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Walking Alongside Children with Progressive Life Shortening Illnesses: Experiences of Pediatric Acute Care Nurses

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Walking Alongside Children with Progressive Life Shortening Illnesses: Experiences of
Pediatric Acute Care Nurses

by

Shelagh Jane McConnell

A THESIS

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ABSTRACT

Caring for children with Progressive Life Shortening Illnesses (PLSIs) in pediatric acute care is both rewarding and challenging for nurses. Despite the significant number of pediatric nurses who care for children with PLSIs and their families on general acute care units, little is known about the benefits and difficulties these nurses experience through their work. The intent of this hermeneutic study is to further understanding regarding the experiences of pediatric nurses in this context and to offer ways of better supporting them in their valuable work. Eight nurses from a general pediatric acute care unit were interviewed for this study. These data were analyzed according to the tradition of philosophical hermeneutics as described by Hans-Georg Gadamer. Findings from this research revealed nurses' struggles to care for children with PLSIs whose lives are shrouded with uncertainty in a death-denying culture that values cure and treatment. Nurses recognized the many rewards and the beauty of their work even though they come to carry a burden and hold a great deal of darkness from the difficulty of what they see and do in their practice. Nurses' struggles also included caring for children with PLSIs when they are excluded from the decision-making table. Nurses acknowledged that their ability to work in this area was limited as they were aware that the challenges of the work would eventually outweigh the beauty and the benefits. For their survival, nurses learned to depend on each other for support and learned from each other what it means to be a nurse in this area. The implications of this research include facilitating bedside nurses to be present at decision-making meetings and the encouragement and facilitation of nurse-to-nurse support.

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To my family who lived alongside me in this long, arduous, but ultimately rewarding and meaningful experience. Thank you for your patience, support, and humour.

DEDICATION

This dissertation is dedicated to children living with Progressive Life Shortening Illnesses,
their families, and the nurses who care for them.

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**PROLOGUE: WANTING TO MAKE LIFE LIVEABLE FOR CHILDREN WITH
PROGRESSIVE LIFE SHORTENING ILLNESSES AND THOSE WHO LOVE THEM**

Grounded Lesson

Life is a treasure.

People should enjoy it,

Even if digging

To it, or

Through it,

Is a challenge.

(Stepanek, 2001, p. 45)

Mattie Stepanek (1990-2004), a young writer and poet, wrote this poem at the age of 10. Mattie lived with a rare form of muscular dystrophy and depended on medical technology for his survival, including a wheelchair, tracheostomy, and ventilator. In his short, but not limited life, Mattie published eight books and spread his love of life, desire for peace, and rare wisdom the world over. Mattie was a child with a Progressive Life Shortening Illness (PLSI) and his insights offer us, among many things, a glimpse into the world of children with PLSIs who are precious and exceptional children.

As Mattie stated in his poem *Grounded Lesson*, life is both a treasure and a challenge. Through my work with children with PLSIs and their families as well as through my PhD work, I have come to a deeper understanding of the complexity of life. I entered the profession of nursing full of hope and optimism of making a difference in the world. Specifically, I entered my undergraduate nursing program hoping to continue my work with children with PLSIs, but equipped with the skills, knowledge, and heart of a registered nurse. Upon graduation, I was

hired to work full-time on an inpatient unit at a children's hospital where many children with PLSIs are cared for. I entered this position with an open mind and open heart. Sadly, in only a handful of years I went from the typical new graduate nurse—enthusiastic and eager to take on the world—to an angry, bitter, and cynical nurse who turned away from the suffering of others as my own suffering had become suffocating. I had become the nurse I never wanted to be: seemingly cold, hard, and uncaring. I became a nurse who would see a mom weeping at the bedside of her dying child, late at night, only visible from the dim light let off by the various life-supporting technology surrounding the crib. Instead of offering my presence, support, and comfort, I would simply walk past and pretend I had not seen her. It was for the reason that I carried within me the burden and consequences of offering such support in the past and not being able to bear the suffering and despair of others. As a result, I became a nurse of whom the student nurse in me was deeply disappointed and ashamed. It appeared as though I had reached the “icy peaks of total detachment” (Hulme, 1956, p. 38), but in fact, I had barricaded my heart against what was overwhelming suffering.

The first time she saw a novice faint in the chapel.... No nun or novice so much as glanced at the white form that had keeled over from the knees.... [T]he surrounding sisters seemed to be monsters of indifference, as removed from the plight of the unconscious one as though she were not sprawled out blenched before them on the carpet. [Then] she realized that she had been staring not at heartlessness but at a display of detachment.... Later on, when she had trained herself to the exquisite charity of not seeming to see a sister in torment, kneeling alone in the chapel and crying quietly into her hands...she would know that few of them ever really reached the icy peaks of total detachment but only seemed to have done so. (Hulme, 1956, pp. 37-38)

It was largely thanks to the work I did in completing my PhD coursework, candidacy, research interviews, and writing of my dissertation that I was able to begin to work back towards the nurse I had always wanted to be. I am no longer the innocent and inexperienced nurse, but I have moved away from being doomed to a life as a cynical and sarcastic nurse.

A favourite question people ask PhD students is “of all the topics you could have picked for your research, what made you choose that particular topic?” Depending on who is asking, I offer a number of answers, but the one that rings most true is that I want to make life more liveable for children with PLSIs, their families, and those who care for them. I fear that cures for the vast majority of the diseases, syndromes, and health conditions that the children I care for live with, will be unattainable in my lifetime. Perhaps cures will not be attainable for many lifetimes. This is a difficult and painful reality to accept—if not accept, learn to live alongside. However, instead of dwelling on the limitations of what I can do for this population of children and those who love them, finding ways to make lives happier and more worth living is what I seek to do. I will forever be disappointed at the limits of our collective ability to cure devastating illnesses that leave children with PLSIs sick and facing death all too soon. Nevertheless, I will take consolation in the fact that I can “still be happy knowing I was part of the effort” (Stepanek, 2001, p. 55).

I Could... If They Would

If they would find a cure when I’m a kid...

I could ride a bike and sail on rollerblades, and

I could go on really long nature hikes.

If they would find a cure when I’m a teenager...

I could earn my license and drive a car, and

I could dance every dance at my senior prom.

If they would find a cure when I'm a young adult...

I could travel around the world and teach peace, and

I could marry and have children of my own.

If they would find a cure when I'm grown old...

I could visit exotic places and appreciate culture, and

I could proudly share pictures of my grandchildren.

If they would find a cure when I'm alive...

I could live each day without pain and machines, and

I could celebrate the biggest thank you of life ever.

If they would find a cure when I'm buried into Heaven,

I could still celebrate with my brothers and sister there, and

I could still be happy knowing I was a part of the effort.

(Stepanek, 2001, p. 55)

CHAPTER ONE: A CALL TO THE TOPIC

Working with children with Progressive Life Shortening Illnesses (PLSIs) is something that I have done for nearly 20 years. I first had the privilege of caring for children with PLSIs and their families when I was hired as a camp counsellor at Camp Easter Seal in Watrous, Saskatchewan in the early 1990s. While other high school students found summer jobs bagging groceries at the local grocery store, cutting grass, taking summer school courses, or simply enjoying the hot (and often short) prairie summer, I worked around the clock at a summer camp designed specifically for adults and children with a variety of disabilities and life-shortening illnesses. I loved the work. I enjoyed it so much that I returned for several summers. My introduction to children with PLSIs through Camp Easter Seal was the beginning of my lasting commitment to this exceptional group of children. I continued to seek out a variety of opportunities to work and volunteer my time with children with PLSIs: respite worker, speech therapy assistant, teacher's assistant, horseback riding aide, swimming instructor, and behaviour therapist. While the jobs were never easy, I found great enjoyment and satisfaction in my work. Spending time with children with PLSIs allowed me to see the joy they possess within themselves and the joy they bring to their families and friends. Through these experiences, I was given the opportunity to focus on the positives, the potential, and the happiness. I found the work so rewarding that despite other job opportunities, I was repeatedly drawn to working with these exceptional children and their families. Therefore, when I began my career as a registered nurse (RN), it seemed only natural that I continued to work with this population. At first I was able to appreciate the joy and delightfulness of these children as I had before. I continued to be engaged with my patients and their families. I was very comfortable working with this population. For 10 years I was employed on an acute care unit with a specialization in respiratory, cardiac, and

gastrointestinal illnesses, with a large patient population of children with PLSIs. I enjoyed the work and had developed good relationships with my colleagues as well as with the patients and families on the unit. I had planned to spend my entire career working as an acute care nurse at the bedside. In fact, I never had any intention of pursuing graduate studies—particularly not a PhD. However, it is “the disruption of success in our everyday practices that allows a topic to emerge” (Moules, Field, McCaffrey, & Laing, 2014, p. 3).

