that children with cancer get a wish trip and if you look at the criteria for getting a Make a Wish trip is that there is a terminal illness or an illness that has a very good chance at shortening your life. And children with cancer are automatically approved. So I guess we understand it to a certain degree but we just choose to frame it differently.

ACM: I wonder what comfort that brings?

Michelle: Probably a great amount. I think that's a great word for it. I think that ignoring death and focusing on cure does bring us comfort that we can do something about it, don't worry, we can fix it you know? I mean your kid has leukemia, don't worry, 90% of the time we can cure this. But we don't want to talk about the 10% that we can't cure. We want to talk about only good happy things. You have to think of it as a hopeful place.

ACM: What if your child is one of the 10%, where do you find that comfort?

Michelle: And that's the journey right. That's part of (pause) that's the hard bit and that's where we fail families. Is in not offering those the supports too and we do, we do eventually. I mean we're not terrible. I'm not trying to poo-poo the program that way but it's just we do hesitate too long because we're uncomfortable.

Ignoring death and focusing on cure, is according to Michelle, a cushion or comfort. There is always more we can do, another treatment, or regime, or research study, or medication to be offered. It would appear that while we are attempting to comfort the families and children by saying “do not worry we can fix this,” we are also comforting ourselves. Talking about death goes against our instincts and training as healthcare professionals (Kuhl, 2002). There is no safe language with which to speak about death. We wish to focus on happy things, on hopeful things. Death is seen as a failure in our war on cancer and our push for a cure and restoration of health. Facing mortality and turning towards the elephant in the room would require us to challenge and look at our en-cultured ways of viewing death in the western world. We prefer, however, to focus on a new cancer protocol in the slimmest of hope that it will work in our measured reality, rather than equivocate an equal measure of gloom. According to Michelle, we choose to frame it differently.

Framing is the act of surrounding situations, acts, or objects with mental or physical brackets that transfer their meaning by defining them as work, home, success, failure, in, or out. Frames cut off and yet define not only different but separate realms of experience. They tell us what to pay attention to and what to disregard. Framing provides lines that separate the sacred from profane, metaphoric and literal, life and death. Inside the frame is only inside against the boundary of outside and is characterized not by its content but by the distinctive way in which it transforms the contents meaning. Framing directs our attention where to look but also where not to look. If it is not within the frame, we are directed not to see it (Zerubavel, 1991). Death is no longer framed as

something that has something to say to us or teach us. It is framed as something to be feared or denied and thus ignored.

How Do You Hide an Elephant Under a Rug?

For all that it happens it's not talked about all that much, death, of children especially. It's just something we push under the rug, kids aren't supposed to die. It's not something we talk about. (Erica)

The trouble with elephants is they are difficult to ignore. Despite our wish to hide and push death under the rug and not talk about it the elephant remains waiting. Their immense size takes monumental energy and skill to turn away from. These two metaphors, the “elephant in the room” and “brushing it under a rug” brought forward by Michelle, Erica, and Jill appear to speak of the tension played out in their day-to-day work as nurses. The stress and anxiety of turning away and ignoring the elephant of death wears heavily on those in pediatric oncology. As Jill pointed out, we work very hard to not use the word death because we as healthcare professionals are uncomfortable with it. Our discomfort, collectively and individually, arises as we navigate the tension fraught by the appearance of cancer and our inability to have come to a place of cure. There is no safe language to talk about death in our society any longer. The focus is turned toward the acceptable language and fight against cancer and away from the disquieting persistence of death.

Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice - value questions, all - in the human condition. Cancer forces us to confront our lack of control over our own or others death. Cancer

points up our failure to explain and master much of our world. (Kleinman, 1988, p. 21)

Kleinman (1988) asserted that cancer reminds us we cannot control death. The normative views of society that have shaped our current prevailing beliefs of turning away from and denying death have shaped and influenced cancer care. Anxiety arising in the face of death, whether the consideration is of our own death or that of others, has long been studied in western thought (Kastenbaum, 1995; Lamars, 2012; Weisman, 1973). Over the past thirty years the anxiety experienced by nurses when confronted with death in practice has been detailed in nursing literature. There is a recognized feeling of dread, anxiety, or fear at the thought of death or anything to do with dying (Lehto & Stein, 2009; Peters et al., 2013). This is not solely a phenomenon found within nursing or the broader healthcare system. The fear of death is considered a universal human terror (Becker 1973). Within the medical field, this pervasive societal aversion to death factors differently. Society advocates preferentially, and justly so, for the preservation of life in the field of medicine. It is in many ways our *raison d'être*, our reason for being, as professionals within healthcare. While individuals hold their own attitudes towards death as influenced by personal, cultural, social, and philosophical belief systems - - societal and cultural systems also collectively shape through the assertion of normative beliefs and stances what we can and cannot do (Retsinas, 1988). Aversion to death, the turning away from it, is thus societally and culturally ingrained (Kastenbaum, 1995).

A typical response to anxiety is to flee or turn away from that which is causing the tension (Peters et al., 2013). In the words of these nurses, this has caused us as a society

and in turn healthcare professionals to not talk about death, to sweep it under the rug. This fits with the premise that anxiety caused by an anticipated threat to wellbeing initiates avoidance behavior as a technique that humans employed to reduce an impending threat. On a survival level this escape or flight response allows us to distance ourselves from the perceived threat (Lehto & Stein, 2009). This may be done instinctually, or without conscious awareness, to the point that it becomes, as Jill denoted, a natural response to not talk about death. Death, however, remains a day-to-day occurrence in all avenues of society and an unavoidable construct within healthcare. These avoidance and escape responses, rather than diminishing our anxiety, seemingly submerge it below the surface to a place of tension that cannot be easily or readily resolved. This tension, however, manifests in particular ways within pediatric cancer care - - in turning towards and focusing on the fight against cancer. In Bauman's stance, we focus on that which we can change, and turn away from that which we cannot.

Strategies that had been deployed through history to make life with fear livable was that of shifting the attention from things one can do nothing about, to things one can tinker with; and to make the tinkering energy - and time - consuming enough to leave little room (better none at all) for the worry about things no tinkering could change. (Bauman, 1995, p. 106)

Death is one of these fundamentals that no amount of "tinkering could change" (Bauman, 1995, p. 106). It is precisely this connection between anxiety and death that led Gadamer (1996) to refer to anxiety as "fundamentally constitutive of lived existence;" it is what "drives human beings to repress the thought of death" (p. 155).

In dealing with the tension that arises when death occurs, we, as Michelle and Erica expressed, wish to push or brush certain issues under the carpet. We wish to avoid and hide them from our sight. According to Erica, although death is ever present we do not wish to engage with it. The science and technology required to find a cure for cancer is where we have thrown our energy, time, and resources. No one could, nor would wish to, presumably argue that this is not a needed and valiant goal. It has however crowded out and left little room for talk of dying.

The Room Down the Hall

There are implications, manifestations, and symptoms evident from sweeping a large elephant under a rug and attempting to not talk about death that played out in the words and stories of these nurses. These societal implications at play have, in turn, shaped how nurses and other healthcare professionals respond to families and children in their care, and how they respond to death and cancer. In their earlier quotes, Michelle and Erica described the idea of death as one we wish to sweep under a rug, not speak about, and forget. Dying children, accordingly, are swept down a specific hallway, beyond a closed door, to the palliative room. Given the quote from Bauman above, I cannot help but wonder if in our consummation with diminishing our anxieties we have left little room indeed for thoughts of death. This room of dying and death shows the separateness of dying children and their families in pediatric oncology. Relegated beyond a closed door, at the end of the hall, beguiles how much room we have allotted dying and death's position, rank, and privilege amongst us. While beautiful, the palliative room is positioned "away" to protect others from the knowledge of death.

Protection is a form of shelter and defense (Online Etymology Dictionary, 2014). One could argue perhaps that we are giving the families of dying children the shelter and quiet they require for an intimate private time of great hardship. Protection, however, is also akin to a covering over or hiding (Online Etymology Dictionary, 2014). In Michelle's words, we are protecting others: protecting other families, and in many ways protecting the healthcare professionals struggling to ignore the looming elephant. The ensuing anxiety and fear, according to Gadamer (1996), "gives us a certain distance from things" (p. 157), and a certain comfort in the distancing and position.

It is interesting because for the most part we are so comfortable here with talking about cancer. We can talk about the fact that your child has cancer all day but for some reason we haven't gotten there with death and dying. (Jill)

Within pediatric cancer care, it is acceptable to talk about cancer. It is acceptable to talk about, and focus on the foe, and the reason for the fight. These, according to Jill and many of the other nurses I spoke with, are a comfortable topic within the program. One wonders if this has to do with being able to speak to topics that we can do something about, that we can fix and heal. Death lies outside of these parameters as something we cannot fix, a blemish in our *raison d'être* and in the confidence and parameters society has outlined for us as a healthcare system.

I think sometimes that's an aspect of nursing that goes to the wayside because we're so focused on curing that sometimes going into a full palliative mode forces you to admit that okay well we can't fix this. I think that's really hard for people too. (Sara)

Being able to admit and face that as of yet we cannot fix all children with cancer is difficult to accept. Hence, the room down the hall is perhaps as much about healthcare professionals wrestling with a sense of control over the dying and death of a child as it is about protection of the child and his/her family. Fears and struggles that have led to the room's position and privilege. An admission, that according to Michelle, is manifested in a tangible manner with the palliative room cloistered off and set apart.

The Grey House of Misery

Fear is huge! Fear is huge. You're scared of what you don't know. Especially, oh you just see pure fear in the face of a new diagnosis' family. That's all it is, just sheer fear in their eyes, because they think their child is going to die in this dark depressing grey house of misery. (Erica)

The dark depressing grey house of misery, for Erica, appears to stand in contrast to the bright primary colors of the Lego house of love and the description of the oncology program as a place of lightness, fun, laughter, and healing. It is instead a place of unknown harm and uncertainty. I hear in Erica's words the dusky nature of death, the greyness we associate with it. This is a place in which the fears and dread of death become realized. Grey is an achromatic colour, a mixture of black and white it is considered a colour without colour (Dictionary.com, 2014). Persons who are approaching their dying time are considered to be in the twilight of their life (Cambridge Dictionary, 2014). Like the colour grey, twilight has features of black and white and stands in between as achromatic. Twilight is the soft diffused light from daybreak to sunrise or from sunset to nightfall. It contains elements of both life and death, day and

night, light and dark, yet it is neither. Twilight like grey contains uncertainty, vagueness, and gloom that stand in contrast against our need to delineate and mark out clear lines and boundaries of understanding and certainty. Grey and twilight are not clean; their ambiguous nature presents a threat to the inadequacies of our classificatory structures and invokes anxiety, fear, and discomfort. This is the unknown manifested as reality in walking through the physical doors of an oncology ward. In Erica's belief, this family's hesitation at the door recognized that entry would change and mark their lives. I cannot help but wonder if Erica recognized that their entry into the world of pediatric cancer was similar to that which marked her and the other nurses. The other side of the door and entry into the unknown and stated final world of cancer has a mark. There is a sense of finality attached to the door, a door that changes you forever.

I remember one night we were working and our oncologist called us and said I have a family coming in we're pretty sure she has leukemia, she'll be there in a couples hours. I remember waiting, waiting, and waiting for them. They came to the door, but they just stood there, because once you walk into those doors it's final. They were told your child probably has cancer go to the cancer unit. I'll never forget just watching them stand there. I'm sure in their mind they just had that fear of cancer, my kid's going to die. (Erica)

This family was standing outside the door, both aware but uncertain how everything in their lives was about to change. Erica recognized this in the silent expression of their fear and in their hesitation. British physicist Brian Cox said, "being at the junction of the known and the unknown is a beautiful place to be for a scientist"

(2011, 3:53). It is a place of ambiguity but also unlimited possibility. He continued in stating that in our quest to understand cancer “it seems the more we know, the more we don’t know” (2011, 4:11). While this might be a beautiful place to be for a scientist, situated at the unknown bounds of possibility, it remains a place of fear, anxiety, and ambiguity for families and healthcare practitioners within pediatric oncology. It is also a realm upon which is crossed over and entry obtained that one is changed and marked. You become the family, or child, or healthcare professional who has engaged with cancer. As in the nurses who enter the world of oncology, their presence is mediated and shaped by the collective image society holds of cancer, and plays out in the work they are then able to do. It is echoed in the phrases, questions, and curiosity framed towards the nurses I spoke with: questions of “*how can you do this?*” “*do they not all die?*”, “*it must be so sad?*”, and judgments “*I could not do it, I am too soft a person.*” These questions and premises also shape and are held by the families who pause at the door of cancer. They will upon the other side have entered into another world, this time of grey and misery, but also of uncertainty and ambiguity, of the unknown known only through our known images of ill bald children and stories of children dying. It pervades a perpetual state of grey, of ambiguity, uncertainty, anxiety, and fear. There is a longing for the bold primary colours of comfort that match a wish for certainty. There is a longing for another reality, that of a Lego house of love that cushions and protects children, their families, and those of us who work in cancer care.

Lego is derived from the Danish phrase *leg godt* that translates into English as *play well* (Lego, 2012). They are colorful building blocks that can create anything, be

taken apart, and rearranged at our will, creativity, and discretion. We control how the pieces go together, how we play well together. These colorful building blocks represent the foundation and structure of the hospital as a place of healing and wellness. They also perhaps unwittingly dispense another message for in “well play” there is little room for the greyness of dying. This message exists in plain sight to all persons who enter into the colorful hospital. At play, the house of grey disappears until the twilight presses upon us and we can no longer ignore its presence. Do we then turn unconsciously away in our own discomfort from children led down specific hallways and instead refocus our intent to make life full of bright colors and well play. Once again it seems that our inability to come to terms with ambiguity, the unknown, and with twilight has arisen. It denotes the tensions between our wish to keep the hospital a place of brightly lit colorful building blocks and the dark grey place of parents and our own fears at bay. It denotes our wish to focus on life and brush thoughts of death under the rug. It indicates our awareness and yet discomfort that cancer changes us regardless of how we engage with it. Making us recognize that, within the Lego house of love there is also a grey house of misery that we may be entering.

The Place of Surrender

There is a need to begin to find ways to talk about death, while supporting and maintaining hope in pediatric oncology. This appears to initially be a contradictory statement. Paige, having worked in palliative care for many years, noted a marked decreased knowledge and skill level of oncology nurses and physicians in working with the children who are actively dying. Paige, like many of the nurses I spoke, with

struggled with how to balance our quest and battle with cure, our will, and skill in providing treatment with the knowledge of when to step aside and “*let it be*” (Paige).

