

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

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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 influences the care they give. Our intent with this philosophical hermeneutic research was to add to understandings of these effects on pediatric oncology nurses and to support them in this challenging component of their work. This is a part of the doctoral research of the first author which is published online (Morck, 2014), and was supervised by the second author. 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 nurses struggled to navigate the ideals of nursing versus the realities of practice when working with children who may die. This called for them to maintain a fine balance between the personal and the professional. This ontological struggle is not absolute but 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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## Keywords

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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. This 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.

### **Research Question, Method, and Design**

The research in this doctoral research conducted by the first author and supervised by the second author was focused on the topic of the impacts on pediatric oncology nurses of the death of a child in their care. We were 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?

The research method employed in this study was guided by Hans-Georg Gadamer's (1960/1989) tenets of philosophical hermeneutics, following the method as described by Moules, McCaffery, Field, and Laing (2015). This study was approved through the University of Calgary Conjoint Health Research Ethics Board. The participants for the study were recruited through email and poster presentation, and 15 registered nurses were interviewed. All participants were women with age ranges between the mid-twenties and fifties. Pseudonyms were assigned.

The interviews were transcribed into text, and analyzed interpretively according to Moules et al. (2015). These emerging interpretations were then fleshed out with relevant literature not limited to nursing but including philosophy and non-academic literary works. The culmination of this intensive interpretive work was intended to extend, disrupt, and transform the theoretical and practical understandings of the topic. Several interpretations were developed around the topic, all of which are featured in the publication of the doctoral study (Morck, 2014). In this paper, we focus on a few of the interpretations that speak to the complexity of this work. The next section refers in first person to the first author Morck.

### **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,

Simsonson, Prins, Angus, and Bell (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 parents’ 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, Hickey, & Magnum, 1994; Kaplan, 2000; Spinetta et al., 2000; Papadatou, 2009; Zander, Hutton, & King, 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 (word, n.d.). 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 imparting 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 (Portare, n.d.). 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 this dissertation for years was *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. 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 one 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.

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, Fleiszer, 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 have 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 (label, n.d.). 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 im-*

*aginable, 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 it’s 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?) (okay, n.d., Merriam-Webster Dictionary).

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” (okay, n.d. Oxford Dictionary Online). 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 workplace 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 (surround, n.d.). 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 it's 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 (number, n.d.). 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 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 (1960/1989), 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.

### **Summary**

The topic of death and loss yield a woven tapestry of history, understandings, personal sensitivities and professional ambiguities. Death 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. The 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 be able to lean

into the question asked by a little boy who wonders if the angels will speak Spanish, as he looks into the face of his own mortality.

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