Working as a nurse in pediatric acute care gave me a different perspective on the lives of children with PLSIs than my previous employment. Prior to entering nursing, I had never seen any of these children suffering from acute illnesses or recovering from surgery. I had not participated in discussions around goals of care. I had never witnessed the grief of a mother whose child was being taken off life support. I had never watched one of these children die. Learning first-hand the difficult realities of illness and death that face children with PLSIs and their families left me grappling to make sense of this new knowledge. Particularly poignant to my own struggle was grief, moral distress, and eventually compassion fatigue. My struggle to manage these difficult experiences nearly cost me my nursing career. I was fortunate to end up in graduate studies rather than avoiding the sorrow and distress by leaving the profession of nursing altogether and choosing a new career. Had I decided to leave nursing, I would have joined an ever-increasing number of nurses who have been forced to leave the profession because of the unbearable distress of the work (Austin, Lerner, Goldberg, Bergum, & Johnson, 2005; Brosche, 2007; Cavaliere, Daly, Dowling, & Montgomery, 2010; Corley, Elswick, Gorman, & Clor, 2001; Kelly, 1998; Pendry, 2007). The topic of nurses’ experiences of caring for children with PLSIs in the inpatient acute care setting calls to me because of my difficult experiences with the devastating and painful aspects of what I have endured as a nurse. However, I am also

reminded that my heart knows of the great joy these children have brought to my life and the lives of others. Therefore, I focused my research on further understanding the positive, negative, and in-between aspects of pediatric nurses' experiences working with children with PLSIs in the inpatient acute care setting.

Children with PLSIs

When people learn that I am a pediatric nurse, quite often they assume that means that I am a pediatric oncology nurse. I am regularly faced with the task of explaining that, while I work as an RN with very sick children, I am not a pediatric oncology nurse. It would seem that many people assume the only children who are so sick that they are at risk of dying are those with a cancer diagnosis. The reality is in fact the opposite, as pediatric oncology patients make up a relatively small portion of the total population of children with PLSIs (Hinds, Schum, Baker, & Wolfe, 2005; Rallison & Raffin Bouchal, 2013; Wolfe et al., 2000). The children with PLSIs I care for are most often born with congenital anomalies and conditions for which there is no hope for cure. Children with PLSIs have conditions which are beyond even our most advanced medical interventions. Children with PLSIs live with illnesses that remain incurable and in many cases untreatable, which will remain the case for the foreseeable future.

This, perhaps seemingly insignificant, example of what I have experienced touches on the larger issue of invisibility that children with PLSIs have in our communities. Children with PLSIs, along with their families, siblings, and caregivers, are often hidden and overlooked in our society. Children with PLSIs often require a great deal of medical intervention and live with much uncertainty around diagnosis, prognosis, and treatment. It is known that families live with great uncertainty as they care for children with PLSIs (Rallison & Raffin Bouchal, 2013; Steele,

2000). Families and nurses who care for children with PLSIs must also live with that uncertainty in the hidden world of children with PLSIs.

Hermeneutics, the methodology of choice for this study, is particularly well suited to understanding and unconcealing that which is hidden in our everyday lives (Gadamer, 1960/2006). Hermeneutics involves the practice of *aletheia*, which is the Greek word meaning "the event of concealment and unconcealment" (Caputo, 1987/2000, p. 115). Furthermore, aletheia "occurs when something opens which was once closed. Aletheia can be represented by the metaphor of opening the lid of a well — of flipping the lid open and letting it rest allowing one to look into what lies beneath it" (Moules, 2002, p. 3). Therefore, through undertaking this research study, I am "flipping the lid" on the topic to better understand the experiences of acute care inpatient pediatric nurses caring for children with PLSIs—a world often hidden from view.

Research Question

The question developed to guide understanding of the topic is: *How might we, as nurses, understand our experiences when caring for children with Progressive Life Shortening Illnesses (PLSIs) and their families in the inpatient pediatric acute care setting?*

CHAPTER TWO: REVIEW OF THE LITERATURE

My purpose in writing this chapter is to review the research literature available on the topic of nurses' experiences of working with children with PLSIs in the acute care setting. In order to better understand the population of nurses in question, and subsequently their experiences, a better understanding of the population of children with PLSIs is essential. Therefore, I devote the first section of this chapter to reviewing the literature on PLSIs and contextualizing it within the palliative literature and pediatric practice context.

There is a paucity of literature on nurses' experiences in caring for children with PLSIs. To date, the studies of nurses' experiences have been conducted primarily in the adult health setting with a particular focus in critical care, but also oncology, hospice, and mental health (Abendroth & Flannery, 2006; Collins & Long, 2003; Dominguez-Gomez & Rutledge, 2009; Potter et al., 2013). A substantially smaller amount of literature is available for pediatric nurses. Of that research, a large portion is focused on specialty areas, specifically pediatric oncology and pediatric critical care (i.e., pediatric intensive care and neonatal intensive care).

While this lack of knowledge and understanding of the topic helps to build support for the unique need for this research, there is no clearly defined body of research to conduct a literature review. Therefore, I carefully selected to review bodies of literature that seemed particularly relevant to the population of nurses and relevant to this proposed study. I divided this search into three parts: the pediatric PLSI literature, the negative experiences for nurses, and the positive experiences for nurses. (See Appendix A for the search terms used to collect literature in these three areas as well as search engines used. See Appendix B for the literature search PRISMA flow diagram.) Because of the gaps in knowledge, following the review of the articles

retrieved through the search of online databases, hand searching was also required in order to complete the review.

Children with Progressive Life Shortening Illnesses

Children with PLSIs are a diverse group (Steele, 2000). Children with PLSIs are also referred to as children with life-limiting/life-threatening illnesses, technology dependent, medically fragile, and children requiring complex care needs. Children with PLSIs suffer from a variety of diseases and conditions as the result of genetic anomalies, environmental effects in the prenatal period, prematurity, or acquired illnesses/infections/injuries either in the post-natal period or in childhood (Himmelstein, Hilden, Boldt, & Weissman, 2004). In broad terms, PLSIs in children are conditions “for which there is no reasonable hope of cure and from which children or young people will die” (Together for Short Lives, 2014b). Therefore, the one feature that unites these children under the broad category of PLSIs is the fact that they are not expected to live into adulthood (Himmelstein et al., 2004; Liben, Papadatou, & Wolfe, 2008; Steele, 2000; Together for Short Lives, 2014b). Furthermore, they are likely to benefit from palliative care services either continuously throughout their lives or periodically for pain and symptom management, grief/bereavement counselling, and end-of-life care (Together for Short Lives, 2014b).

Defining PLSIs

Defining and capturing the subtleties of PLSIs is a difficult task because of the wide variety of conditions and diseases encompassed by the term. The association Together for Short Lives (formerly the Association for Children with Life-Threatening or Terminal Conditions—ACT) developed categories to help describe the types of illnesses that affect children with PLSIs. The categorization offers understanding in terms of types and groupings of diagnoses; however,

the spectrum and severity of illness cannot be captured in the broad categories and must be assessed on an individual basis (Together for Short Lives, 2014b). There is debate as to whether further categories should be included in this conceptualization, for instance, prenatal diagnosis and sibling care (Quebec Government, 2006). The categories as described by Together for Short Lives are as follow (2014):

- Category 1

Life-threatening conditions for which curative treatment may be feasible but can fail.