And even then, well we’re going to try this, we’re going to try that, because you’re trying with the intention of maintaining hope and support, but not really having that skill set. And I think when your focus is to cure, cure, cure, treat, treat, treat, it is hard to turn that off and find let it be. (Paige)

Many of the nurses struggled with this line of knowing when and how to “*turn that off*” (Paige). These instances provoked fear and in how to react and position their discomfort. When I asked the nurses to recount a child’s death that shook or disquieted them, I heard the story of a young girl from five separate nurses. They described how their encounter with this girl’s life and death brought things to the surface that the treatment team had not wanted to face or think about. Her story below is told through the voices of three of these nurses.

Paige: She was a teenager. She had terrible disease to start with she was taking different treatment in Vancouver. When it was clearly evident that she was deteriorating she came back to Calgary in crisis, and her lungs were filled with tumour.

Heather: We hadn’t yet gotten to the point where her family was ready to take her down a level. They still had been in treatment mode that whole time. We were trying to figure out what we were doing basically and that Saturday night things kind of went south with her.

Paige: She had refused the palliative team, so they just met her that Saturday and she's in crisis, and so they're trying to get her pain under control. Her parents are saying "we don't want her too sleepy but oh we don't want her in pain." The nurses are freaking out because they don't deal with that.

Heather: She was air hungry and saying, "I can't breathe, I can't breathe." (The charge nurse was asking) "she is on how much oxygen?" and she kept saying, "don't let me die." She kept on saying (choking up), "don't let me die, I don't want to die." And just like those pleads (crying), and she can't do anything. That night having to change her code status right there in the situation, it was such a messy horrible one.

Paige: She was distressed. She was anxious. She was air hungry, and just not good. But, she died the way she lived, right? Fight, fight, fight, fight, fight, fight, fight she was not just going to go, she was clawing, and kicking, and screaming right to that very end.

Heather: That nurse was in such a bad state for weeks maybe even longer, because having someone plead with you and grab your hand and saying "don't let me die, I don't want to die." just breaks you down (crying).

Sara: I think it was really hard for them because it is one of those things that kind of sticks with you. I wasn't there, I just heard about it, and it stuck with me just imagining her last couple of moments on earth were really difficult. I think that whole situation was very difficult because they tried really hard to for a cure.

They tried everything and did everything. So I think not just for the nurses that

were there, I think for the whole unit, it was very difficult because it brought out a lot of things.

Paige: In terms of her personality she absolutely died the way that she wanted to and you know the way that she was going to go. We had a debriefing session on the unit and I was trying to tell the nurses and they were angry, they were angry, “why didn’t this get, and this shouldn’t have been done and duh duh duh duh and the hospitalist that was on that evening should have called for help, should’ve had somebody come in way sooner than they did.” I said, “you know sometimes that’s the way it goes.” Sometimes it doesn’t matter how much drug you give, this is the way it is. People have that distressful death and it doesn’t matter how much Medazolam they push. It doesn’t matter how much. I’ve seen it. I’ve, I’ve done it, I’ve pushed drugs where you cannot believe the person is still alive but they have that fight for whatever reason so we couldn’t give her a drug.

ACM: She had to fight what she was fighting?

Paige: This was just, it was unfortunate, but there was nothing you could do and to know that right? Sometimes you don’t have all control, all power sometimes you just have to surrender.

ACM: What does it take to get to that place of surrender?

Paige: I think it takes a lot of experience. I really do, I think it takes a lot of experience.

ACM: How has it been for those nurses now?

Paige: You know it is Unit 1, it is not a palliative unit, and it's a huge skill set that you need to identify things. But again that's what she felt and she didn't think she was dying to her last bloody breath she didn't think she was dying. But it didn't surprise me when I heard.

This experience brought many things to the surface for the treatment team. It was an uncomfortable incident that affected the entire oncology program. The death of a child from cancer has been acknowledged as a parent's worst nightmare (Levine, 2009; Moules, 2009). It is out of sync, out of order, from how we presume the world ought to be. Heidegger (1962) believed death to be the defining aspect of the universe in which we live. Our fundamental human condition and concern involves a conflict between the desire for permanency, life, and the inevitability of death (De Unamano, 1954). Nevertheless, "we fight to sustain life, to avoid death, and to avoid the pain of loss" (Moules, Simonson, Prins, Angus, & Bell, 2004, p. 104). Nurses and physicians alike strive for this avoidance at all costs until confronted with a situation that impedes their ability to do so. This, by the words and story of this young girl, was one of those situations. Death entered and wrestled with the treatment team in many ways as much as it did with this girl and her family.

Dramatic increases in scientific knowledge over the past several decades have significantly contributed to advances in the treatment regimes of children with cancer (Ellison et al., 2009). We have prevailed in many areas, remission rates have increased and mortality rates substantially decreased. If the battle is not won and cancer progresses onward despite everyone's best efforts the battle metaphor leads us problematically to a

narrow precipice. On this precipice, we find our options are cleaved to continuing a fight that cannot be won or face defeat and surrender. Defeat and surrendering are often equated with failure. A shaming or humiliation can ensue as we presume the patient and/or treatment team did not battle hard enough, long enough, or valiantly enough. The prevailing battle metaphor motivates some patients and families to ask for, even beg for, another round of treatment to continue the fight. This happens at times even in scenarios when the treatment team believes more intervention will not help and only cause harm (Bearison, 2006; Papadatou, 2009). It is also particularly difficult to give up the fight and to stop when it is a child's life that hangs in the balance. There is however little room in the warfare metaphor for the realization that some battles cannot be won despite everyone's best effort.

In our efforts to name, control, and mitigate the presence of and experiences surrounding death, we have evolved theories, discourses, and societal norms that can perpetuate, if not intensify suffering (Moules, 2010). Many of us feel fear or a sense of aversion in the face of dying. It brings up too much in the presence of pain and suffering. There is too strong a reminder of our own mortality and the fragility of not being able to save all children, and the ensuing sense of loss this evokes. This pain and loss conflicts with our need to foster and maintain hope. There seems to be a sense that hope is what keeps the Lego house of love from becoming the enduring and unredeemable dark house of misery.

Oncology is an area where you are expected to have 100% hope all these kids are going to get better. I think we need to talk about that. This is not always a happy place to be. (Sara)

Pediatric oncology is not always a happy place to be. Sometimes the dark grey house of misery usurps the Lego house of love and we are left in longing. Hope perhaps, cannot in these situations, be framed as our ability to bring them all home. Hope needs to be inclusive of life and the unfortunate encounters with death. The culture and workplace of pediatric oncology holds up hope as a bastion of the finality and relief that a cure for cancer will bring. In the meantime, for those working and those experiencing cancer this understanding of hope is fraught with tension.

I think we look at hope the wrong way. There's hope, maybe no hope for a cure, but there might be hope for a good quality of life for the remainder. (Michelle)

I really believe that you can still have hope, but the hope shifts. Instead of hoping for a cure you're hoping for more - you know a beautiful day with your family or you're hoping for this or that, but you can still have hope. (Paige)

The elephant in the room is asking of us to practice an acknowledgement of dying and death. While individual nurses are able to do so, to work amidst children's dying and death, to talk and be comfortable in their work, it appears that perhaps they are asking for us as a society and within the culture of pediatric oncology to broaden our vision and realign death as part of life. There is a request and a need positioned from them to begin to respect and risk recognition that death and life are inseparable. This is recognition that perhaps we have understood hope in a narrow view. Should this happen perhaps our

approach to death and to hope would be different. We would no longer be in collective denial, suffering anxiety and fear, over the constant need to avoid thinking and talking about death. Perhaps we can retrieve a vision of our relationship as healthcare professionals with dying that makes it possible for us to embrace the unknown without being paralyzed by our anxiety and fear. This is a retrieval that acknowledges death and that sometimes we cannot control who or when it calls for one of our own.

In order to accept something that we previously believed to be the truth, in Paige's belief, we need to surrender. Surrendering in this stance does not mean to give up, but rather to reflect on our experiences. This is a reflection on what we feel, have come to know, and how we know it. It is a restorative surrendering not a failure or a loss. This repositions surrender as a giving into the functional reality of the situation in pediatric oncology. It tackles the difficulty of determining how to take what one knows from experience and challenge the rhetoric of the unspoken as metaphors. Surrendering entails an individual, cultural, and societal response to change and adaptation. These are viewed as key elements that influence the reconstruction of one's way in the world as a nurse who works amidst dying and death in pediatric oncology. This requires clarity around the fact that children do continue to die from cancer. Nurses, and the larger treatment team, according to Paige and many of the other nurses I spoke with, need to begin to think they can broach this topic in meaningful and beneficial ways. It is in the strength found through surrender to this challenge that change will manifest. Acceptance of a new vision of hope does not mean resignation. Surrender thus repositioned is not the

failure to win the battle, but another form of letting be. This is not the end of the battle with cancer but a living with, until death calls, in a new way.

Addressing the Elephant

It's not a failure, and I think a lot of physicians really feel like they failed. In med school how do you deal with death? What is this, what is that? If you're in healthcare you need to deal with death. It doesn't have to be a specialty. Palliative care is awesome, but gosh, you need to be able to, especially in this, in cancer you've got to bring it up. It's not like you're not going to bring up anything that's not in here already for parents anyway. Sometimes it's getting that elephant right in the middle of the room, saying okay, let's go to very dark side, what's the very worst thing, outcome that could happen. (Paige)

In Paige's assertion what is required is to bring the elephant into the middle of the room and begin to talk about how death is manifested in cancer care. There needs to be a reminder that death continues to be a simple reality of the work that we have engaged in as healthcare professionals. A reality that in many ways society has turned away from and hidden, a reality that has shaped the way death is handled within healthcare. For Kleinman, this reality is that:

To care for humans is to be human and to see the limits and failures and also successes of our small humanity writ large in the struggle to help someone who hurts and fears and just plain is in need. ...this is what our life is about, too, what we prepare for. I think at heart it's about the simple realities in life that all of life

covers over because they are precisely that: too simple, too real. (Kleinman, 1988, p. 215)

This is a conversation that evokes and disrupts the normative beliefs of society and those that have shaped “failure is not an option” within the culture of pediatric cancer care.

This is a realignment and assertion that we are human and that our failures and fallibilities are a component of this.

Meditation invokes a contemplative state of awareness. It also demands practice, thought, reflection, and study. While seemingly simple, it requires arduous pursuit and persistence to quiet the mind and turn towards understanding our experiences in a new way. A meditation on elephants requires a new form of address. An address can indicate our home or abode. It is where we feel comfortable, in our element, and secure. It also indicates a sense of duty or courtesy. Address also means to go straight toward, to set right, and be direct (Online Etymology Dictionary, 2014). To direct spoken words toward a particular audience is another form of address. A meditation on the elephant in the room begs a turn towards and an address with dying and death. This is an address that begins to open up and considers death, not as a failure of medicine and healthcare professionals, but as a teacher of life.

Chapter Nine: Do You Think the Angels Will Speak Spanish?

The little boy actually said to his parents that he didn't want chemo again, that he was done with that. It made him feel awful, he got sick, the cancer just came back and "I don't want to do this." His parents were not ready to let go. He was six at the time. It was amazing to me, they brought in child psychologists, they brought in child life, they did all of these interviews with him: "Do you know what being alive is?" "Do you know what being asleep is?" "Do you know what being dead is?" "Do you know what the difference is?" He knew and he was fine with that. He said, you know, "I want to go be with the angels." All his biggest concern was: "do you think the angels will speak Spanish?"

So they, they let him, and they took him home and he died peacefully at home. That was my first experience... It was sad, it was heartbreaking, but it was okay because it was his choice and his family came around to it. And you know, they didn't take it lightly. It was not ah "okay, you know, whatever", it was "do you understand, if you don't get chemo this is not going to sleep?" And it, it was pretty amazing. His whole family was around him. That was my very first experience with a patient dying. (Shannon)

Shannon's first experience with death was "sad" and "heartbreaking." Through her words we begin to get a glimpse into what this was like for her, as a new nurse, to be involved in this little boy's life and the process that unfolded towards his dying and death. It was, to her, heartbreaking and yet amazing that, despite all adult concerns he wondered if the angels upon his arrival among them would speak Spanish, if he would be

able to talk with them in his own language. We would expect and not be surprised that the family of this little boy was thrown upon his death into the complex landscape of grief. Northern American society expects and allows those who have suffered such a jarring loss to grieve (Corr, 2002). Can the same be said of the pediatric oncology nurses, such as Shannon, who worked alongside this and other families, were involved in the child's care and eventual death? Can or should we anticipate and assume to know what they are experiencing throughout these undeniably difficult professional encounters? Moules et al. (2004) wrote, "When death and loss arrive they arrive accompanied by grief. The arrival stays with us, haunts us, wakes us at night, asks questions of us, and needs to be answered and re-answered over time" (p. 104).

This has been an undeniably difficult topic for me to navigate. Cancer is formidable. I am the member of a family who has been eviscerated and eaten by cancer. The steady and continual suffering cancer has wrought on my family makes it difficult to stand back from my own grief surrounding this topic. I have often wondered as I write about my own responses to patients dying and death how my personal journey with cancer leaks into the spaces and presence with those whom I work. I have begun to wonder what indeed I did feel when they died. These are some of the questions that arrived with this topic, questions that flourish unanswered.

Historically, nurses were mentored to maintain an appropriate demeanour and emotional distance from their patients (Henderson, 2001; Papadatou, 2009). As Doka (2010) stated, however, this is difficult to achieve in practice. Lines are often murky; relationships encouraged and strong bonds are forged. This may be particularly true in

pediatric oncology where long treatment regimens foster relationships over months or even years. When a child dies, nurses face that loss, as well as the end of the relationship with the family. It has been said that the very nature of long-term cancer treatment protocols exacerbates the potential for vicarious grief (Kastenbaum, 1987). Times of intense crises, such as an ill or dying child, forge a strong bond more quickly than other situations. Relationships and bonds formed vary, and not every nurse is attached to the same degree to every child and family. Certain losses, however, may provoke a strong response. Working in an environment where the death of a child stands in contrast to normative beliefs can leave pediatric oncology nurses vulnerable to expressions of failure, despair, sadness, and regret in the pursuit of unmet goals of care (Bearison, 2006; Doka, 2010; Papadatou, 2009). Papadatou (1997) indicated nurses often view the death of a child as a “triple failure” (p. 576): they lacked the necessary skills to save the child’s life, to prevent the child’s suffering, and betrayed the parent’s and society’s trust.

Death may evoke a reflection on one’s own mortality or on those in our personal lives. We see the faces of children and their family reflected back onto our own children and family. The personal and professional encounters with death and loss become intertwined and reciprocally affect each other. The tension between cure and care, of having the elephant in the room, remain unchallenged can exacerbate feelings of powerlessness and distress. Through all of these threaded and diverse points of connection and disconnection, grief may manifest along with a sense of loss.

Doka (2010) expressed that grief may arise in such instances, emotionally evident as anger, anxiety, hopelessness, powerlessness, sadness, remorse, or guilt. Many express

it as being emotionally depleted, exhausted, or depressed. Some may become preoccupied with the death, transferring it to hyper-vigilance in their work or personal lives, or become conversely defensive, unfocused, rigid, or apathetic. They may question their beliefs or sense of purpose, or become skeptical. There may be physical manifestations of stress such as aches and pains, sleep or appetite changes, or other manifestations (Figley, 1995). These reactions may interfere with their relationships with others at home and work. There may be responses of anger, impatience, or withdrawal, or distrust. These responses can affect the work environment, lowering morale and contributing to staff turnover (Figley, 1995; Papadatou, 2009). The manifestations detailed correspond and intertwine with those experienced in stress, burnout, vicarious trauma, compassion fatigue, and moral distress research (Figley, 1995; Hinds, Quargneti et al., 1994; Kaplan, 2000; Spinetta et al., 2000; Papadatou, 2009; Zander et al., 2010).

Grief is a Word

I mean that's all it is - grief - is a word, right? (Michelle)

This statement and question from Michelle bring me to the heart of the nurses' responses to childhood death in pediatric oncology. It places into question society's understanding and beliefs around grief, and around the relationship nurses have with grief in pediatric oncology. It places into question what a word like grief is. A word is a sound or combination of sounds that has a meaning when it is spoken or written (Merriam-Webster Dictionary, 2014). Some words are different. They hold a hallowed, revered, or feared place in our language and history. Grief is such a word. The word grief has an ancient history and an expansive kinship. It is the focal topic in the oldest

surviving written work of literature, the *Epic of Gilgamesh*, dated between 2750 and 2500 BCE. The story of Gilgamesh follows his unrelenting grief over the death of his friend Enkidu and the reconciliation to his own finitude that ensues (Anonymous, 2003). Grief from the Old French *grever* denotes hardship, suffering, pain, distress, wretchedness, burden, or wound. From Latin, it originates from *gravare* and *gravis* meaning to weigh down or heavy. In Sanskrit, and perhaps its oldest origination it is derived from *gurus*, a venerable teacher or priest. This refers to the imparter of knowledge, and is connected to the word *gur* meaning to raise, lift up, or to make an effort. It is based on the interplay between darkness and light. The guru, or venerable teacher, is seen as the one who dispels the darkness of ignorance (Hoad, 1996). Grief brings forward pain. It cannot be easily turned away from or ignored. Grief is defined as the “multifactorial response - be it psychological, social, or somatic response to the perception of loss” (Rando, 1984, p. 15). Yet, it is so much more.

I feel like if you're an oncology nurse there's always some underlying sadness in a lot of ways even if you're an upbeat positive person. I think families would probably say that too. It's just, there's a sad undertone to being there because there's always something sad happening on the unit at any given time really.

(Sara)

Sadness is deeply entwined with grief. There is, according to Sara, always a sad undertone in pediatric oncology. That, despite the bright colours, play, and celebrations, there is a sadness that marks everyone's presence and reason for being there. This is an undertone, a subliminal current of sadness, that runs perhaps below the surface colouring

and shaping every encounter within pediatric oncology without conscious awareness. It is if to say that sadness runs beneath in the day-to-day reality of children living and dying now with cancer, in the spaces that treatment and a move towards cure cannot fill. Many of the nurses spoke of this sadness whether in their own experiential responses or in witnessing and being with children and families. Sadness appeared and lingered for the nurses and others, but did grief and its many messy and shared connections arrive? What became of those?

I don't know maybe grief is more profound than sadness. Like, they're all related but grief is just more all encompassing in your life. Kind of affects your whole being. (Shannon)

For Shannon, grief, sadness, regret, despair, and sorrow arrive together entangled. It becomes difficult to disentangle these interpretations and understandings, messy and overlapped as they are. The weight of the word grief in our language, however, stops people in their tracks. Grief arrives heavy. There is neither innocence nor naiveté to grief. It is substantive. It is important.

I think it is important enough to be called grief. I just don't know if it's the same. But it's important enough to have a word like that associated with it; what it does to you and how it changes the way you look at life, and the way you deal with people going through. (Michelle)

Important is related to the Latin *portare* meaning to bring in, to carry, hold, or shelter (Online Etymology Dictionary, 2014). A word like grief, imports a message to the hearts and minds of humanity, to take notice, to pay attention, stop and heed its call.

It is an indication that this experience matters. In this way, an important experience, such as the effects wrought from a child's death, can be viewed in another connection to a port or a wound, a portal, or opening to a new lesson. A word like grief embodies profound feelings of sadness, hurt, a heaviness of one's heart with a gravity of meaning, which is how Michelle expressed her experience with the death of her young patients. Through her encounters with the death of these children, Michelle has changed the way she looks at life and the way she attends to, and cares for, the people she is looking after. One can begin to see reflections of the guru; she has been taught, learned, and been transformed through her encounters with death in pediatric oncology. For Michelle, however, and for many of the other nurses, grief was not a word that felt comfortable for them. Their experience was like grief, important enough to be called grief, yet not. Grief as a descriptor simply did not fit.

Davey (2006) specified "words carry a heavy burden of meaning and association, which can be difficult to set aside" (p. 149). Perhaps none so much as the constellation of words that surround and point to grief in its etymological root of heavy, weighted, or grave. These words of sadness, regret, despair, loss, and failure are ancient kin who have borne and carried the divergence of expression surrounding the death of a child from cancer. They are steeped in societal discourses that shape our beliefs, understandings, and practices surrounding death, loss, and grief. They hold onto us and weigh us down.

Maybe is it that we believe that grief should be overwhelming sadness instead of just reaction to loss. Certainly I feel sadness when a patient dies, but mostly I feel

sad for their parents and all these different kinds of sadness. Whereas when you lose someone you feel sorry for yourself. (Michelle)

The way in which Michelle interprets grief is from her experiences of loss from both her personal life and from her encounters as a nurse. Michelle delineated a difference in meaning between that of a patient death to those in her personal life. To her, the experiences are not felt the same. There is a sense of personal proximity and professional distance that separates the two. When you lose someone, you feel sorry for yourself, but when you lose a patient you feel sorry for his or her family. It appears Michelle is describing the difference between the experiences of loss in our personal life with those at work. We grieve those we are personally close to; we express sadness for those we worked with, cared for and about but were not close to in a personal realm. Michelle delineates these experiences as explicitly different. She does not interpret the death of one of her patients as a loss that necessarily evokes grieving. There seems to be an awareness of space between her and the child that perhaps cushions away grief, and helps keep the loss in perspective that she is a caring professional and not part of their family. This delineation between feeling grief or deep sadness is related to her interpretation of grief being a complex response to the death of someone close to her in family or friends. This does not negate that grieving for a patient is possible, but rather, it is a patient-to-patient nurse-by-nurse response. We do not hold grief; it holds us. It redefines us in its wake, shapes, negates, and redefines who we are. We all experience sadness, learn how to live through it and heal. Grief is a place to experience the pain, loss, and for the relationship with our loved one to be housed. Death within this context is always felt; it

is what humanizes us, and what we need to discover within ourselves is the divide between personal and professional expressions of loss.

Lost Loss and Grief Gone Awry

Loss is often denoted as the precursor or partner to grief (Papadatou, 2001; Rando, 1984). Like grief, loss it has roots and derivations in many languages signifying regret, miss, lacking, perish, absence, and lament (Hoad, 1996). Death is usually taken to be the paramount source of loss (De Unamano, 1954). Hence, the working title of my dissertation over the past four years has been *Marked by Loss*. At conferences and in class work, I have used this phrase; I have written, and spoken about the impacts of loss on pediatric oncology nurses. This title arose from a video clip of a Los Angeles area pediatric oncology nurse receiving a Day of the Dead tattoo as a commemoration to her young patients who had died (von Drachenberg, 2010). She marked her skin in a visible reminder of the ways she had been marked by the loss of these lives cut short by cancer. Some cultures confront death through their rituals to symbolize death and rebirth. *Día de los Muertos*, or the Day of the Dead, is a holiday celebrated in many Spanish-speaking countries to commemorate friends and family members who have died (National Geographic Education, 2014). The tattoo for this nurse was a tribute and permanent reminder of her *los angelitos*, or the little angels, who were lost and her struggles to come to terms with how this affected her.

I awoke last night with a start and thought, “where was the loss?” It was not there. The word loss was lost. I looked back through page after page of transcripts searching for a glimpse of it. I did not find it. None of the nurses I interviewed used the

word loss to describe their experiences of childhood death. I sat perplexed on my office floor surrounded by the scattered pieces of paper and contemplated this absence. What did the loss of loss indicate? Like Michelle, two nurses used loss to describe deaths in their personal life of family or friends. They spoke of their grief, of the gnawing pain and suffering they experienced when a loved one died. Yet, the death of a patient was set apart and separated as something other. I question this separation and wonder how it can be that death and loss can be cleaved apart. How can death just be death and not loss? What marks the difference? This was curious to me given the prevalence of the word loss in our common vernacular of death and within the grief literature. What are the ways in which the nurses did not experience death as a loss? These nurses believed there was a difference in their experiences of personal and professional encounters with death. They taught me that those who have remained in pediatric oncology practice had found a way to separate the personal from professional as evidenced in their language of delineation. In other words, these nurses reserved loss and grief for personal traumatic events; sadness and compassion arose in a professional manner for the children and families.

This reminds me we cannot assume that all deaths are experienced as a loss. Responses to loss through death are mitigated by our beliefs, values, societal and cultural expectations, and personal history with death amongst other factors. Our responses are dependent on our relationship with the person who has died, as well as on the meaning we attribute to the loss (Corr, 2002). We also feel for others through their proximity to us, which may be a critical element when we experience or do not experience grieving.

Death, while universal, does not hold a universal meaning. Nor does loss through death affect all in a universal manner; each loss, each death, affects persons in singular and particular ways (Moules, Simonson, Fleischer, Prins, & Glasgow, 2007; Papadatou, 2009). While a family and healthcare team members experience the loss of a child, the experience appears to hold different meanings and expressions to each person involved (Papadatou, 2009). As a nurse, if I understand my role in healthcare means that sometimes people die despite our best efforts, then I might be considered by some to have developed a healthy professional perspective. Treatment and cure do not always co-exist. If we perceive that the death of a child is not a professional failure but a limitation and a harsh reality of being human, does this in turn affect the way loss and grief are interpreted? The death of a child is an undeniably difficult and sad experience as Anna denotes below. There is, however, seemingly a difference of perspective; rather than a personal loss, this is a professional sadness and caring for the loss experienced by the parents and family.

I came to sort of realize that it is very sad always for the child, for the family, the whole family that has to go through a child who dies from cancer. But I don't think it was necessarily grief that I was feeling. (Anna)

I had come to believe there was a symbiotic relationship between death and grief, the two coexist, one following after the other. I can see now, through the words of these nurses, that there is a danger inherent in this assumption -- an assumption as perilous as presuming all grief is experienced similarly or that it follows prescribed stages or processes. This assumption can lead us to view nurses who are not visibly grieving or

who state they do not grieve the loss of their young patients, as hardened or embittered, or that their grief is disenfranchised, disallowed, or hidden. If the protestation that they are not grieving is too loud or long, they can be deemed to be in denial, or the system has taken away their means or awareness to grieve, or they are simply burnt out. This is an interesting position, which places the nurses in an almost passive response in their inability to accept that grief naturally follows and is the appropriate response to a patient's death. It is an interesting position as well to assume that this should or could be the case. It is a challenging and confusing continuum for nurses to traverse, assuming that on the other end of the spectrum nurses should not or must not grieve because it can be interpreted as unprofessional. It strikes me that we are once again setting up another dichotomous choice of values, this time one of grief - no grief, which leaves little room for the messy shades of grey toned reality along the way.

My look into these nurses' experiences of grief had gone awry. Lost loss and no grief threw me off of the course I had expected to find. In this, I began to wonder about the connection that arose earlier between professional failure and loss, and the demands relegated to "bring them all home" and that failure was not an option.

Not that the physicians don't, but cure is not my intent generally in my interventions. It's not cure, it's you know coping, and helping people live through what we're doing to them in order to try and cure them. That is what nursing does. (Michelle)

Nursing work in Michelle's words is caught in the tension between cure and care. There seems to be a wish to open and retrieve a broader remembrance of what nursing

does, of their role and responsibility in cancer care. The death of a child, not perceived as a professional failure, seemingly opens up the space for this death to not be perceived as a loss. By this, I refer to a professional loss or failure to cure cancer and win the battle. It is rather viewed, as not a failure to cure, but an unfortunate loss of a life. The intent and focus has shifted to care versus the failure to cure and seemingly softens the affectual responses by the nurses. While there is recognition of the family's grief and loss, there is not the overwhelming response that disables. One wonders if, in this delineation, nurses are striving to find a conceptual allotment and permission to view death not as a failure but rather as an unfortunate reality of their work. There seems to be a desire to reconcile that good work can be accomplished and fulfillment achieved despite the death of children from cancer.

It's different because when I think of grief I think of sort of an overwhelming sadness. Not to say I'm not sad when I lose patients but it certainly doesn't overwhelm me. So there must be something about it that's a little bit different or the way it's approached. (Michelle)

The nurses I spoke with acknowledged a child and family's loss, cried for the family, perhaps attended the funeral, or had alternate ways to recognize and remember a young life cut short. There seemingly was, however, a capacity or need for this to be set outside and separate as a work experience. It was distanced from who they were as people and integrated as a component of the work they did as pediatric oncology nurses. Many of the nurses I spoke with were open and frank in their responses to me. I did not get the sense they believed they could not share how they felt after a patient's death with

either me, their colleagues, or within the system. Their grief was neither hidden nor disallowed; many reported feeling like they were supported in being able to respond as needed to a child's death. It was, however, as Michelle states, a different response than one found in their personal life. They approached it differently.

A New Label

I think it would be a step backwards to say grief versus burnout. It's a new label.