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples: cancer, irreversible organ failures of heart, liver, kidney.

- Category 2

Conditions where premature death is inevitable

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: cystic fibrosis, duchenne muscular dystrophy.

- Category 3

Progressive conditions without curative treatment options

Treatment is exclusively palliative and may commonly extend over many years.

Examples: batten disease, mucopolysaccharidoses.

- Category 4

Irreversible but non-progressive conditions causing severe disability, leading to

susceptibility to health complications and likelihood of premature death

Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event of episode.

Researchers interested in the population of children with PLSIs have tried to estimate the number of children affected. This is a particularly difficult task to undertake because there are no formalized and standardized systems to record cases (Hain, 2004). Studies conducted in the United Kingdom produced estimates of the number of children with non-malignant PLSIs ranging from 10 in 10,000 (Lenton, Stallard, Lewis, & Mastroiannopoulou, 2001) to 20 in 10,000 (Baum, 1998). In the United States, estimates of children with PLSI across the country range from 400,000 children (Jennings, 2005) to 500,000 children (Himmelstein et al., 2004; Hynson, Gillis, Collins, Irving, & Trethewie, 2003; Knapp, Thompson, Madden, & Shenkman, 2009). Unfortunately, I was unable to locate any specific data regarding the number of children with PLSIs in Canada.

Palliative Care

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organization, 2014). In Canada, the Canadian Hospice Palliative Care Association (CHPCA) uses the term hospice interchangeably with palliative and defines the concept of *hospice palliative care* as “pursuit of excellence in care for persons approaching death

so that the burdens of suffering, loneliness and grief are lessened” (Canadian Hospice Palliative Care Association, 1999).

Palliative care is a relatively new health care initiative with its early beginnings in the 1960s with the work of Elizabeth Kübler-Ross (1969) who drew attention to the needs of the dying. Palliative care made its initial appearance as a medical specialty in the 1970s and in 1987 became a recognized health discipline (Hynson & Sawyer, 2001). The hospice movement began to spread worldwide following the initiatives of Dame Cicely Saunders in the United Kingdom (Ferrell & Coyle, 2010). In that time, palliative care initiatives for adults have made significant strides worldwide (Clark, 2011).

Pediatric Palliative Care

While adult palliative care has become increasingly available in many parts of the world, pediatric palliative care has not caught up in terms of its availability to children and families who could benefit from its services (International Children's Palliative Care Network, 2014b). It might seem surprising that pediatric palliative care has struggled to find its place alongside adult palliative care and that it is only beginning to establish itself in the sphere of health services (Davies & Howell, 1998). Nevertheless, there are a variety of reasons for the fact that pediatric palliative care has lagged behind in terms of its development (Goldman, 1998; Rallison & Moules, 2004). Perhaps the most obvious reason is that relatively few children die in comparison to the number of adults. It is estimated that every year approximately 2.5 million people die in the United States; 50 000 of those death are children (Crozier & Hancock, 2012; Heron et al., 2010).

Pediatric death is a comparatively rare event and that appears to be one of the barriers to the successful implementation and expansion of pediatric palliative care programs around the

world. Another barrier is the nature of PLSIs that children present with makes the transition between curative treatment and palliative care for children not as clear as it is with the adult population (Hynson & Sawyer, 2001). It is more difficult to identify when this transition should be made and the appropriate time to involve palliative care specialists in the pediatric setting (Hynson & Sawyer, 2001). Furthermore, predicting the timing of a child's death is difficult (Himmelstein et al., 2004; Steele, 2000). However, one of the most significant barriers in the developed world is the reluctance to recognize the fact that children die (Rallison & Moules, 2004). It would appear that it is the culture and expectations of the developed world that pose the biggest challenges to the implementation of palliative care for children (Doorenbos et al., 2012; Haut, Michael, & Moloney-Harmon, 2012). As a result, pediatric palliative care faces a unique challenge.

The Unspeakable Nature of Death in Childhood

In the developed world, the death of children goes against our deeply held beliefs that children are not supposed to die (Jones & Weisenfluh, 2003; Rushton, 2005). While the mortality rate for children has decreased significantly over centuries, children continue to die. This is despite the fact that we might strongly believe and hope that children do not die and do everything in our power to combat the threat of death for children, but unfortunately children sometimes will die. Historically, it was more commonplace for children to die than it is today. In fact, in the early part of the 1900s in Canada, 20% of deaths were children under the age of one (Statistics Canada, 2008). Therefore, death in childhood was a relatively common experience among Canadian families. However, with the unprecedented advances in medical science that the western world has seen over the past 40 years, health care professionals have the knowledge and the technology to cure illnesses and prolong life in ways that were previously not only

unattainable, but inconceivable. As a result of this advancement, today in Canada, less than 1% of deaths are children under the age of one (Statistics Canada, 2008). Therefore, the death of children is rare in Canada and for much of the developed world (Whittle, 2002). Of those children who do die, the vast majority die from non-preventable causes, namely PLSIs (Keele, Keenan, Sheetz, & Bratton, 2013). Because of the rarity of childhood death in today's society, people are not often faced with the death of a child close to them. As a result, the general population is unfamiliar with it and we lack familiar rituals and processes to acknowledge and integrate it into our lives (Whittle, 2002). Therefore, the rarity of childhood death resulted in a society with little experience dealing with it. What is more, contemporary society cannot easily talk about death of any kind, but particularly the death of children. In today's western culture, there is an unspeakable nature when it comes to the death of a child (Rallison & Moules, 2004). People do not want to think about death and certainly not the death of a child.

Living in a Culture of Cure

Not only is death a taboo subject in contemporary society, but we also live in a culture of cure and treatment. The desire and the need to tirelessly seek cures, interventions, and treatments is a powerful force (McCallum, Byrne, & Bruera, 2000). Under the "cure at all costs" culture of care, children with PLSIs are often given many burdensome medical interventions in the hopes of prolonging their lives (Keele et al., 2013). The care of the dying child is predictably focused on achieving cure even when the child's prognosis is poor and death appears to be imminent (Rini & Loriz, 2007). It is because of these factors that excessively invasive treatments are being offered to children, which in many cases prolongs suffering without improving quality of life (McCallum et al., 2000). Furthermore, the availability of medical technology and its use offers families, as well as health care providers, a false sense of hope for better prognosis and outcome

(Brien, Duffy, & Shea, 2010). Even with sophisticated medical interventions, children with PLSIs continue to endure substantial suffering and a lack of symptom control (e.g., dyspnea, nausea/vomiting, fatigue, and constipation) (Kane & Primomo, 2001). What is more, this overshadows the obligation to provide dignified, humane, and compassionate care of children with PLSIs (Rushton, 2005): “Add life to the child’s years, not simply years to their life” (Nelson et al., 2000, p. 357).

Uncertainties for Children with PLSIs

There are uncertainties around diagnosis and prognosis, which may lead health care professionals to seek cure, especially when insufficient evidence exists to justify a different course of action (Rushton, 2005). Very little is known about many of the rare conditions captured under the broad title of PLSIs (Steele et al., 2008). The one exception is for those children who have been diagnosed with cancer. Extensive research in pediatric oncology has been ongoing since the 1970s (Bluebond-Langner, 1977, 1980; Martinson et al., 1978). Even though pediatric oncology cases make up a small number of the overall number of children with PLSIs, what is reflected in the literature is a nearly exclusive focus on oncology (Hinds et al., 2005; Rallison & Raffin Bouchal, 2013; Wolfe et al., 2000).

Technology and Children with PLSIs

Because of the lack of knowledge and often lack of palliative services involved with care, children with PLSIs receive many burdensome treatments and interventions. Not only are these interventions painful and involve suffering on the part of the child, but they also require highly advanced and specialized care for a considerable length of time (Cook et al., 2012).

Sophisticated medical interventions and technology presents a major barrier for children to be discharged home to live with their families (Hewitt-Taylor, 2005). What is more, the number of

pediatric patients with long-term dependence on technology admitted to hospitals is steadily increasing (Hewitt-Taylor, 2005). Even if children with PLSIs are able to be discharged home, they are frequently admitted to hospital where the admission can be for a prolonged period of time (Himmelstein et al., 2004). It is during their frequent and often lengthy visits to general inpatient acute care units that pediatric nurses encounter this group of children and their families.