For me it's a journey and each one is different. It's the timing, when does it happen in your career, where does it happen. Have you just had three deaths? I think when I broke was when I was like "enough already." (Sue)

Labels are meant to instruct and inform us about the world in which we find ourselves. They are intended for convenience and safety (Merriam-Webster Dictionary, 2014). They tell us the content of our food, the size of our clothing, and delineate dangers. The outward sticker label becomes our position of identification. When we label people or experiences, however, we set up the possibility that we begin to believe things are solely as labeled. This is problematic when the label of schizophrenia or Down's syndrome, for instance, becomes who someone is rather than something someone has. The world of people living with mental illness and disabilities has suffered profoundly because of labels; reduced to stereotypes, these labels acknowledge superficial aspects of the person rather than the entirety of their experience. The new label of grief, as interpreted by Sue, demonstrates that the label does not humanize the way in which death was experienced; nor does it reveal that each experience is different and as such is beyond, or more specifically lives underneath the label.

Labels do something else as well. As identifiers and positioners of content, they tell us what we need to know; often, this is where our search for knowing ceases. In the identification and labeling, we believe we know them, or the product, or experience that we have “got it.” The search for anything more or deeper often ends. If grief is delineated as just a new label, one wonders if Sue worries our quest to understand nurses’ experience of death has been realized or fulfilled or that we now have “got it” in terms of pinning meaning down. I hear in her words, though, a marking that this is just one more label applied to the surface of an experience that exists below, in a depth beyond our attempts to apply a word to it. I also wonder if she hopes the conversation about nurses’ experiences will continue to be opened and explored rather than shut down by the conclusion that often arrives when we believe we have captured an experience.

The experience of death was different for each nurse in this study at different times in her life, for different reasons, and different with each child. They have convinced me, to my own chagrin and my own needs to fit it in a box, sand off the rough edges, round the corners, and fix it, that I cannot. I do not know what the “it” is. That is perhaps the fallibility of our language to describe an experience that belies words to find one or even many that capture what it is. Perhaps at the end of the examination there are many “its,” many places of dark and light, and places that rest between. These nurses expressed no need to encapsulate their experiences under a banner, a word, label, or a condition. They instead offered through their own words and insights into the complexity of how they felt, responded, and continued to understand their experiences with dying and death.

Grief, like burnout, vicarious traumatization, compassion fatigue, and other terms is a placeholder for these nurses. It does not fit, nor do they wish to have the label applied without discussion and awareness of the fluidity and changeability of the experiences associated with the affects of childhood death. In the end, they are attempting to make sense of how they can continue, or not, being involved in this work. They are in many ways attempting to be okay.

Being Okay

Erica: I believe thirteen children passed away in three months. I started in an extremely bad time. I was basically surrounded by kids going south right from the beginning. I'd walk by the room, and I'd see them just lying in bed, and just hooked up to every tube imaginable, and mom crying at the bedside. I remember thinking that looks terrible, and I remember when they passed it was "okay, good, no more tubes everywhere no more mom crying at the bedside." That's mostly what I remember about those thirteen kids. I remember that they suffered. That's what I remember most.

ACM: It sounds to me like somehow you came to the belief that death was better than suffering?

Erica: Yeah, having to watch a child or anybody suffer when we've done everything, when they pass its okay. When we've exhausted every avenue, when we've exhausted everything and it's just suffering and miserable, to me death is okay. That's why I find that the death of our kids doesn't really bother me,

because I know especially four years in, we do everything, we exhaust every option. So if they pass, that's all we could do. (Erica)

When all medical and treatment options have been exhausted, Erica's belief in our ability to attempt any and all necessary means of healing enabled her to reconcile that it was okay for death to be the alternative. There does not appear to be a notion of failure for her, or an exploration or torment that more could or should be done, she was able to let it go. For her, this was the making of meaning on a middle road of okay. What the nurses I spoke with, including Shannon in the retelling of her first experience with patient death, were and continue to hope for is to be okay with it. To find a way and means to stand in the midst of a work practice where they will encounter death over and over again and to be able to continue to stand and bear the weight of the families with whom they work. What, however, did being okay mean; why did this language continue to arise and stick with me in the words of the nurses I spoke with?

If it's not for you, that's okay. It's not something that you should have to force yourself to be okay with because you're going to have a hard time. You shouldn't have to force yourself to be okay - and not okay with a child's death but at peace with what has happened in their life. (Erica)

Okay is the position of non-commitment, as though we are unsure what is going to come at us next, whether the next entails good or bad. It occupies a space, which is neither positive nor negative. Although many would argue it holds more of a negative persuasion than that leaning towards the positive. It is a zero-sum holder, allowing the positive and negative to exist without cancelling them out. Okay allows one to exist in a

place of ambiguity and openness. It fills a void in our language for that which is mediocre, all right, or average. It also indicates assent but with a question tagged on, as if to say I agree but not whole-heartedly, I hold out a certain amount of resignation or taciturn reluctance. Okay is also connected to borders and boundaries in its relation to something one is able to bear, endure, or tolerate. It does not indicate a love of, but neither does it forward an outright dismissal nor inability to get through what one is faced with. It indicates an air in some ways of reluctance, yet it can also deny permission to engage further. As an adjective or adverb, okay means adequate, acceptable, or mediocre. It is often used in contrast to good, as in “the food was (just) okay.” As an interjection, it denotes compliance (okay I will do that), or agreement (okay, that’s good). As a verb and noun, it indicates assent (She said it was okay). As a versatile discourse marker or back-channeling item, it can also be used with appropriate voice tone to show doubt or to seek confirmation (Are you okay?) (Merriam-Webster Dictionary, 2014).

While pervasively used in the North American English, the origin of okay is a point of debate. It is premised by that okay may have originated from the North American Indigenous language Choctaw. Missionaries working in this community provided translation of the Bible into Choctaw. Many lines of translation ended with the particle “okeh,” which meant “it is so” (Oxford Dictionary Online, 2014). In this origination of okay, we can begin to see connections to letting it be and a sense of permission and surrender to the realities of dying and death in pediatric oncology that many of the nurses I spoke with reiterated.

In their attempts to be okay, nurses saw or understood things differently in terms of their approaches to children dying. For many of the nurses, they came to believe that death was a better alternative to enduring endless suffering. Like Erica they struggled with how to make sense of a child in pain.

How you're able to make meaning. What meaning you derive from that and how you process that and if you think that's okay. If you think it's unfair and not okay than you can't work there right? So somehow you have to be able to process it to being something that's okay somehow. Something terrible and you make it kind of like well, that's just the way it is. (Michelle)

Arriving at a stance and understanding that, “that is just the way it is,” “it is so,” and being at peace with that, was a struggle and middle road for these nurses. This was a making sense of the death versus make sense of death globally as part and parcel of their work place and of the world of pediatric oncology. There seems to be a need to make meaning of their experiences and encounters with childhood death. They are not hoping to excel or relish in their work with dying children, nor do they strive to run away and continue to avoid it in their practice. The nurses I spoke with are trying to maintain the balance of being okay, of that middle ground, neutral position, and placeholder for zero. Being okay becomes a reasonable response to the day-to-day encounters with children who may die. This does not presuppose that there are not moments of joy, relief, or humour; yet neither does it disallow explications of sadness. Okay holds and protects the nurse in a space of openness to remain professional with the potential to respond to the needs of children and their families.

Suddenly You Are Surrounded

Suddenly you are surrounded by it. Your colleagues are experiencing it, you're experiencing it your physicians are experiencing it. It's just one of those moments. I think there is actually a threshold when you have this incredible, too many, whatever that line I'm talking about, it gets a little frail and you can't deal with it anymore. But I don't think it is grief. It's like, it's just too much, there's only so much you can witness. It is sort of a witness thing. As pediatric nurses we witness a lot. (Sue)

The stance of being okay is in continual flux and reconciliation. There were times when experiences became too much. Sue shared that, when the line became frail, her ability to maintain a position of being okay was disrupted. There are physical thresholds, tangible ones we see and walk over, and there are temporal ones, marked by lines of distress or suffering that wear. These too are palpable. Thresholds create the fulcrum around which our internal state changes, around which we function; sometimes you only notice you have crossed from one place to another and stepped over the threshold once it has happened. This appears to be the case for Sue, she was aware she was in a position of being suddenly surrounded, as if she and her colleagues were taken off guard.

The term surrounded originates in being overflowed or submerged under water (Online Etymology Dictionary, 2014). There is a sense in Sue's words of being enveloped and overcome by water, with little or no room to breathe. To be surrounded indicates one is besieged on all sides, with no position of defense, or safety, or recourse. The fullness of witnessing and bearing the experience of children and families was too

heavy and there was no room left to hold it. There was no reprieve and the space of being okay was disrupted.

Being Not Okay in Black August

That was probably the lowest point that I have ever seen in the unit. It was like one after another of the patients that had been there forever. Lowest morale, people, I'm pretty sure people were thinking about quitting. We call it Black August when we talk about it now. You bring it up and everybody just knows, if they've been there that long, know how hard that was. At that time there were a few in just 24 hours and it was just one after another. I can't even describe it. And it was when I was pretty new too. It was the busiest I have ever seen the unit and everyone was so sick. On a particularly horrible day you'd go to the supply closet, take a deep breath, try not to cry, grab what you needed and leave. It was a hard time. (Heather)

Heather's words reveal the struggle to get through a time she calls the lowest in her work in pediatric oncology. There is a feeling or sense of being besieged, struggling with the volume of despair and distress, and of finding brief moments of respite in deep breaths in the supply room. By all accounts and from numerous nurses I interviewed, this was a distressing and difficult time. During times of multiple patient deaths, such as was the case for Black August on Unit 1, nurses struggled with being okay in their attempts to maintain their position of emotional safety while standing in the midst of death. They struggled to find ways to continue in their work through seemingly endless stretches of one after another of their children dying. During this time, they were attempting to

appreciate the work they did amidst suffering from the sting of cancer, and to reconcile their place, as nurses and people. This affected not only the nurses who were working but, as Heather remarked, the entire unit was affected and experienced low morale. There appears to be a threshold. When this threshold was breached, a struggle ensued to maintain the perspective and distance Gadamer (1996) noted in his description of balance. Equilibrium shifted heavily towards proximity. It became difficult to get away from or to have any distance from death. There was little or no time for reflection, and death continued to unrelentingly pervade and be the focus of the unit. For many of the nurses who worked amidst the dark times of Black August, the unrelenting nature of deaths, of children they knew well and had worked with for many years, took a toll. They were no longer able to maintain the balance of being okay.

Nurses such as Amy struggled with the meaning of what she was doing as a nurse in pediatric oncology. She no longer believed that children with cancer lived. Her optimism was drowned in darkness. Her perspective had been altered and reframed to one of disappointment and disillusionment and she was no longer okay. She was surrounded by death, submerged, and no longer believed she could continue her work in a positive manner.

For me leaving pediatric oncology I wouldn't say burnt out, I loved what I did. But, I knew it was time to go, because it was (pause) I don't know how to explain it but I was seeing more, more death and more. I didn't have the same positive outlook. By that point last year every kid that came to the hospital died. And I'm like, that's not what I went into it with, that we can fix these kids and this is

positive. If you don't believe it, it's hard to tell these kids and it's hard to tell the parents that, because I'm not going to, it's very hard, they'll know. When I first started I strongly believed that every kid had a fighting chance and I think it was just the amount of kids that lead up to before I left that I knew very well that passed away. I did have that negativity that no, I don't believe or I think most kids that come into this hospital now died. I'm like maybe it is time for me to change. I don't think it was burnt out. I think it was my awareness that I needed a change and that I wasn't as happy coming to work or positive that I was more focusing on the negative and focusing on the cancer and not the kids. Probably change, not necessarily burnt out or grief I think it was a desire to change. (Amy)

A long succession of dying children wore many of the nurses on Unit 1 down. There was no reprieve or safe space of distance from death. Amy no longer believed children had a “fighting chance,” her work became focused on beating cancer and not on the children. Her work had lost its heart and positivity and she was no longer okay with her place among the distress and despair that Black August brought. This shift of balance towards a negative outlook was the threshold for Amy and she decided she needed to leave pediatric oncology. For Kate as well, this change in perspective from being okay, to not okay, came when she no longer believed she was making a difference in children's lives; rather, despite all efforts the unrelenting nature of cancer continued forward. She could not reconcile this fact nor make sense of how she positioned in the work of pediatric oncology that included these times of death.

Kate: I do find after your first few years and its not as you thought you know "I am helping people, I am making a difference." It seems like you have one die every month or every two months you sort of start wondering, "what am I doing? I am making the last months, year of their life miserable and then they die." It seems like if they don't die they go out into the world, and they come back five years later, and they come back ten years later with something new or the thing has recurred. So for the kids that we did not lose that went off into the world and were supposed to get better and never come back again, when they started coming back on year four, year five, that's what really did it to me. I was kind of okay with the kids that got better or are going to get better and just know that some just don't. But when the kids that got better, that are supposed to be off living their lives, started coming back again with the same thing recurring or with something new that we gave them because we gave them chemotherapy or radiation and now they have a new tumour somewhere else, I wasn't okay with that. I had a really tough time. That was probably my worst thing, because you are seeing these families again and it's very unfair, very unforgiving the second time around. It just does a number on these families. It does a number on all of us.

ACM: How did you cope?

Kate: I didn't. I left.

Kate was unable to reconcile the remission and subsequent death of children she had previously worked with. This, for her, was her threshold of too much. The delicate balance she had created, of being okay with working in a place where children die, was

shattered. This return of children the second time appears in many ways to be understood as a failure to Kate. There is a stated disillusionment with her position in not being able to help children and families. Instead, Kate now perceived her role in their life as postponing the inevitable or making matters worse. She felt the damage and failure too closely and chose to leave pediatric oncology. To Kate this shift, return, and multiple deaths of children she knew did a number on her. To do a number on someone refers back to a musical “song and dance” that has been colloquially termed as a “number.” To do a number on someone is also referred to as beguiling or hoodwinking him or her. This was often used in reference to running a con or a confidence game on an unsuspecting someone (Dictionary.com, 2014). In this instance, cancer conned Kate and others into believing children were cured and would be okay; however, in its wily unpredictable nature cancer returned, took everyone by surprise, and wreaked devastation.