Children with PLSIs in the Context of the Canadian Health Care System

Children with PLSIs from any of the four categories (Together for Short Lives, 2014b) obtain services from a variety of settings throughout the health care system. Children with certain PLSIs will receive care delivered from specialized units such as the case for pediatric oncology. However, this will not occur for the vast majority of children with PLSIs who require hospitalization. These children will be admitted to general pediatric wards for pain and symptom management (e.g., seizure management, feeding difficulties, and mobility issues) as well as for the treatment of acute illnesses and for post-operative care. This being said, children who have had cancer and are considered cured, but who have suffered a lasting PLSI caused by either their cancer or from the treatment, will be admitted to general inpatient units should they require treatment for their non-oncological PLSI.

For the majority of children with PLSIs, very little is known about their rare conditions, which leaves many uncertainties around diagnosis and prognosis (Steele, 2000; Steele & Davies, 2006). This lack of knowledge often leads health care professionals to seek cure, especially when insufficient evidence exists to warrant a different approach (Rushton, 2005). Therefore, in today's cure-focused, technology driven health care system, children with PLSIs are often treated aggressively for their incurable conditions. Through the "cure at all costs" culture of care, children with PLSIs are often given many burdensome medical interventions in the hopes of

prolonging their lives (Keele et al., 2013) and excessively invasive treatments are being offered to children, which in many cases prolongs suffering without improving quality of life (McCallum et al., 2000). Even when children with PLSIs are dying, care is predictably focused on achieving cure even when the child's prognosis is poor and death appears to be imminent (Rini & Loriz, 2007).

The number of pediatric patients with long-term dependence on technology admitted to hospitals is steadily increasing (Hewitt-Taylor, 2005). Even if children with PLSIs are able to be discharged home, they are frequently admitted to hospital where the admission can be for a prolonged period of time (Himmelstein et al., 2004). It is during their frequent and often lengthy visits to general inpatient acute care units that pediatric nurses encounter this group of children and their families.

Pediatric Nurses Working on Inpatient Acute Care Units

Pediatric nurses frequently encounter children with PLSIs in the acute care inpatient setting (Cook et al., 2012; Gupta, Harrop, Lapwood, & Shefler, 2013; Hewitt-Taylor, 2005). However, on general inpatient units, many of the pediatric patients are healthy and are being treated for transient illnesses (e.g., injury or infection) or for the management of a chronic illness not considered to be life-shortening (e.g., diabetes or asthma). As a result, the work of pediatric nurses is predominantly based on the cure model (Haut et al., 2012). While a cure-focused approach is appropriate for children who do not have a PLSI, the exclusive focus on cure has led to nurses being grossly unprepared to deal with the issues surrounding children with incurable illnesses, appropriate use of palliative care, and end-of-life issues (Field & Behrman, 2003; Malloy, Ferrell, Virani, Wilson, & Ulman, 2006). Regardless of pediatric nurses' lack of preparation and education, it is this group of nurses who are the primary care providers when

children are dying in the hospital setting (Haut et al., 2012). However, nurses lack the education on how to manage the emotional aspects of the dying child and family (Whittle, 2002).

Furthermore, nurses lack the knowledge, education, and resources to manage their own emotions and feelings around the death and dying of children and grieving families (Iglesias, Pascual, & de Bengoa Vallejo, 2013; Malloy et al., 2006).

Nursing Education in Palliative Care

Studies have suggested that student nurses are grossly unprepared to deal with palliative and end-of-life issues particularly in pediatrics (Field & Behrman, 2003; Malloy et al., 2006). This is because pediatric education for nurses is limited in its coverage of pediatric palliative care and relatively little time is dedicated to teaching palliative and end-of-life care (Kane & Primomo, 2001). This lack of education has ill-equipped pediatric nurses to deal with issues of death and dying; this is particularly noticeable in the acute care setting (Malloy et al., 2006). This lack of education is leaving front line pediatric nurses inadequately prepared to manage the responsibilities and challenges of ongoing palliative care and end-of-life care (Haut et al., 2012). Furthermore, pediatric acute care nurses are the ones managing it as it is the nurses who become the primary care providers when children are dying in the hospital setting (Haut et al., 2012). In fact, of children who die, 82% die in the acute care setting (Field & Behrman, 2003). What is more, there is a public and professional expectation that pediatric nurses should care for all aspects of a child—including death and bereavement (Totka, 1996; Whittle, 2002). However, nurses lack the education on how to manage the emotional aspects of the dying child and family (Whittle, 2002). While palliative and end-of-life care is taught in nursing schools, nurses working in clinical practice could benefit from continuing education (Iglesias et al., 2013).

Models of palliative care are taught to nursing students and are, on occasion, revisited in nurses' continuing education courses. In fact, the model developed by CHPCA indicating the introduction of palliative care at the time of diagnosis is commonly presented in undergraduate nursing courses in both pediatric and adult health and during professional development courses in Canada (Canadian Hospice Palliative Care Association, 2013). Even in traditionally cure-focused arenas of pediatric health care, space has opened up for a discussion of palliative care. For instance, the American Heart Association who deliver the Pediatric Advanced Life Support program, have now included an entire chapter in the textbook devoted to end-of-life and palliative care (American Heart Association, 2011). Therefore, steps are being made to further the education of health care professionals caring for children about the tenets of palliative care. Nevertheless, the dominant discourse of pediatric health care is focused on cure and sustaining life at all costs. Often the practice of including a palliative specialist comes when disease modifying therapies fail (Carter, Hubble, & Weise, 2006; Doorenbos et al., 2012). Therefore, despite education being offered to nurses and other health care professionals both in training and practice, the work of pediatric nurses is predominantly based on the cure model. Even when in situations where aggressive care is inappropriate and in some cases unethical, both parents and health care providers desire it for the child (Byrne et al., 2011; Doorenbos et al., 2012). No one wants to give up on the child (Morgan, 2009; Rushton, 2005).

Therefore, pediatric nurses caring for children with PLSIs frequently find themselves responsible for maintaining overly burdensome interventions to sustain life. This way of caring for children with PLSIs and their families is not only causing great suffering and burden to the children and families, but it is also taking its toll on the front line nurses.

Experiences for Nurses Working with Children with PLSIs

Little is known about the experiences of pediatric nurses working with children with PLSIs on acute care units. The vast majority of research on this topic is found on nurses working with adult patient populations (Cavaliere et al., 2010). Certainly there are similarities in the experiences of nurses caring for adult patients; however, there are some important differences between the two populations. Morgan (2009) described the death of a child as a triple failure because some nurses feel that they lacked the skills and means to save the child's life, that they were unable to protect a child from harm, and that they betrayed the parents by failing (Morgan, 2009; Papadatou, 1997; Rashotte, 2005). Research conducted with pediatric nurses has focused primarily on the experiences of pediatric oncology nurses (Aycock & Boyle, 2009; Davis, Lind, & Sorensen, 2013; Feldstein & Buschman Gemma, 1995; Hinds et al., 1994; Kushnir, Rabin, & Azulai, 1997; Macpherson, 2008; Wenzel, Shaha, Klimmek, & Krumm, 2011) and pediatric critical care nurses working in Pediatric Intensive Care Unit (PICU) and Neonatal Intensive Care Unit (NICU) (Austin, Kelecevic, Goble, & Mekechuk, 2009; Cavaliere et al., 2010; Gill, 2005; Gupta et al., 2013; Hefferman & Heilig, 1999; Iglesias et al., 2013; Lee & Dupree, 2008; McGibbon, 2004; Meadors & Lamson, 2008; Mekechuk, 2006; Rashotte, Fothergill-Bourbonnais, & Chamberlain, 1997). While there are similarities in experiences among pediatric nurses, the context and nature of general pediatric nursing in acute care have some unique features. Nurses caring for children with a cancer diagnosis are challenged in managing a child who had been previously healthy, but now is facing a life-threatening illness. The long-term survival rates of children with cancer has greatly improved over the past 30 years and a substantial body of knowledge is available to nurses in terms of prognosis and diagnosis; making this population of nurses different than general pediatric nurses. General pediatric nurses are

quite familiar with children with PLSIs and with the technology now available on general units (e.g., ventilators and cardiac monitors), inpatient nurses are caring for critical care patients in the context of general pediatrics where resources and support are notably lacking. There are certainly similarities among the various specialty areas; however, general pediatric practice has its unique challenges. Unlike PICU or NICU, general pediatric nurses do not have access to a multitude of other health care professionals and their patient assignments often involve three or more patients rather than the customary one-to-one assignments found in critical care. Patient/nurse ratios on general acute units are a noteworthy difference to the PICU/NICU as research suggests that it is highly taxing, difficult, and draining to step from a dying patient's room into the room of an otherwise healthy/healing patient and needing to "change face" in between (Cook et al., 2012; Maunder, 2006). This need to change behaviour and affect between rooms, to hide true feelings, and to pretend that the dying child is not affecting them is emotionally exhausting (Cook et al., 2012; Maunder, 2006). The phenomenon of having to disconnect and to change gears multiple times throughout the day may be in fact more draining than the stress of caring for a single critically ill child in the NICU/PICU (Cook et al., 2012). Therefore, the research on pediatric oncology and critical care nurses offer something to the topic; however, the information is not readily transferable.

Nurses' Experiences: Both Positive and Negative

Little is known about the experiences of pediatric nurses caring for children with PLSIs in the general acute care setting. Research done on nurses working in other areas suggests that the experiences for nurses are complicated. On the one hand, studies suggest that nurses find rewards and meaning in their work where the challenges are great (Lee & Akhtar, 2011; Taubman-Ben-Ari & Weintroub, 2008). However, they are faced with issues of moral distress

from the use of technology to sustain and extend the lives of children who may be suffering, trauma from the heartbreaking stories and unrelenting burdens that come with the work, and from the grief that comes from loss.

Negative Experiences

The literature on moral distress, compassion fatigue, burnout, and grief offer a glimpse into what may be negatively affecting nurses and influencing what nurses experience in their clinical practice. While there is substantial literature on stress and job dissatisfaction for nurses, I did not include this literature because it was not specific to areas where nurses face death, grief, and loss as part of their work.

Moral Distress

One experience for nurses that has been documented in the research literature is moral distress. Moral distress is a relatively new concept in the health ethics literature and describes a person's reaction when she or he believes to know the right course of action in a situation, but is prevented from doing it (Austin, 2012; Austin et al., 2009; Gaudine, LeFort, Lamb, & Thorne, 2011; Jameton, 1992; Joinson, 1992; LaSala & Bjarnason, 2010; Nathaniel, 2006; Pye, 2013; Varcoe, Pauly, Storch, Newton, & Makaroff, 2012). Moral distress is a pervasive problem, although poorly understood, seldom recognized, and impedes nurses' ability to deliver optimal care (Cavaliere et al., 2010; Erlen, 2001; Hamric, 2000; Hardingham, 2004; Hefferman & Heilig, 1999; Nathaniel, 2006; Sundin-Huard & Fahy, 1999). While nurses are not the only professionals who encounter moral distress, they are particularly vulnerable to it because of the nature of their work and their positioning in terms of decision making within the health care system (Austin et al., 2009; Jameton, 1992; Joinson, 1992). As a result, nurses develop close professional relationships with patients and families and are involved in important conversations around

hopes and expectations for treatment and quality of life, yet nurses play no active role in decision making (Austin et al., 2009; Austin et al., 2005; Cavaliere et al., 2010; Gill, 2005; Peter & Liaschenko, 2004). Consequently, nurses' responsibilities for administering treatments and delivering life-sustaining interventions far exceed their authority for influencing decisions around such topics (Montagnino & Ethier, 2007). Furthermore, the shifting focus in health care organizations has also contributed to the increasing rates of moral distress of nurses as well as other health care professionals (Austin, 2012). The increasing preoccupation of health care organizations with efficiency and modelling their organizational structure on those found in the business sector has caused profound problems within the hospital settings (Austin, 2012). While hospitals are large organizations, they differ from other similarly large establishments in one particularly profound way: hospitals are organizations where, as a normal part of the routine, people suffer and die (Austin, 2012; Chambliss, 1996). As a result of this cultural shift, nurses' primary commitment is to their employer, not their patients (Rankin & Campbell, 2006). As the result of new policies and management to reflect the efficiency mandate, a code of silence has been created where nurses quickly realize that their voices are not heard, nor wanted, thereby leaving nurses powerless (Austin, 2012; Corley, Minick, Elswick, & Jacobs, 2005; Pauly, Varcoe, Storch, & Newton, 2009).

When nurses encounter situations that are in conflict with their own beliefs and require them to carry out treatment decisions for which they may feel is unethical, moral distress is often the result (Austin, 2012; Austin et al., 2009; Jameton, 1992; Joinson, 1992; LaSala & Bjarnason, 2010; Nathaniel, 2006; Varcoe, Pauly, Storch, et al., 2012). Thus, nurses are left feeling helpless, sad, angry, and frustrated (Austin et al., 2009; Cavaliere et al., 2010; Davies et al., 1996; Kain, 2007; Nathaniel, 2006) with a third of nurses emotionally withdrawing from the nurse/patient

relationship (Pye, 2013). What is more, studies have shown that moral distress has a negative effect on nursing practice and patient outcomes (Cavaliere et al., 2010; Corley et al., 2001; Nathaniel, 2006) and it influences the quality, quantity, and cost of nursing care (Cavaliere et al., 2010; Nathaniel, 2006; Wilkinson, 1987).

The effects of moral distress have been documented in relation to nurse attrition rates. Moral distress has been shown to force nurses to leave not only their current practice setting, but leave the nursing profession altogether (Cavaliere et al., 2010; Corley et al., 2001; Davies et al., 1996; Kelly, 1998; Meltzer & Huckabay, 2004; Nathaniel, 2006; Redman & Hill, 1997; Sundin-Huard & Fahy, 1999; Wilkinson, 1987). One study reported that 43% of nurses left a position because of moral distress (Austin et al., 2009; Nathaniel, 2006). This is a costly problem when replacing a single medical-surgical nurse is estimated to be \$92,000 US and the cost is even higher with specialty nurses at \$145,000 US (Cavaliere et al., 2010; Hatcher et al., 2006). Not only can the system ill-afford the financial expense of replacing nurses, but moral distress may be one of the contributing factors affecting the critical nursing shortage across North America (Austin et al., 2009).

Regrettably, those nurses who continue to practice are working in increasingly stressful work environments, which further their risk of moral distress presenting as stress-induced physical, emotional, and psychological pain/anguish (Austin, 2012; Cavaliere et al., 2010; Corley et al., 2001; Elpern, Covert, & Kleinpell, 2005; Wilkinson, 1987). Nurses who lose the capacity to care fail to provide good care, avoid patient contact, become emotionally aloof, deny their emotional pain, and become cynical and sarcastic (Cavaliere et al., 2010; Corley et al., 2001; Hanna, 2004; Hefferman & Heilig, 1999; Millette, 1994; Redman & Hill, 1997; Wilkinson, 1987). What is more, moral distress affects nurses so deeply that nurses begin to struggle to face

themselves in the mirror: “I don’t go home feeling just like a bad nurse; I go home feeling like a bad person” (Austin, 2012, p. 28). Therefore, moral distress impacts nurses not only in the workplace, but in their lives outside of work including how nurses interact with their friends, families, and even their own children (Gordon, 2005; Mekechuk, 2006).

Traumatisation

Nurses are at risk for being traumatised through their work with patients. Traumatisation has been documented as a risk for not only first responders, but also for health care providers (Abendroth & Flannery, 2006; Beck, 2011; Coetzee & Klopper, 2010; Czaja, Moss, & Mealer, 2012; Figley, 1995; Inbar & Ganor, 2003; Meadors & Lamson, 2008; Mealer, Burnham, Goode, Rothbaum, & Moss, 2009; Mealer, Shelton, Berg, Rothbaum, & Moss, 2007; Robins, Meltzer, & Zelikovsky, 2009; Sabo, 2008; Tabor, 2011).