Reconciling Your Place in it All

I think you at the end of the day you want to be able to at least reconcile what's happened at work with who you are as a person. I think it's just hard to reconcile a child's death. (Sara)

Reconciling, for Sara, positioned bringing together who she was a person with the work she encountered in pediatric oncology. There was a need to bring the discordant events or facts of her life and work together in a way that made it okay. Sara has to be able to go home at the end of a shift and be okay with the work she has done as a nurse, and who she believes herself to be as a person. These two parts of self had to be brought together in a way that made sense and meaning to her. It is difficult, however, to

reconcile a child's death. It goes against the belief that children should not die. To sit at the bedside of children who take their last breath and to be okay or to find a place of being okay with the work that they have to do is a struggle for these nurses. Reconciling these discordant events is challenging. I sense for Sara and the other nurses a struggle to find a safe place to be okay: not okay with a child's death per se but with their work and place in the child's life and death.

Conciliatory gestures related to reconciliation or bringing discordant points of view together often happen at the end of a battle or fight; on one side, either the winner or the loser, approaches the other party to find a common ground for the common good. It is a show of good faith and a wish to move forward despite their differences or displacements. There is an inherent sense of needing to placate or pacify something that is causing discord or disharmony, to make them be able to work together again despite differences. Reconciliation and conciliatory gestures are often a matter of changing or joining perspectives. For Paige, this form of reconciliation meant *"having a very good sense of life and death, and recognizing my place in the big picture"* (Paige). This indicates how she understood her position within the life and death rhythm of the world as a nurse but also as a person. Perspectives shift with changes in the angle approached, or in the lighting; means of understanding, and framing change over time, child-to-child, family-to-family influenced by home and work life. Who they are as nurses and a people, and where they are, crescendo together lending to their angle in and their perspective on death. The perspective then frames the meaning they give to the situation

and to the individual children within their care. This is in essence, how they look at a particular situation or an encounter with a family.

I see it as like a negative or positive perception of where we are working.

Because I can see it and I certainly remember going through periods of it myself where nurses become very focused on the negative of everything...things that are challenging to deal with you can see the environment turn to being a lot more negative and I think that doing that for periods is certainly normal being able to get through that and gain perspective that it doesn't mean that you work in a terrible place and that we still do good things makes a really big difference. (Jill)

A shift in perspective from negative to one of greater positivity was prefaced by Jill as the ability to still view the value and good in the work done in pediatric oncology. The optics that frames the culture and mood of the unit also influences how they perceive their work and the meaning they then attribute to what comes towards them in practice. They were once again, in my estimation, looking for balance and the middle way.

The Middle Way

I think you just want people to know that you genuinely care about these kids.

Even though you may not throw yourself on the floor crying when they die it still has meant something to you and it still has affected you as a person probably in good and bad ways. I want people to know that that was really tough for me, but I was able to find something good in it and I hold onto that in a lot of ways.

(Sara)

Finding something good in a terrible experience is a matter of finding that middle way and route of being okay. It is a matter of finding something to hold onto while you are holding up others. “In the experience of giving care there is a delicate balance between opening our heart endlessly (compassion) and accepting the limits of what we can do and how we and others feel (equanimity)” (Halifax, 2008, p. 44). Equanimity, prevalent in both eastern and western philosophical and religious thought, is described as an evenness of mind, neither elated nor depressed. It stands in a middle ground. Equanimity is the capacity to attend to suffering and yet not be overcome. It is the strong back that supports the soft front of compassion. These interdependent qualities are the foundation for effective work with suffering. It offers characteristics necessary to walk the fine line between openness and protection. In German, equanimity is comparable to *gelassenheit* and arose from the work of Meister Eckhardt. Heidegger referred to it as openness to the mystery at play in the world. Equanimity is found in the experience Gadamer referred to as letting go or letting be (Bruns, 2004). It is a means of living without why.

The mean, middle ground, or *mitte* is according to Gadamer where understanding takes place (Gadamer, 2004). This common middle ground is what nurses called for in order to navigate their experiences within pediatric oncology. It becomes the place where knowledge and experiences about children dying is spoken about, ideas are shared, and ways to learn to be okay with dying and death are openly discussed and explored. There is a need for ways to share what they have experienced, how they have been affected and transformed, narratives where support replaces isolation and distress. This is the ground

where risk meets protection, where we move past fear and anxiety, not forgetting the elephant or pushing it aside but walking with intent and purpose towards tenderness and learning. This calls for transparency. This calls for seeing the world clearly in the manner Gadamer (1996) stipulated as requiring awareness of the wholeness of experience and life - - nurse and person, bright colours and grey, life and death, and of letting the world see into us.

All Manner of Ups and Downs

One never meets just Cancer, or War, or Unhappiness (or Happiness). One only meets each hour or moment that comes. All manner of up and downs. Many bad spots in our best times, many good ones in our worst. One never gets the total impact of what we call 'the thing itself.' But we call it wrongly. The thing itself is simply all of these ups and downs: the rest is a name or an idea. (Lewis, 1961, p. 21)

"Experiences of joy or of grief share a complexity that escapes easy linguistic expression" (Davey, 2006, p. 149). In journeys of gaining experience in pediatric oncology, of learning that their work encompassed the death of children, nurses spoke to me of stories woven and influenced by their individual and collective history, cultural and societal norms, and institutional regulations. They shared in a human struggle to speak about and name an experience that is messy, painful, and shifting.

According to Gadamer (1989), experience negates our prior knowledge, tempers and transforms us. We work to find an understanding, through dialogue, that replaces a profound internalization of our experiences, back into the world. This process may

disrupt our previous ways of knowing and being and expand our horizons. Intense experiences such as the death of children challenges our thinking and understandings of it - - things are not as they ought to be. This leaves us feeling uncertain or unclear about how we position in the midst of our practice as nurses. Our work is to help bring to form, through language, an articulation of such experiences so we can better know what it is like for these nurses to work where children sometimes die.

The topic of death and loss yield a woven tapestry of history, understandings, personal sensitivities and professional ambiguities. Death, as the elephant in the room, is asking to be addressed. This does not mean that we make things similar and accordant. This does not mean we understand experiences as solely grief, or burnout, or compassion fatigue. Rather, it is the arriving difference that propels us to look at our own prior understandings, assumptions, beliefs and in doing so, challenges us to think differently. Through this process we may be transformed, and, in doing so our practice is transformed.

Chapter Ten: The Matters That Matter

There is a weight to this topic. I have at times, over the past four years of dwelling with this topic, felt it crush down upon me relentlessly. As I declared in the previous chapter there have been dark hours and restless nights as I have fought my own entwinement with cancer, death, and nursing. Over fifteen interviews and one thousand pages of transcripts I have carried the topic with me. My wish is that I have followed it to a middle common ground of rest that resonates, that addresses the question of so what. When we consider the “so what” of anything, we are asking why something matters, or more precisely, why should it matter to me or to healthcare and the broader society. It is the time in this research endeavour to discuss the matters at hand: the topics and questions that matter to nursing practice, research, and education.

Research and Education as a Fusion of Horizons

The fusion of horizons, Gadamer contended, reveals that what we have learned must be translated into our present and in doing so becomes applied. Application is a key element in his take on understanding. “To understand is not only to swallow, as it were, an intellectual meaning it is a “grasping” in which we are also the ones who are “grasped” by what is at stake” (Grondin, 2011, p. 15). This is a process where in we put the experience and our understandings of it into our own words. As our horizons widen, we become cultured. The experience of education is this process of becoming cultured. Culture is the “domain of all that which becomes more by virtue of the fact that we share it” (Grondin, 2011, p. 15). It is a collective experience of being human. The nurses in my research, through their experiences with families and children in practice, were

transformed. These experiences were often uncomfortable and difficult to undergo. They felt confused, alone, and lost. Many were quite vocal in their wishes, their laments, criticisms, and accolades. They often expressed detailed plans of what they thought would have helped them, or what they hope will help others stay in this area of practice longer and to be healthier whilst doing so. It is for this reason, that throughout this section detailing the research and educational implications of this research, I have continued to use their words and their voices.

Sombre Statistics

Canada's healthcare system has a predicted shortfall of 113,000 nurses by the year 2016. This shortage is coupled with an estimated 53.4% potential increase in the demand for nursing services (O'Brien-Pallas, Alksnis, & Wang, 2003; Ryter, 1997). Working with terminally ill and dying patients has been found to be emotionally draining and challenging (de Carvalho et al. 2005; Kaplan, 2000; Rashotte et al., 1997). Pediatric oncology nursing has been identified as a particularly high stress area of clinical practice (Fitch et al., 2006; Papadatou, 2000; Vachon, 1987). Research has identified pediatric oncology nurses are at an increased risk for grief (Kaplan, 1997, 2000; Papadatou et al., 2002, Papadatou, 2009), stress, burnout, and related sequelae (Hinds, Quargneti et al., 1994; Zander et al., 2010) leading to decreased job satisfaction, increased sick time and attrition, and depersonalization of patients (Docherty et al., 2007; Spinetta et al., 2000). Canadian cancer statistics (Canadian Cancer Society, 2009) show a steady rate of the incidence and prevalence of pediatric cancer cases, indicating the continued demand for nursing services in this speciality area. This specialization area is confronted and will

continue to be tasked with recruiting and then retaining nurses in an increasingly depleted nursing workforce. Given these grim realities, the sustainability of the pediatric oncology nursing workforce is a critical issue confronting decision-makers. There is a continued need to examine these issues to better understand factors influencing the recruitment and retention of pediatric oncology nurses (Bakker, Fitch, Green, Butler, & Olson, 2006; Canadian Nurses Association & Canadian Federation of Nurses' Unions, 2006).

Becoming Aware of Death in Practice

Becoming aware of the ways in which death impinges upon our nursing practice and personal lives was punctuated by all of the participants. This refers, not only to the diseases or traumas that result in death, but also to the ontology of the death. We live and die within the lives of others. Our lives are interconnected with those whom we come in contact; we are social and relational beings. The ontology of death differentiates dying into how we interpret its proximity to ourselves and how we connect or disconnect from the death of others. We feel a different intensity for those who die, by how and why they died, and who they were to us relationally. The death of an older person who has led a long life and dies peacefully is felt differently, interpreted as the expected. However, when a child dies from a disease such as cancer these expected life trajectories are shattered and the death is often experienced as disconcerting and wrong. The implications for nurses, according to my research participants, are often unclear, hidden, or not talked about. The consequences can be devastating.

People need to know what they're coming into and they need to know what to do about the feelings that they're going to encounter. Because if they're left to their

own devices and they're worked very very hard especially as a new nurse on inpatient you're working 12 hour shifts, most of them work full-time, that's a lot of you know, that's a lot of burden and if you don't know how to manage that then you're just going to say "what, get me away from here, get me away, put me somewhere where not all the kids are going to croak all the time." (Michelle)

There is a reality to practice in pediatric oncology that the nurses I spoke with believe is vital for nursing students considering specializing in this practice area should know. The reality for many of these nurses centred on the aspect that children do still die from cancer.

I think they need to know the reality of what they're coming into. My students say all the time, "oh I want to be a ped's onc nurse and I go really? I said, you know they die right?" "Some of them die. And you need to be there and you need to be the one that's there." I often will talk to them about things like the reality of it and really a lot of the reality is like every other nursing unit we're short staffed, we don't get breaks, we stay for free overtime, you get peed on, pooped on, barfed on, we get all of that just like anywhere else but then we have this piece, of things go bad and children die. I think it's important for new nurses to know what the reality is on those units. (Jamie)

For Jamie, it was important for nurses entering into pediatric oncology to know that beside the trials of practice faced by many nurses, that there was another reality that centred on children dying. An estimated 80% of pediatric cancer patients in Canada are either enrolled in a clinical trial or receiving treatment according to a registered protocol

established by a clinical trial (Ellison et al., 2007). There have been substantial improvements in prognoses and longer survival times. Yet a considerable percentage of children still die. The majority of children with cancer die in a hospital setting (Bearison, 2006; Libin et al., 2008) a significant portion whilst receiving active cancer treatments (National Cancer Institute, 2009).

Research and clinical wisdom support a blended approach to end-of-life oncology care. This combination includes disease-directed treatments together with palliative measures. Most often favoured by parents, this approach attempts to balance hope for the child's life to be prolonged while providing as much comfort from pain and suffering as possible. Underlying this approach is the belief that children and their families should not face the choice between life-prolonging treatments, such as chemotherapy, and palliative care (Libin et al., 2008). Fowler and colleagues, in a survey of pediatric oncologists discovered continued disease-directed therapy was the most commonly cited reason for not making a hospice referral. This was particularly the case if the receiving hospice was not equipped to admit children receiving chemotherapy. Hence children dying with advanced cancer often remain in hospital to be cared for by pediatric oncology nurses, who by all accounts are less experienced end-of-life care practitioners (Fowler et al., 2006). Dissonance and distress, such as was detailed by the nurses I spoke with, may continue to arise in the shifting demands of working between cure and palliation efforts, while feeling ill prepared and ill-informed (De Graves & Aranda, 2005; Olson et al., 1998).

The nurses I spoke with were often quite explicit in the educational needs they believe are required to bolster their knowledge, skill, and confidence in an area where the death of children is an ongoing reality of their practice. Education was also believed to need to include assisting them to begin to understand their own beliefs about death and dying, its proximity and distance to their personal and professional lives and the relational complexities of being with children and families over long periods of time.

Ongoing Mentorship

Ongoing staff mentoring, whether formal or informal, was an often-mentioned needed component of their practice.

I think the whole idea of supporting nurses in being knowledgeable about what the risks are at the place that they work, and that the encounters they're going to have, and giving them opportunities be it by education, well I guess an education session, or a group of sessions on how to deal with patients who are dying I think is helpful. Giving, empowering with them with knowledge of what to do and how they might feel and what to do about those feelings and you know what are healthy ways of doing that. (Michelle)

Support for newer staff came up often as well. There is also a stated need for established lines of staff mentoring as “on the go” mentoring by older to newer staff is decreased due to lessened overall staff seniority. Within this need for continued support for nurses are two separate yet often connected approaches -- that of mentorship and preceptorship. Often used interchangeable in the literature, there are some key facets that distinguish the two approaches as they apply to clinical practice settings. Preceptorship is a means of

transitioning student nurses or new nurses into a workplace setting. A preceptor is assigned to work with the nurse with the focus being that of increasing the clinical knowledge and skills relevant to the clinical area. The relationship is often outlined for a prescribed short amount of time (Sedgewick & Harris, 2012; Watson, Raffin-Bouchal, Melnick, & Whyte, 2012). Mentorship, in contrast, is often a less formalized relationship between mentor and mentee and is focused on the continued professional development of existing nurses. The relationship has no prescribed time frame and may continue for years (Yonge, Myrick, Ferguson & Luhanga, 2012). At present, a substantial percentage of new nurses employed by Unit 1 have completed their final university preceptorship on the unit. They then transition into a new role as a staff RN upon completion of their oncology unit orientation where in they may or may not identify a mentor. There is no formalized preceptorship model in place. Formalized preceptorship models have been shown to increase nurse retention rates and are positively correlated with the translation of new knowledge. There has thus been a move across healthcare organizations to explore this model and to begin to integrate it into clinical venues where nurse recruitment and retention are challenged, where staff turnover is high, and where few “senior” nurses exist (Myrick, Luhanga, Billay, Foley, & Yonge, 2012; Watson et al., 2012; Yonge et al., 2012).