Post-Traumatic Stress Disorder

Based on the nature of nurses’ work and their proximity to traumatised patients, nurses are at a particularly high risk for developing Post-Traumatic Stress Disorder (PTSD) (Czaja et al., 2012; Mealer et al., 2009). In the adult critical care practice settings, 20-30% of nurses were found to have PTSD symptoms related to work, which is a significantly higher rate than in the general population at 3.5% (Czaja et al., 2012; Kessler, Berglund, et al., 2005; Kessler, Chiu, Demler, & Walters, 2005; Mealer et al., 2009; Mealer et al., 2007). What is more, traumatic situations involving children have a greater psychological impact because of children’s particular vulnerability and dependence on adults, making pediatric nurses at a notably increased risk for PTSD (Beaton & Murphy, 1995; Czaja et al., 2012; Figley, 1995; O’Connor & Jeavons, 2003; Robins et al., 2009). Nurses living with PTSD are significantly impacted by this in terms of the nurses’ wellbeing, but also in terms of nurse retention and care of patients (Czaja et al., 2012).

It is often assumed that PTSD is caused by directly witnessing violent trauma or death (Czaja et al., 2012). However, one study discovered that a stressful work environment could induce PTSD symptoms in nurses working with sick and dying patients, making the feelings of being overextended, fear of adverse events to patients under their care, poor teamwork, and direct threat of combative patients and abusive family members equally threatening to a nurse's ability to develop symptoms of PTSD (Czaja et al., 2012). Therefore, stressful experiences found in acute care settings, which are not usually seen as catastrophic, may contribute to the development of PTSD in a population of vulnerable nurses over time (Czaja et al., 2012).

Secondary Traumatic Stress

Secondary Traumatic Stress (STS) is the natural behaviours and emotions that occur as a result of caring for a traumatised patient and learning of the traumatic event the patient experienced (Beck, 2011; Figley, 1995; Rourke, 2007). Therefore, simply learning about a traumatic event that has happened to someone else has the potential to traumatise and cause STS (Beck, 2011). This experience of STS is further intensified through the desire to help and directly caring for the traumatised or suffering patient (Beck, 2011; Figley, 1995; Rourke, 2007). STS can develop suddenly and with little warning (Beck, 2011; Figley, 1995) with symptoms including helplessness, confusion, and feeling isolated from a support system (Beck, 2011; Figley, 1995). Nurses are at a particularly high risk for developing STS (Beck, 2011; Czaja et al., 2012; Maytum, Heiman, & Garwick, 2004; Meadors & Lamson, 2008). Perhaps not surprisingly, STS has similar symptoms as PTSD, but the chronicity and the degree of functional impairment with STS is not as clearly defined as with PTSD (Czaja et al., 2012; Elwood, Mott, Lohr, & Galovski, 2011).

Compassion Fatigue

The terminology of traumatisation to describe the experience of health care professionals has been used for over a century (Figley, 1995) and continues to be used by researchers and clinicians. However, in the 1990s, the language of traumatisation was largely replaced by the term compassion fatigue. The labelling of the experience as compassion fatigue was taken up in order to offer a “friendlier” term to describe the phenomenon of health care provider traumatisation (Figley, 1995; Joinson, 1992). While these terms are often used interchangeably, it is not always the case. Therefore, STS and compassion fatigue have been presented separately, although they are highly similar constructs.

Compassion fatigue is the result of a progressive, cumulative process, which is caused by prolonged, continuous, and intense contact with sick and dying patients (Coetzee & Klopper, 2010; Neville & Cole, 2013). This manifests with notable physical, social, emotional, spiritual, and intellectual changes that increase in intensity over time (Coetzee & Klopper, 2010; Neville & Cole, 2013). Symptoms of compassion fatigue include the re-experiencing of the primary survivor’s traumatic event, avoidance of reminders of event/person, and numbing in response to triggers and persistent arousal (Figley, 1995; Meadors & Lamson, 2008).

The cumulative impact on nurses who routinely experience the death of children may be significant (Rourke, 2007). Furthermore, the repeated exposure to dying children can erode the myth of safety that guides most people through life, revealing a harsh and frightening reality that nurses struggle to live with (Bride, Radey, & Figley, 2007; Rourke, 2007). Nurses who develop compassion fatigue lose the ability to provide the same level of compassion and care for others following repeated exposures to trauma (Figley, 1995; Meadors & Lamson, 2008). Nurses who care for very sick and dying children are denied the time to recover in between traumas, making

nurses' ability to cope with compassion fatigue particularly difficult (Meadors & Lamson, 2008; Pfifferling & Gilley, 2000). Furthermore, the set-up of health care organizations often overlook and can even contribute to the increasing rates of compassion fatigue in nurses and other health care providers (Austin et al., 2013; Meadors & Lamson, 2008).

What is more, compassion fatigue also has significant costs to patients, families, and the health care system. Compassion fatigue is associated with decreased quality of care (Meadors & Lamson, 2008) as well as decreased productivity, increased turnover, and greater number of sick days (Austin et al., 2013; Meadors & Lamson, 2008; Pfifferling & Gilley, 2000).

Grief

Grief is a universal human experience that is pervasive and dynamic (Jacob, 1993). Compared with research on other types of grief, such as that of family members, nurses' grief is not well understood (Papadatou, 2000, 2001; Rashotte et al., 1997). Even so, the research that has been done on the topic supports the fact that nurses do experience grief through their work (Clements & Bradley, 2005; Costello & Trinder-Brook, 2000; Davies et al., 1996; Feldstein & Buschman Gemma, 1995; Macpherson, 2008; Marino, 1998; Morgan, 2009; Papadatou, Bellali, Papazoglou, & Petraki, 2002; Rashotte, 2005; Rashotte et al., 1997; Saunders & Valente, 1994; Wrenn, Levinson, & Papadatou, 1999).

Papadatou identified seven categories of grief and loss for nurses and other health care professionals (Papadatou, 2000, 2001, 2009). Not surprisingly, those who work and care for patients grieve their deaths as well as the loss of the professional, therapeutic relationship (Clements & Bradley, 2005; Davies & Orloff, 2005; Kushnir et al., 1997; Lamers, 2002; Lev, 1989; Liben et al., 2008; Macpherson, 2008; Marino, 1998; Papadatou, 2000, 2001, 2009; Wrenn et al., 1999). Not only this, but they share in the loss of the relationship with the patient's family

(Morgan, 2009; Papadatou, 2000, 2001, 2009; Saunders & Valente, 1994). In addition, health care professionals may identify with the pain and suffering experienced by the family members (Lamers, 2002; Morgan, 2009; Papadatou, 2000, 2001, 2009). This, in turn, can sometimes trigger anticipatory grief over possible future losses (e.g., patients, nurses' own family members) (Gerow et al., 2010; Lamers, 2002; Lev, 1989; Marino, 1998; Papadatou, 2000, 2001, 2009; Wrenn et al., 1999) or remind the nurse of past, perhaps unresolved, losses (e.g., other patients, loved ones) (Davies & Orloff, 2005; Lamers, 2002; Lev, 1989; Papadatou, 2000, 2001, 2009). Sometimes the loss occurs when the professional's previously held beliefs or assumptions about life are challenged (e.g., children should not die before their parents) (Clements & Bradley, 2005; Davies & Orloff, 2005; Gerow et al., 2010; Papadatou, 2000, 2001, 2009; Rashotte, 2005; Rashotte et al., 1997) or a nurse's professional goals and expectations are not met and medical interventions fail (Clements & Bradley, 2005; Gerow et al., 2010; Kushnir et al., 1997; Lev, 1989; Marino, 1998; Morgan, 2009; Papadatou, 2000, 2001, 2009; Rashotte et al., 1997; Wrenn et al., 1999). Furthermore, nurses may grieve when confronted with issues of loss related to their own mortality (Churchill, 1999; Lamers, 2002; Marino, 1998; Papadatou, 2000, 2001, 2009).