Unfortunately there is so much turnover on the unit that the senior nurses aren't that senior. I think it is so intimidating when you are new in an area that it can be really hard. You don't know who to go to for that type of support and you don't necessarily look like that you are struggling or having issues. I think that

educators that they have on the unit are probably one of the stronger supports because they are involved with the new staff kind of right from the beginning and tend to be go to people. (Jill)

Support, whether through mentorship, preceptorship, or a combination of both approaches also needs to include ongoing open, honest, and courageous conversations about staff's experiences with death and dying. These are conversations that uncover and challenge beliefs, attitudes, and practices regarding individual and the program of oncology's responses to death.

Providing more opportunities for people to connect and to talk and address for themselves what their perspective on this is because we might do things a certain way because we have an inherent belief but maybe we don't even know that we think that because we have never been asked to put it into words or to frame it. I think it would be nice if we had an opportunity - we have to do CPR every year - that is important. So doing something where we have to address this side of our practice would be beneficial. (Jill)

These conversations also need to address some of the perceived stigma of being emotionally affected by experiences in practice. There is also a stated need to reassess the tone and content of debriefing sessions. There is also a stated need to reassess the tone and content of debriefing sessions. Debriefing as an organizational construct originated during World War II by Brigadier General Marshall of the US Army as a way of "getting the most factual and detailed information" (International Combat Stress Conference, 2014, para 16) from soldiers post mission. Soldiers reconvened and were

questioned by superior officers in a process designed to analyze what had occurred and to develop new strategies for future missions. This was not a conversation, but a one-way question and answer to establish facts. The “Marshall Method” has been appropriated into educational, psychological, and healthcare settings as a catch-all phrase for a debriefing meeting following what is often deemed as a critical incident, such as a death in pediatric oncology. Debriefing as found in most healthcare organizational contexts, differs greatly from the critical incident stress debriefing (CISD) psycho-educational program developed by J.T. Mitchell in the 1970s that requires highly trained personnel to administer (Mitchell, 2005).

And dialogue, having those dialogues: “What frightens you?” or “How did you do after the child died?” “Are you finding you’re thinking about it a lot?” “Are you finding you’re still crying a month after?” We don’t have a process, a really good process of debriefing. (Paige)

Debriefing in its original instructions from Marshall included a component of acknowledging emotional responses from participants and then a conscious intent to move away from and not engage with the emotional or psychological aspects of the experience in favour of an articulation of the facts (International Combat Stress Conference, 2014). I question, with this history and structured format, if debriefing in these situations is an appropriate modality to encapsulate the emotive responses of nurses and other staff. Perhaps what is ultimately required is a shift from debriefing to consider the emotional side of care as a pre-emptive component of a safe and healthy practitioner.

They practice the skills over and over again but they never touch on the emotional side until after it's happened. Then they do a debriefing which lasts an hour and they say contact us if you have any problems after this and move along your merry way and you go back to work, see you tomorrow. (Kate)

The need for training in therapeutic communication as interventions for staff, as well as children and families, was highlighted. Information regarding the dying and death process were also punctuated as being needed as means to demystify the experience, quell anxiety and fears while increasing knowledge, skills, and confidence.

For nurses to understand the differences between nuances and between like a therapeutic relationship and what we're here to do and how we can help in that, like what that conversation can be and giving them tools to deal with death. Like actually deal with the process of death, so having them comfortable with palliation, supportive meds, understanding pain medication, language around what do you say to a family who actively has a child that's dying in your bed. Conversations that are therapeutic and helping them really train up to, it's not going to be a formula, but having them trained to feel more confident in approaching it, and feeling good about what that relationship is, and should be, and how they can intervene, and help that journey. (Sue)

Organizations in Canadian oncology care, such as the de Souza Institute and the IPODE project, are providing on-line courses and training in therapeutic communication, family nursing, death and dying, distress management, amongst other topics to begin to address the informational and practice needs of nurses in oncology at a continuing education and

graduate professional level (de Souza, 2014; IPODE, 2014). While not realistic that all nurses practicing in oncology are able to access and attend these programs, they present valuable resource links.

Staff Orientation

The need to address death and dying in undergraduate curriculum and during the pediatric oncology orientation was one of the most noteworthy issues forwarded by the participants. The majority of nurses believed they were ill prepared and uninformed about the relational and emotional aspects of their nursing practice. This included the realities of the dying and the death process of children as well as how to navigate the therapeutic relational needs of children and families. Inherent in this lacking knowledge is one of self-care and the demands and risks of emotional involvement.

Their second semester of practicum a lot of our students are in nursing homes and we had last semester a patient die. I don't know if it was the student that came across them or they died right after the student had left for the day. That poor student just had a horrible time dealing with it. We don't, we don't even touch grief and loss until they're in third and fourth year. Well, that's not realistic in supporting our students. And then we're teaching about mental health and all of those things so we're bringing up things that are just so heavy for these students without any support to back them up. I think that that's a huge mistake we're making. (Jamie)

Several nurses highlighted the medical components of the orientation, yet found it substantively lacking in end-of-life care.

The orientation was nothing on death and dying process, nothing like that. No, no, no it was all on the basics, well not basics but sepsis, airway, breathing, circulation, med administration. There was nothing on the death and dying part. Which probably would be beneficial to be like, what do you say at that time? Or at least have an education class time on that. We have it for central line certification and epidurals. We don't have one on how do you go into a room with a kid that's going to die in a few hours. Which is important, it's super important. And a lot of nurses don't know how to do that. Especially all the new staff that have never been with a kid that died. You always want those tools. And we get the how do you teach central line teaching to a family well then how do you go over the dying process? Right? Like we do have a great palliative care unit, palliative staff that I'm sure would be more than happy to come over and talk about that and not just be like, oh we've got to call palliative for that question. Well we should probably be knowing what to expect when they do die.

(Amy)

Amy continued by distinguishing between relying on the palliative care team as an expert entity to answer questions and one as a training resource to increase pediatric oncology nurses' knowledge and skill. There is a stated will from these nurses to garner and increase their own skill and confidence if the resources were availed to them. Spending time at the pediatric palliative care hospice (Rotary Flames House) was mentioned as an important learning mechanism during orientation. It was mentioned by several nurses that it would have given them valuable insight and skill as to what to expect rather than

“winging it” or “being thrown into the deep end” and having to figure things out as they went along. Exposure to palliative care settings and information regarding end-of-life care situated there-in has been shown to be positively correlated with oncology nurses increased comfort in entering into situations surrounding death and dying in their own clinical practice settings (Esplen, 2014; Fitch, 2010).

I think it would be awesome if they could spend some time at the Flames House.

That’s sort of part of an orientation. (Paige)

Paige, a nurse with an extensive background in palliative care was forthright throughout our interview on the benefits of integrating end-of-life care into the culture and fabric of pediatric oncology.

The use of simulation exercises was brought forward by many of the nurses as an important learning tool.

Some type of preparation for it would have been nice. We had overviews of how to do a central line, how to give multiple infusions they tell you how to how to do all the physical things you need to do but they don’t really prepare you for the emotional part of it and um there is not a whole lot in place in terms of resources that you can use. And I don’t know that people know to use them or think there is stigma in using them. (Kate)

Many universities and healthcare facilities have simulation centres. Simulation, whether through high fidelity, live actor, or alternatives, has been shown to increase patient outcomes, and patient safety while increasing health professional knowledge, skill, and confidence in therapeutic communication skills (Aebersold & Tschannen, 2013). It

would be of use to consider these resources for end-of-life training for undergraduate, post graduate, and professional training in oncology. For practicing nurses, simulation training offers an opportunity to re-rehearse an actual event, or to continue to learn how to communicate with patients and families as continuing medical education.

I would probably make nurses take it before they started on the unit or within their orientation. Just to understand the process of the whole death experience. It could be days, it could be hours and how to approach it with the families, how to approach it with patients. Different things, you could do different ways, to talk about it or not talk about it, whether to touch them, not touch them. A lot of nurses are uncomfortable with this. (Leah)

A major challenge exists in knowing how to integrate the burgeoning field of end-of-life care into health profession education programs. Surveys undertaken in North America and Europe indicate that education in end-of-life care remains sporadic and fragmented. Faculty report they felt unprepared to teach key components of end-of-life care, while students indicated a lack of mentorship to offer feedback and support when they care for dying patients. Research has also reported physicians often feel unprepared to cope with end-of-life issues. There is a tendency to avoid or withdraw from uncomfortable situations while simultaneously reporting difficulties in communicating with dying children and families (Barclay, Wyatt, Shore, Grande, & Todd, 2003; Dickenson & Field, 2002; Solomon et al., 2005).

Research of pediatric oncologists in the USA, Canada, and the UK overwhelmingly indicated they felt lacking in formal end-of-life education and struggled

through by increasingly stress-filled trial and error encounters in clinical practice. Those who did feel comfortable reported having strong mentors and role models throughout their training (Dickenson & Field, 2002; Liben et al., 2008; Solomon et al., 2005). These findings and the statements from the nurses I spoke with reiterate the importance of developing alternative modalities for training in end-of-life care for practicing nurses who do not specialize in palliative care. It also appears equally important to assist undergraduate students to come into contact with dying persons and to be mentored through these experiences to learn to build meaningful connections with patients and families while learning to position their own boundaries.

Death Draws Them Away

The turnover is like 18-24 months probably. People come and they, they try it out for a bit and then they can't. A lot of people can't. (Michelle)

If we first consider the statistics of attrition given above by Michelle, over 50 % of nurses who complete orientation on Unit 1 have left by the end of year two, 75 % by year three. Aside from the high cost associated with pediatric oncology orientation; this also means a steady stream of new nurses are required to continually fill the void left by others. This has implications for patient safety, patient outcomes, and nurse work level satisfaction (Bakker et al., 2006; Fitch et al., 2006; Fitch, 2010). Newer nurses, by their own admission, struggled with the mechanics and high learning curves of medical treatment regimens in pediatric oncology. They found little time or confidence to provide emotional care of children and families and often found the dying process uncomfortable and avoided contact.

I honestly think it is a really hard place to work and I think the reason is because they don't have retention of staff. So where did they all go? They left! Because I think there's burnout and I think, I think they have a really difficult time retaining staff. There's sometimes a really low morale there. I mean this is all like aside from the death piece but that's what I think draws them out of there. (Leah)

Such significant turnover benefits no one. It is counterproductive on a management budgetary level due to the high cost of orientation per nurse in the oncology program; as well as diminishing opportunities to develop a strong cohesive team. Staff retention decreases organizational costs by reducing the need to continually hire and provide orientation for new staff (Bakker et al., 2006; Fitch et al., 2006).

I can walk on the unit after my mat leave and I don't know 90% of the nurses because the turnover just happened. So I think retaining a workforce is where you get to build it you know? If you can keep people there for long enough you can build their skills and make them make that a really strong nursing workforce and then their patient care is going to be stronger. (Michelle)

As Michelle stated, retaining nurses in practice is key to a strong and safe workforce. This speaks to more than being a nurse in a challenging work environment, but is also to how nurses feel about her/himself whilst in the work. This highlights, once again, the relational aspects of working together that matter. The more challenging the work, the more we need to appreciate this work as different, emotionally challenging, and valued (Bakker et al., 2006; Fitch, 2010).

I think we're not retaining because we don't support them and because it's a very emotionally laden work. If nurses don't feel supported and appreciated then they're not going to stay. (Michelle)

Although we can come to appreciate the quality or quantity of our own work, being recognized and valued by families, colleagues, management, and the healthcare system remain essential and key in retaining nurses and keeping them sustained in practice (Bakker et al., 2006).

Support and Recognition

If I had all the money in the world I would look at supporting nursing staff because I think that's how you get a really good patient care. (Michelle)

Co-creation of an environment that supports nurses working in pediatric oncology is essential. The ongoing distress experienced by nurses needs to be directly addressed in an approach that assists nurses to work through their experiences with childhood death and the tensions inherent in this area of practice. By identifying the complexities, for nurses and other healthcare professionals, the metaphorical elephant-in-the-room shrinks with every open conversation and purposeful intervention offered.

I think role models and good leaders that really support you and help you put words to what you're thinking... that is key and that's big time lacking here I'm sure you've heard that from lots of people...It's just sort of the times that we're in here too with the cut backs and people's roles are being scrutinized and cut the fat, cut the fat is sort of the expression that we toss around all the time. So you don't really want to rock the boat. I think it's hard, I just have a really strong

belief that nursing that the nursing workforce is what sort of runs this joint and if we don't support them and if they're not healthy, then patients aren't healthy.

(Michelle)

We sometimes speak of chewing the fat with someone as a colloquial means to express having a long or meaningful conversation (Idiomquest, 2014). What the nurses in my research expressed was their desire to have the opportunity to discuss their concerns with nursing, medical, and systems level management. This seems to stand in direct contrast to cutting the fat, or rather to cut expenses, wastes, and lower expenditures. When cutbacks become the focus this often sends a message to not “rock the boat,” engage in difficult conversations, or challenge normative views. When pediatric oncology nurses no longer believe they have a voice to chew the fat, to engage in meaningful conversation about the implications and struggles faced in their work, they voice their opinion in alternate means, by leaving. Four of the nurses in my research have left pediatric oncology due to feeling not supported, alone, and overwhelmed in practice. They did not believe support was available, nor did they believe the emotional challenges of their work was acknowledged, recognized, or appreciated. While conversation need not be quieted during challenging economic times, the idea of cutbacks with implications for jobs and roles serves to oppress and quiet dissension.