Context of Nurses' Grief

While grief is generally understood to be an individual experience (Attig, 1991; Cowles & Rodgers, 1991; Jacob, 1993; Klass, 2006; Rando et al., 2012), for nurses, it is also experienced within the workplace setting and culture. The workplace setting itself has a powerful influence on how nurses experience and manage their grief. For instance, workplaces have explicit and implicit systems of goals, values, and assumptions about the care provided in illness and dying as well as how nurses are expected to conduct themselves in these situations (e.g., always be cheerful, do not cry on duty, be strong) (Costello & Trinder-Brook, 2000; Davies et al., 1996;

Papadatou, 2000). Clearly, the professional work stance does not necessarily match the personal reaction a nurse may have to a loss or death. Feeling obliged to ignore or suppress their grief reaction can have long-term negative consequences for nurses such as burnout (Costello & Trinder-Brook, 2000; Davies et al., 1996; Kushnir et al., 1997; Papadatou, 2000).

Cumulative Nature of Nurses' Grief

One of the features of nurses' grief that makes it particularly distinctive is the cumulative nature of loss and grief through their work. The daily exposure to loss, suffering, and death builds up over time. Researchers have identified this accumulation of loss as particularly problematic and not well understood (Brunelli, 2005; Costello & Trinder-Brook, 2000; Marino, 1998; Papadatou, 2000, 2001; Rashotte et al., 1997; Wrenn et al., 1999). Marino (1998) defined cumulative grief for nurses as the emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died. The traditional models of understanding of the grief process, as established for other bereaved groups, have specific stages, phases, and tasks (Papadatou, 2001) but these do not address the accumulation of grief as experienced by nurses for whom suffering, loss, grief, and death are part of their daily work (Papadatou, 2001).

Nurses struggle with the cumulative nature of grief following the death of several patients within a short period of time or having to cope with patient deaths over many years. This is particularly true in acute care settings where nurses are often forced into the nearly impossible situation of being expected to care for several critically ill and dying patients simultaneously, while at the same time attempting to deal with previous losses (Marino, 1998; Papadatou, 2001). This situation can cause extreme emotional exhaustion for the nurse (Marino, 1998; Papadatou, 2001). Furthermore, it can lead nurses to the total denial of grief, distorted grief, or masked grief,

feelings of decreased professional competency, diminished self-esteem, and/or chronic grief (Marino, 1998). This accumulation can place physical, emotional, and spiritual burdens on the nurse (Brunelli, 2005), especially when he or she has not had the opportunity to find closure or has not had time to process their reactions to each death (Brunelli, 2005; Rashotte et al., 1997; Wrenn et al., 1999).

Nurses as Disenfranchised Grievors

Disenfranchised grief, as Doka (1989) explained, is grief that is inhibited by “grieving norms” in our society when the loss is unusual. In the case of nurses, they are often not seen to be a member of the bereaved. Therefore, they hesitate to express grief, which often forces them into silence (Kuhn, 1989). This is disenfranchised grief. When nurses experience loss, they often believe that they neither have the right to grieve nor is it their place to do so (Lev, 1989). Even when the nurse has developed a close relationship with a patient who dies, they are denied the opportunity to grieve (Clements & Bradley, 2005). These painful experiences often remain hidden from others and are frequently concealed by the nurses themselves (Papadatou, 2000). Because of this, nurses do not have access to the usual sources of support and are forced to grieve in silence (Lev, 1989).

Burnout

Burnout is the end result of a gradual process of wearing down and develops gradually over time as a state of physical, emotional, and mental exhaustion which is caused by the involvement in emotionally demanding situations over long periods of time (Beck, 2011; Figley, 1995; Pines & Aronson, 1988; Rourke, 2007). Burnout is defined as a global, long-term consequence of working in a stressful caregiving environment and includes the experience of emotional exhaustion and depleted sense of personal accomplishment and achievements (Figley,

1995; Maslach, Jackson, & Leiter, 1986; Rourke, 2007). Burnout can include chronic fatigue, anger, feelings of helplessness, headache, gastrointestinal problems, increase/decrease weight, insomnia, and depression (Davis et al., 2013).

Burnout has an adverse effect on quality of care provided to patients (Davis et al., 2013; Lee & Akhtar, 2011). Burnout leads to increased absenteeism as nurses begin to psychologically and physically withdraw from patient interactions (Peterson, Demerouti, Bergström, Åsberg, & Nygren, 2008). Chronic burnout can result in conflict with colleagues and indifference towards patients and their care (Davis et al., 2013; Quattrin et al., 2006). However, one of the most devastating results of burnout in nurses is that nurses leave the profession altogether (Davis et al., 2013; Sadovich, 2004). Burnout and nurse attrition has been well documented (Albrecht & Burgoon, 1982; Czaja et al., 2012; Maytum et al., 2004).

Positive Outcomes

The challenges and risks nurses face in their daily work with children with PLSIs are significant and not to be underestimated. Yet in spite of these challenges, nurses continue to work in areas where children are very sick and dying. Furthermore, nurses report that they experience personal and professional benefits from their work (Clarke-Steffen, 1998; Hinds et al., 1994; Macpherson, 2008; Olson et al., 1998; Rashotte, 2005; Sinclair & Hamill, 2007; Taubman–Ben-Ari & Weintroub, 2008; Tedeschi & Calhoun, 1995). According to one study, pediatric nurses found deep meaning in the midst of experiencing painful emotions through their work with dying children and their families (Lee & Dupree, 2008). Some nurses came to understand their negative experiences as a sign of their ongoing commitment and connection to their patients/families and described the sadness and pain they felt as a result of a child's death and witnessing a family's grief as welcomed as an indication of their humanity and emotional

availability (Lee & Dupree, 2008). A variety of terms have come from the literature to describe such positive outcomes to the work of nurses including self-transcendence, compassion satisfaction, and meaning making (Abendroth & Flannery, 2006; Farran, Miller, Kaufman, Donner, & Fogg, 1999; Frankl, 1966; Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Neville & Cole, 2013; Noonan & Tennstedt, 1997; Rashotte, 2005; Rasmussen, Sandman, & Norberg, 1997; Taubman–Ben-Ari & Weintroub, 2008). The concepts that seem to best describe the positive experiences for nurses and encompass some of these other terms are captured in the concepts of personal growth and finding meaning in life. Studies have revealed that nurses working in highly stressful areas of practice where trauma and death were common experienced increased meaning in life and personal growth as a result of their chosen area of practice (Clarke-Steffen, 1998; Farran et al., 1999; Noonan & Tennstedt, 1997; Olson et al., 1998; Rashotte, 2005; Rasmussen et al., 1997; Taubman–Ben-Ari & Weintroub, 2008).

Finding Meaning in Life

Finding personal meaning in life describes the value people place upon the events and course of their life and the significance they attach to their own human existence (Reker & Wong, 1988; Taubman–Ben-Ari & Weintroub, 2008). Finding personal meaning in life is individually constructed and influences a person's choice of activities and goals along with providing life with a sense of purpose, personal worth, and fulfillment (Taubman–Ben-Ari & Weintroub, 2008; Wong, 1998). Finding meaning in life for survivors of trauma, either the victims or those caring for victims, occurs when the survivor comes to realize that living can no longer be taken for granted and begin to shift from focusing on understanding the meaning of life to a focus on the meaning in life (Janoff-Bulman & Yopyk, 2004; Taubman–Ben-Ari & Weintroub, 2008; Tedeschi & Calhoun, 1995). Studies with both family and non-family

caregivers found that they create meaning by choosing to help, care, and support others and that they find a higher meaning in life as is related to higher psychological well-being and more positive self-esteem (Cohen, Colantonio, & Vernich, 2002; Farran et al., 1999; Noonan & Tennstedt, 1997; Taubman–Ben-Ari & Weintroub, 2008).