I felt that more could have been done to help out the nurses and, and to keep nurses around. There was a high turnover at that time. I wasn't the only one that had to leave at that time. It was a stressful time and a lot on us. I really wish that there was more and I don't know if it's funding wise but in Emerg they have

nurses that took classes on grief counseling and things like that, maybe we need more of that. But, no I found there wasn't any (help). Even from the higher-ups to the basic management I find that there isn't. (Amy)

If we do not continue to make explicit the entwinement of life and death within the work of pediatric oncology and begin identify and pay heed to these issues nurses will continue to struggle on their own accord, and in that either find a middle ground of safety and comfort or leave what they now perceive to be the dark grey depressing house of misery behind them.

A Change of Mindset

Paige: I think it would take education. What do other centers do, that's always a good question, and then if there was any research to back up the value of that. And a real change of mindset, a change of mindset.

ACM: And that change of mindset is?

Paige: That dying is as much a part of living. So I think it would be a change of attitude, a change of culture. I think how we process death as a program.

Marg Fitch (2010), a Canadian oncology education and practice leader, wrote that “no matter where you are in your career or how much experience you have had, personally or professionally, talking about dying and death is hard” (Fitch, 2010, p. 6). Paige, with a long history in palliative care, believes that staff in pediatric oncology must be and are up to this “hard” challenge of facing conversations about death and dying and ultimately change how death is processed in the oncology program. Paige has articulated two distinct but interconnected needs of the pediatric oncology program, that of

education in death and dying, and a cultural change into which this educational shift might become possible. To address these wishes, I turn my attention to one potential orientation of cultural change grounded in the adult learning theory of transformational learning theory as it might be integrated with the underlying principles of knowledge translation. It is my intention to provide a brief overview as they might be applicable to this situation, given the depth and breadth of these concepts and learning theories, it is beyond the scope of this work to comprehensively engage with them.

The type of cultural change or attitudinal shift that this requires is neither an immediate nor easy solution. Education is often held up as a panacea, a “one-stop shop” for all that ails healthcare practice. The generic use of education without the underpinning of appropriate learning theory often trickles down into the appropriation or application of standardized toolkits, checklists, or practice regimes. Little attention is often paid in healthcare and professional education to the underlying educational philosophy. The result is often perceived or felt by the learners to be a top down directive or mandated acquisition of skill, knowledge, or in the case of debriefings legalities. Educational needs must therefore be matched with appropriate educational theories and resources in a manner most fitting for the learning situation (Merriam, Caffarella, & Baumgartner, 2007; Taylor & Cranton, 2012).

For nurses stepping into the world of pediatric oncology and learning how to be with children who may die, the transition can be a disorientating one, filled with experiences and emotions they have never before experienced. This kind of learning cannot be solely presented through simulation with standardized patients, or in a

classroom environment; it is a type of learning that develops and happens in real time, with real people (Fitch, 2010). The undergraduate educational preparation of nurses may be grounded in pedagogical learning theories; however, the actual experience of being with children and their families, is personally and professionally transformational. Pedagogical applications of learning theory are in these instances less appropriate than those found in adult learning theory (Merriam et al., 2007). For these situations in particular, I position with the transformational learning theory of Jack Mezirow (2000), as one among the plethora of learning theories that is appropriate, given the transformative and often disorienting experiences described by the nurses in this research. The transformational learning process is intended to create a deep engagement of new knowledge, and ultimately, adaptation to and re-configuration of such knowledge back into one's professional life. Among all possible adult-learning theories, transformative learning theory resonates because it is intended to provide an educational experience consistent with the purpose of making sense or learning to live within challenging circumstances (Taylor & Cranton, 2012). Mezirow contended all learning is shadowed by the possibility of life altering experiences (2000). Transformational learning theory provides the opportunity to learn, confront, and engage in critical reflection of the possibility of how dying and death are processed in the pediatric oncology program and the need to explore the new meaning, roles, relationships, and actions contained to attend to this change. This process is guided with and from others who have gone before them, as teachers, mentors, and preceptors to help with this process. The affective, social, and

cultural components of the learning process are thereby simultaneously addressed (Taylor & Cranton, 2012).

A disorienting situation, such as the death of a child and the tensions inherent in pediatric oncology in speaking about death, can be viewed as a trigger for a needed change. In transformational learning theory this disruption moves individuals from experiencing knowledge as a series of facts disconnected from their meaning and context (theoretical understanding) into a relevant perspective or one that has particular meaning for the learner. Unlike informational learning, which refers to extending already established knowledge, transformational learning is about changing what and how we know. This is done through the learner or learners in their exploration of their experiences and in their critical reflection on those experiences as a means to adapt to new and challenging situations. This process is not left to the learner alone but through a continued engagement with others (Merriam et al., 2007; Taylor & Cranton, 2012).

Changing culture: Changing mindsets. The word culture is derived from the Latin root *colere* meaning to tend, guard, cultivate, or honor. The figurative sense of *cultivation through education* first appeared in the 1500s. From the 1800s culture came to mean the collective customs and achievements of a people (Onions, 1966). Anthropologists have defined culture as the universal human capacity to classify experiences, to encode, and to communicate them symbolically through artifacts and behavior (Kimball, 2005).

An organization is a formalized group, or community of people, who share common goals. It consists of individuals, who simultaneously belong to some other,

larger collective whole or entity (Wilbur, 2000). The concept of organizational culture might best be described as the collective personality of an organization. Organizational culture refers to the taken-for-granted values, beliefs, attitudes, underlying assumptions, collective memories, and socially constructed customs of an organization (Gergen, 2009). It conveys a sense of identity, and provides unwritten, unspoken, and often unconscious guidelines for behavior and social norms within the organization (Schein, 1999). Reinforced over time, the collective unconscious manifests itself as “the way we do things around here.” Individuals often remain unaware of the pervasive influence of their organizational culture until it is challenged, threatened, or disrupted (Cameron & Quinn, 2006).

Organizational cultures are complex. Research has found that one of the major reasons impeding organizational change efforts is a lack of understanding regarding the significant role of culture (Kimball, 2005). There is a growing realization that, despite the best-laid strategic and tactical plans, significant organizational changes must include not only changing structures and processes, but also address the underlying organizational culture. Appreciating the complexity of culture is particularly important when attempting to manage change that affects organizations at multiple levels, as culture is multifaceted, deep, broad, and stable (Cameron & Quinn, 2006; Kimball, 2005).

Bridging knowledge translation and transformational learning theory.

Knowledge Translation (KT) has been defined by the Canadian Institutes of Health Research (CIHR) as the “exchange, synthesis, and ethically-sound application of knowledge - within a complex system of interactions” (2006, p. 2). It is relational,

dialogic, and multidimensional (Nutley, Walter, & Davies, 2003). KT has come to be viewed as an ongoing cyclical process of research and education to practice that accommodates the macro and meso system levels, cultural, and organizational aims of evidence-based practice and the micro and individual considerations of healthcare professionals, patients, and families (Davis, 2006). If KT is revealed and situated within and through human relationships, then it inherently encompasses the development of a shared understanding of the knowledge being translated. This occurs through the merging of the relevant considered research and educational evidence with the cultural, socially constructed and contextually embedded, experiential knowledge of the stakeholders. Together this ongoing process of shared understandings and different levels of evidence blend to advance the quality of healthcare and the overall health of the healthcare professionals themselves (McWilliam, 2007). Both of these factors must be attended to in order for the pediatric oncology program to be sustained.

This conceptualization of KT predicates altered roles for the involved stakeholders. Researchers and educators are no longer framed as the experts with knowledge to impart nor are healthcare professionals cast as the potentially recalcitrant learners of knowledge to be gained. Knowledge users no longer hold sole responsibility and accountability for achieving evidence-based practice; but are also an integral component of the research and educational process. KT in an integrated format invites the evolution of continuing strategies in which multidimensional and multidirectional knowledge is co-constructed by all involved through interpretation, synthesis,

dissemination, and uptake components (CIHR, 2006; Mykhalovskiy & Weir, 2004; Timmermans & Angell, 2001).

In order for this conceptualization of KT to be realized, all involved stakeholders must be meaningfully engaged in this shift of how death and dying are processed and spoken about in the pediatric oncology program. This originates in the building of a common understanding of its purpose and objectives. This requires a transformative shift in which stakeholders are engaged in developing a deeply felt interest in this process that is relevant to their everyday practice, as well as, ownership of that knowledge and its application. Kotter and Cohen (2002) referred to this process as the necessity to be able to both think and feel positively about what needs to be done and why it needs to be done. According to Kotter and Cohen both the heart and the head must be engaged or change is less likely to occur. “People change because they are shown a truth that influences their feelings, not because they were given endless amounts of logical data. When changing behavior, both thinking and feeling are essential” (p. 182). The nurses in my study are saying through their words, stories, and tears that this change is necessary. They are in many ways demanding it to continue as healthy practitioners and for the program to continue to assist children and families through their cancer journeys.

This change involves approaches to address the intimate, highly personal, socially constructed experience integrating cultural knowledge, affective responses, and both factual evidence and humanistic understandings (Kimball, 2005; McWilliam, 2007). The approach provides a venue that promotes the valuing of new understandings in terms of staff’s own practice, addresses shifts to culture, reluctance, and trust in ways that are

appropriate to their professional practice needs. The approach overcomes feelings of coercion and betrayal, exposes distorting self-doubts, promotes openness, affords a vehicle for the expression of empathy and concern about how others think and feel. It provides a forum in which all can weigh the new understandings, assess arguments to alternative directions, and critically reflect on their assumptions (Kimball, 2005; McWilliam, 2007).

Research in the fields of education (Mezirow, 2000), psychology (Deci, 1999), and business (Kotter & Cohen, 2002) has suggested it is the meaning any knowledge holds for a person that transforms it into applicable knowledge. People who are presented with new knowledge that capitulates into change must have an opportunity to filter what they hear and feel. It is only after this can they then evaluate the applicability of the information (Mezirow, 2000). This process is thought to change peoples awareness, receptivity, and motivation to move into the unknown realms that change calls for (Bridges, 1993). Understanding requires that the involved stakeholders together assess the meanings behind what is being asked of them in moving towards a new manner to process death and dying. They must collectively explore the clarity, truth, and appropriateness of what is being communicated; the truthfulness and credibility of the leadership; and the authenticity of expressions of feeling (Mezirow, 2000). Unlike instrumental transactions, in which logical problem solving dominate, transformative changes in culture use metaphor, stories, and reflective dialogue, like those found throughout this research endeavor, so that all involved are given the opportunity to revise their interpretations and socially construct new understandings, appreciation, and

commitment to act on and maintain change (Gergen, 2009; Kotter & Cohen, 2002; McWilliam, 2007). The participants' frames of reference and perceptions about what would be most useful to create meaningful lives beyond their previous experiences with cancer, treatment, and the possible death of children should count, as much as, if not more than, biomedical skills.

With purposeful examination, we can begin to re-conceptualize how experiences with cancer, dying, and death affect pediatric oncology nurses, the program, children, and families. This necessitates further exploration to expand our understandings and keep the conversation open. If nurses can be helped to feel more comfortable and competent within the ontology of dying and death, as much as they are trained to perform their biomedical skills, perhaps we would witness less attrition. This research has elucidated that the educational issues related to insufficient end-of-life and death experiences do not rest solely in practice environments. Training and the practice of meditating on dying and death must begin when and where nursing education begins, and must continue in organizational practice environments. This will take, as Paige described, a change of mindset, and a change of culture as to how we process and understand death; and how we stand in the midst of it. The first step is recognition and attention to the credo in the words of His Holiness the 14th Dalai Lama that "death will come because it is part of life" (Dalai Lama, 2013, para 21). The effects on nurses, of the dying and death of children, needs to continue to be explored, questioned, and spoken.

Chapter Eleven: The Safety of Distance

It had been a lengthy interview, as many of my research interviews were, when she leaned forward, sighed, and after a long pause exclaimed “*I just want to share one more little story.*” “*Of course*” I replied, “*share as many stories as you wish,*” but there was something in the look in her eyes and the tremor of her hand as she brushed her hair back that told me that this was neither a little story nor was it just one more.

It is about a little boy who loved Adele’s music. He was first diagnosed at a month old, right when I started work. The whole two years they were very close to me. We raised him. He was our mascot (laughs). They had been in ICU for probably 2 months at the very end. Me and the other nurses on night shifts we’d be like, we’re not busy, lets go over. I’d go in after my shift just to say goodnight. By the end they were having such a hard time, he would never let them put him down, they would take turns, one would sleep and one would hold him. They were in this ICU room, it was just so dark and there would always be tears in her eyes [Mom] when we came to visit because it meant so much to her.

I visited him at 7 am and he was sating at 60% and so I had pretty much said my goodbyes because I knew it was coming. It happened at 1 pm. I came in for that night shift and the first thing we did when we got our report, the three of us [nurses] ran over to ICU to see if Mom and Dad were still there and they had just left and we were (crying) crying...so we came back (choked up) to the unit... and... oh... (pause - crying)...we were all red eyed trying to start our shift (handed tissue).

(long pause) I remember one of the girls was in the bathroom and me and the other girl were in the staffroom and she just walked over to the lamp in our staffroom and turned it on...(continues to cry) and I just fell to the floor and started crying. We sat in the staffroom for the next 20 minutes, and just cried together, and hugged each other, and looked at the light, because that weirdly helped. It was probably the most I've felt working there in two years, he was in ICU for 2 months we knew it was coming. But it was just the fact that he lost the fight, he was such a fighter and just that that flick of the light -- like him going -- that just broke me down. (Heather)

This story, for Heather, was her place of light and dark within her two years of work in pediatric oncology. It revealed the love she had for a little boy she helped raise, a little boy who loved Adele, and the pain that overcame her with the flick of a light at his death. It broke her down; it broke me down as well. What you cannot hear in the transcript of her words and tears are that my own tears matched hers that day. We sat for a long time, two nurses in a sterile white walled room, one crying for the loss of a beloved child the other, me, for the pain cancer brings. When she did speak again she said *"I can't listen to Adele anymore."* *"I get that,"* I managed to stammer out and then as if by some weird twist of reason, at the same time, we both said *"cancer sucks."* Heather wished this story to be heard so that we could get a glimpse of where this work can take pediatric oncology nurses, that they are not just another *"warm body"* looking after sick children but that they feel love and sadness, joy and pain, heartache and despair, they can be broken down and yet still continue to come to work and care for

families. *“It’s hard to prove, telling one story doesn’t prove the need for...for us, but you feel it. You’re there.”*

The interview ended and we said our goodbyes. I transcribed this interview with a box of tissues beside my computer and sobbed. I then put it in a file in my head that could best be described as labeled “do not open, do not enter.” Heather had brought me along with her to that place of feeling, of being there, and I could not retreat fast enough or get far enough away. I stand in many ways outside of this topic. I am neither a pediatric oncology nurse nor am I, given my body’s failure to comply, a mother. I hoped or perceived that this might be a safe enough distance. I was wrong. For, I do unfortunately know cancer. Cancer is not something I can get away from. It is not something that affords me any safe distance. Its many cellular mutations and combinations have decimated my family -- grandparents, aunts, uncles, cousins, and my beloved father fallen mercilessly into graves too early. The holes left by their departures shape and mold those of us who remain. They preface the stories we can tell of our family as we wait and watch for where cancer calls next. During my doctoral work the tally card for cancer has added five more of my family’s names, the last name being that of my wee Mom. This time it is a new particularly nasty iteration and a new name to learn -- leiomyosarcoma stage IV grade IV. It is an understatement to say that it has been a devastating time.

When noted American novelist Flannery O’Connor was asked why write, she shared “I write to discover what I know” (O’Connor, 1979, p. 173). In writing, we can illuminate our world and the world of others. We can indeed figure out what we know,

what we think, and how we feel. We can too, however, also volitionally or unbeknownst to us dampen, darken, and cover these over. It is in these times when we cannot see our retreat or need for safety and distance that we need others to show us other words and forms. We need them to gently show us the way back even in times when we were not aware we had wandered. The email below, sent by my PhD supervisor, is one such needed nudge back.

I've also been thinking about your topic and wondering if there is something in it that is too personal, too hurtful, too close to home and has perhaps invited an intellectual distancing from it - I'm not trying to psychologize here but it is just a wondering. You have also been going through such personal shit - one thing after another during all this - that can't NOT have an effect on you and your writing.

Flannery O'Connor also wrote that the "truth does not change according to our ability to stomach it" (O'Connor, 1988, p. 86). This was not an easy email to receive, nor was it an easy realization to sink down upon me. As much as I struggled against the truth of the words shared, I have also had to wrestle with my need for distance and safety from a topic that provided neither. I have had to examine my ability to stomach the exposure and emotional demands of this topic. I needed to come face to face with my safety of intellect and decide if I could in fact open up that closed file in my mind and enter. In going back and retrieving Heather's story and sharing it in the way she hoped, I am taking what I hope to be a step towards this end.

With that end in mind it was time to go back to the beginning. It was time to start over, to pull this thesis apart, and to write in a new way, to again feel, and to again be a

lot more “*there.*” In returning to the beginning of this work I hope I have brought it now to a suitable place of ending.

Chapter Twelve: Of Beginning and Endings

And
 I thought
 this is the good day
 you could
 meet your love,
 this is the black day
 someone close
 to you could die.
 This is the day
 you realize
 how easily the thread
 is broken
 between this world
 and the next.

(excerpt from *The House of Belonging*, David Whyte, 1997, p. 10)

*It is an interesting thing when you think about it, that intensity that you really
 want to retell the beginning of life and the end of life - - the departures and
 emergences that mark beginnings and endings. (Ursula)*

Stories retold of beginnings and endings are at the heart of this work. These are
 the stories shared of children, families, and nurses marked by their entrance into the
 world of pediatric cancer. These are the stories that for some children and families

recount their exit from this world of life. These are the stories of nurses who sat at the doors of the world of cancer assisting those intimate beginnings and endings - - of the thread that is easily broken between this world and the next. There was intensity and urgency to speak these stories aloud, to place them in the world outside, to acknowledge those lives lived, affected, and marked by cancer.

I wanted to talk just to acknowledge this little girl's life. It was short and it was pretty bad near the end, but it was still a life and it was still beautiful and she was a beautiful little girl. And so I just wanted to put that into the Universe that this little girl existed. And not just to her parents but to me. And so, that's why, it was nice to talk to you about that so her suffering was not in vain. Her life had meaning to somebody, her parents, and to me. (Erica)

There is a need to tell these stories of beauty and suffering, of departures and emergences that speaks to our human need to acknowledge and remember. There is a need to acknowledge and remember the lives and the deaths of those we work with as nurses, and to remind us that our work matters. This humanity of speaking who we are as nurses and emotion are intertwined. To deny this intertwinement relegates our ordinary language incomprehensible and our world mute (Abrams, 1996). It is in speaking these words of beauty and suffering that we begin to find our connection with others and with our world. Imaginative possibilities exist in the opening of emotion and remembrance of its affects. "Remaining open to the arrival of things (both in the life of the body and breath, and in the life of human understanding) - such 'undergoing,' such 'suffering' - is where our humanity lies" (Jardine, 1999, p. 125).

This work is as well the story of my struggles of standing outside of this topic, my attempt to find a beginning, an entrance into this work, and of my reluctance, once in, to remain. These stories of hope and heartache reflected too closely on my own connection to cancer and death. There was a connection between entrances and exits, in the rawness and exposure of human frailty and emotion that had me fighting my own reluctance, boundaries, and barriers to find a way to look for a clean ending and a clean decisive way out. As a writer of short stories, I have been “schooled” to believe that, when faced with multiple ways to enter into a topic, leading down multiple different roads, the best beginning is to know your ending, to know where your story and characters end up. The ending should dictate the correct beginning. Without this pivot, how can you know where the story is going and when and what is the right experience for your protagonist? Without this formula, how can you discern when the story truly ends?

I would now respond back to my esteemed writing mentors that beginnings and endings are a lot alike. There is a pivot, a leap, a weightless suspension, a fulcrum that holds the space between beginning and endings. This connection I believe to be true. There is a certain capriciousness, however, in this presumption that we can fit our endings so cleanly, that we can venture that far forward without risk. Philosophical hermeneutics and life does not work this way; they are about falls and scrapes, dangers along the way, how nurses are changed witnessing a child take their last breath and a mother wail her first. These are paths and adventures that situate us at the borders and boundaries of the unknown. This is the treacherous landscape of Hermes; revered at borders, worshipped at boundaries, he was tasked “with keeping open the gates between

one realm and another” (Jardine, 1998, p. 51). The messages between the two realms were never straightforward, the passage and price of understanding involved risk.

“‘Understanding is an adventure and, like any other adventure, it is dangerous’ (Gadamer, 1983, p. 109-110). Involvement in interpretive inquiry runs the risk of getting lost in the flurries of sense that make up our lives” (Jardine, 1998, p. 50). This getting lost presupposes that our endings are not known, not clear-cut - - that to get somewhere we risk ourselves to the world of the venture.

Knowing when a story truly ends in this work is difficult. The finality of conclusions, I submit, is a tricky proposition in philosophical hermeneutics. They are antithetical to the fundamental premise of openness and unending interpretations. “Each remark calls for another, even what is called the ‘last word’ does this, for in reality the last word does not exist” (Gadamer, 2001, p. 60).

The word conclusion derives from the Latin *concludere* meaning to shut up, or enclose. It refers, in essence, that to conclude is to draw an argument to a finalized deduction (Hoad, 1996). In reference to the finality of research, based in philosophical hermeneutics, for a practice discipline such as nursing, Gadamer (2001) wrote:

...Have their special significance in the fact that no experience they deal with can be closed, wrapped up, finished...in contrast to the natural sciences, the humanistic disciplines have no methodically “assured” results that we can pass along free of questions. Rather, in the *Geisteswissenschaften* we are constantly learning new things from what has been passed down to us. (Gadamer, 2001, p. 53)

There is however another derivation of conclusion related to the Old English *windan* to move by turning and twisting; and to *wendh* - - to turn, wind, or weave. It is related to wend, and can be traced to wander (Hoad, 1996). This derivation in deference indicates that to conclude is to wind down. It is to this meaning I look to in ending and thus concluding this research venture. For “in the end...hermeneutics does not lead us back to safe shores and terra firma; it leaves us twisting slowly in the wind” (Caputo, 1987, p. 267).

These effects on nurses of dying and death of children are not clean cut. They are messy, heart wrenching, tightrope walking stories of discomfort and transformation. They ask us to keep the question open - - to keep asking how they are doing in practice, how they are able to enter rooms of dying children and bear the unbearable for others. They ask us to keep asking what is this and where are we going. “And so it can claim here only to end, not to conclude. We do not seek a closure but an opening up” (Caputo, 1987, p. 294). Death, cancer, children, and nursing ask of us to look again, to keep the topic in play, in motion, and open.

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Appendix A

Recruitment Poster

The Impacts of a Child's Death on Pediatric Oncology Nurses --A Research Project--



What is the research about?

- Caring for a child dying of cancer and a family experiencing immense suffering is challenging complex work. Pediatric oncology nurses are frequently the healthcare professional bearing witness to this vulnerable and intimate time of profound loss. What however is the impact on nurses?

Why are you asking me?

- There is limited literature on the impacts of a child's death on nurses. As a practicing pediatric oncology nurse, you hold the key to understanding how this impacts your practice, and how we can in turn best support you through this experience.

Who is doing the research?

- My name is Angela Morck, RN, MN. I am a practicing nurse in psychosocial oncology and an ACHRI PhD trainee researcher. Along with my supervisor Dr. Nancy Moules, I am conducting this research as my doctoral research project toward a PhD in Nursing at the University of Calgary.

What would I have to do?

- **If you are interested in becoming a participant**, I am asking for approximately one hour of your time for a one-to-one interview. The interview would occur at a place and time convenient for you.

How do I contact you?

- If you would like to participate, or need more information, please contact me at the following email address or phone number:
- amorck@ucalgary.ca
- Home phone: xxx-xxx-xxxx

Appendix B

Draft Research Interview Questions

- Has the death of a child while in your care affected you? If yes, how so? If no, why do you believe this is?
- In what ways has it influenced your nursing practice? Your home life? Are you ok with this influence? Or not ok with it?
- What language (words) do you use to describe your experience with childhood death? Are these words helpful? Or not helpful?
- Do you think anyone else has noticed that you this has impacted you? If so, what have they noticed? What do they say to you in regards to what they have noticed?
- For someone that does not anything about working with children living with and dying from cancer how would you describe it?
- What would be the most important thing you think I should know about your experiences with patient death?
- What are some of the things that you would want other nurses to know about children's death before they become a pediatric oncology nurse?
- What are the ways in which you would like your unit, co-workers, healthcare system to support you? What is not helpful?

Appendix C

Consent Form For Interview (U of C Letterhead)

TITLE: With Our “Hands, Voices, and Hearts”: The Impacts of a Child’s Death on Pediatric Oncology Nurses

INVESTIGATORS: Dr. N. J. Moules, RN, PhD
University of Calgary, Faculty of Nursing
Professor (403-220- 4635)

Angela Morck, RN, MN (PhD student)
University of Calgary, Faculty of Nursing
PhD Program

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

BACKGROUND

Pediatric oncology nursing is an area that is at once both rewarding and stressful. It can be expected that professionals who witness the pain and suffering of children and their families may also experience pain and suffering themselves. However, there is very modest literature in this area and relatively little is known about how pediatric oncology nurses are affected by the death of a child in their care. This research will focus on how pediatric oncology nurses are affected by their day-to-day involvement in the complex navigation of circumstances and relationships surrounding the death of a child from cancer.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to discover the impacts, responses, and effects on you as a pediatric oncology nurse to having a child die in your care. In a context, where relationships form and are sustained over time by the very nature of the trajectories of childhood cancer, how do you as a nurse navigate, live alongside, and experience your own losses when a child for whom you have cared dies? This research will serve to add to our understandings of these relational impacts on pediatric oncology nurses and to translate this understanding into ways to support nurses in this important work.

WHAT WOULD I HAVE TO DO?

You are eligible to be in this study as you are a currently practicing Registered Nurse working in or have previously worked in a pediatric oncology specialty area. If you take part in the study Angela Morck will interview you about your experience. The interview is expected to last approximately 1 to 1/2 hours, it will be held at a location of your choice, at a mutually convenient time. The interview will be tape recorded and transcribed (typed out word for word). Everything you say will be confidential.

WHAT ARE THE RISKS?

There is very little risk to you in taking part in this study. It is possible that you may recall unpleasant memories surrounding a patient's death during this discussion, which may make you, feel uncomfortable and may leave you feeling worse than before you participated.

Should you experience any distress and feel you need support to overcome these feelings, you can speak to the principal investigator who is an experienced family therapist. Should you (or the principal investigator) feel it is necessary; the researchers can refer you to a range of counseling services, including the Grief Support Program of Alberta Health Services.

All responses from the interview will remain confidential. A fake name will be used in any written information, publication, or presentation of the study results. There is a small risk that the something that you had to say in the study would be quoted in material used for publication or teaching. These quotes would be used in a way, which does not identify you.

WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study there may or may not be a benefit to you. The information we get from this study may help us to better understand the complexity of nurses' experiences with patient death and ultimately how we can provide better care for patients and nurses alike.

DO I HAVE TO PARTICIPATE?

You are under no obligation to participate in this study.

Participation in this study is voluntary. You may stop the interview at any time. You can withdraw from the study at any time up until data analysis has started. After data analysis has begun, there will be no way to pull out your information as it will all be blended in with others' information.

You may withdraw from the study in a number of ways:

- By contacting the principal investigator or doctoral student with your decision to withdraw;
- By not attending, or canceling, your interview appointment;
- By stopping an interview and advising the researcher that you cannot stay, wish to leave and/or withdraw from the study.

In the event that you withdraw from the study, any information from your interview will be destroyed and will not be used in the study.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for taking part in this study. If you have parking expenses the co-investigator will reimburse you.

WILL MY RECORDS BE KEPT PRIVATE?

No identifying work details, patient or colleague names will be used in this study. The interview is confidential, and your name will be removed from the typed interview and substituted with a pseudonym (fake name). The only exception is, if urgent risk to self or others is reported. In which case, the appropriate legal authorities will need to be contacted. Written and audio recording of interviews will be kept in a locked cupboard at the University of Calgary. Written transcripts will be kept for five years and then destroyed. Audiotapes will be erased when the study is complete. Only the research team will see the complete transcripts. It is possible that a member of the University of Calgary Conjoint Health Research Ethics Board will look at the information for audit purposes.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your healthcare. If you have further questions concerning matters related to this research, please contact:

Dr. Nancy Moules (403) 220 - 4635

Or

Angela Morck (xxx) xxx -xxxx

If you have any questions concerning your rights as a possible participant in this research, please contact The Chair of the Conjoint Health Research Ethics Board at the Office of Medical Bioethics, 403-220-7990.

Participant's Name

Signature and Date

Investigator/Delegate's Name

Signature and Date

Witness' Name

Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.