Personal Growth

Personal growth is defined as enhanced personal resources, such as increased self-esteem and social resources, as well as new coping skills and by changes in life philosophies, including deeper spirituality, redefined priorities, and greater appreciation of life (Taubman–Ben-Ari & Weintroub, 2008; Tedeschi & Calhoun, 1996, 2004). Evidence suggests that some people show tenacious resilience in the aftermath of trauma, loss, and adversity where they ultimately experience personal growth (Schaefer & Moos, 1992; Taubman–Ben-Ari & Weintroub, 2008; Tedeschi & Calhoun, 1995, 1996). Studies indicate that clinicians working with trauma survivors perceive important work-related and personal benefits (Noonan & Tennstedt, 1997; Rashotte, 2005; Rasmussen et al., 1997; Taubman–Ben-Ari & Weintroub, 2008). In these cases, clinicians reported positive changes in their own personalities, including greater sensitivity, compassion, insight, tolerance, increased appreciation for the resilience of the human spirit, personal growth, and spirituality (Arnold, Calhoun, Tedeschi, & Cann, 2005; Taubman–Ben-Ari & Weintroub, 2008). Furthermore, personal growth develops through nurses' work and its inherent challenges (Taubman–Ben-Ari & Weintroub, 2008). In situations where nurses care for patients who are severely ill, injured, and dying, they have the opportunity to uncover personal benefits such as increased sensitivity, compassion, and tolerance (Taubman–Ben-Ari & Weintroub, 2008). Under these circumstances, nurses are given the opportunity to re-examine their personal philosophy of life and re-evaluate for themselves what is truly important in their lives, based on their workplace

experiences of grief and compassion fatigue (Rashotte, 2005; Taubman–Ben-Ari & Weintroub, 2008).

Summary

Little is known about what it is like for pediatric acute care nurses caring for children with PLSIs on inpatient units (Cook et al., 2012). Gaps in the literature exist in terms of what it is like for nurses to care for children with uncertain illness trajectories, difficult symptom management, invasive procedures, and a challenging work environment. Gaps exist regarding what it is like for nurses to come to know patients and their families well over years of frequent and lengthy admissions, caring for children and families in the uncertainty that surrounds a PLSI, and living with the knowledge that children suffer and die. The context in which this all takes place is important and little research has focused on how pediatric acute care nurses who expect their patients to recover manage while caring for a dying child and how nurses come to live with this burden (Cook et al., 2012).

The issues of burnout, moral distress, compassion fatigue, traumatisation, and grief are highlighted throughout the nursing literature with evidence presented in the pediatric literature (Brosche, 2007; Kushnir et al., 1997; Marino, 1998; Papadatou, 2000, 2001, 2009; Pendry, 2007; Rushton et al., 2006). The symptoms nurses are experiencing should not be ignored or belittled, as they indicate that nurses need support to stay healthy both mentally and physically in order to provide the best care to their vulnerable patients and their families (Cook et al., 2012).

Equally missing in the literature are the positive aspects of what nurses experience as a result of their work with children with PLSIs. A better understanding of the challenges nurses face is important in better understanding the problems. Furthermore, by gaining a better understanding of the benefits and positive outcomes for nurses working with children with

PLSIs, this could potentially offer ways to balance the negative aspects and challenges with the positive outcomes.

CHAPTER THREE: THE ART OF UNDERSTANDING—HERMENEUTIC INQUIRY AND RESEARCH DESIGN

Hermeneutics is the practical art, that is, a *techne*, involved in such things as preaching, interpreting other languages, explaining and explicating texts, and, as the basis of all of these, the art of understanding, an art particularly required any time the meaning of something is not clear and unambiguous. (Gadamer, 2007, p. 44)

Hermeneutics offers a way to know and understand the world and thus the topic (Gadamer, 1960/2006). Hermeneutics, as the art and practice of interpretation, aims to respond to the question: how is understanding possible? (Gadamer, 1960/2006). Hermeneutics is the tradition, philosophy, and practice of interpretation (Binding & Tapp, 2008; Moules, 2002; Moules, McCaffrey, Field, & Laing, 2015). The world is interpretable and, in fact, we are constantly in the process of this interpretation (Moules, 2002). Even in quantitative research, some degree of interpretation is necessary. Some believe that we should “let the data speak for themselves” (Keller, 1985, pp. 129-130). Of course, “the trouble with this argument is... that data never do speak for themselves” (Keller, 1985, pp. 129-130). Therefore, regardless of a chosen research method, a degree of interpretation is always necessary. For those engaged in the philosophy of hermeneutics, all understanding is achieved through interpretation. The interpretations that we make are influenced by our observations of the world in which we live. Hermeneutic inquiry aims to express how things are in the world, how it is to be in the world and of the world (Grondin, 2003). What if those interpretations are incorrect? “The possibility that the other person may be right is the soul of hermeneutics” (Grondin, 1994, p. 124 cited Hans-Georg Gadamer at the Heidelberg Colloquium, July 9, 1989).

Hermeneutics and Truth

The notion of truth in hermeneutics is cultivated and gained through interpretation. Truth is not a static, unchangeable reality. Rather the truth, as it is understood in hermeneutic philosophy, is always shifting, always changing. Reality and truth are constantly evolving in the in-between of what is and what may be (Caputo, 1987/2000). In this space, interpretive inquiry allows for the unconcealing of something about the world and for continual openness where new understanding is always possible. Therefore, hermeneutics accepts not only the possibility, but also the reality that there are multiple truths in the world and multiple interpretations of those truths. As a result, any interpretation of the world can be explained differently. In fact, we are always in the process of interpretation and understanding: “interpretation is always on the way” (Gadamer, 1981, p. 105). In short, hermeneutics is the answer to a question that can always be answered differently (Moules, 2002). The moment that we begin to believe that we are right, or believe that we have found the truth, is the very moment that we betray the philosophy of hermeneutics (Moules, 2002). “It would be a poor hermeneuticist who thought he could have, or had to have, the last word” (Gadamer, 1960/2006, p. 581).

Gadamer criticized the notion that implementing a method is the only way to uncover truth and he did not believe that truth was adequately explained by method alone (Gadamer, 1960/2006). Furthermore, Gadamer objected to the attempt of method to exercise a monopoly on the notion of truth (Grondin, 2003). Gadamer argued that history and tradition are essential to hermeneutics where the aim is to understand conditions that make truth possible within the human sciences (Gadamer, 1960/2006). Thus, Gadamer believed that researchers should recognize that the role and understanding of truth for the human sciences is not the same as with the natural sciences. Hermeneutics acknowledges that much of what happens to us in life,

although anecdotal, contains truth. Nevertheless, with hermeneutics, there is no definitive truth to be found: “In the end...hermeneutics does not lead us back to safe shores and terra firma; it leaves us twisting slowly in the wind” (Caputo, 1987/2000, p. 267).

History of Hermeneutics

Hermeneutics has a long history, which has been influenced and shaped by many philosophers and scholars over the past several hundred years. My purpose in writing this chapter is not to recount the history of hermeneutics. Not only has that been previously written by others (e.g., Palmer, 1969), but it is also beyond the scope of this dissertation. All the same, when taking up the philosophy of hermeneutics it is essential to acknowledge, even if only briefly, its history. Therefore, I offer a very brief account of some of the philosophers and scholars who have influenced the evolution of hermeneutics—particularly their influence on Gadamarian hermeneutics, which is what guides my research.

The tradition of philosophical hermeneutics has a history with roots in early Greek culture. The word “hermeneutics” comes from the Greek verb *hermeneuin* meaning to interpret, to say, or to translate; the name *hermeneus* refers to the Greek messenger god Hermes—a mischievous and playful fellow (Gadamer, 2007; Moules et al., 2015; Rodgers, 2005). According to this tradition, Hermes was a “trickster” who was also a messenger for the gods who relayed proclamations to humans (Moules et al., 2015; Rodgers, 2005). Yet in relaying these messages, Hermes “lies, he jokes, he speaks by indirection as often as he speaks clearly” (Hirshfield, 1997, p. 186).

There are several early writers who have had significant influence on the evolution of hermeneutics. Augustine (354-430) receives credit for the development of theories related to meaning and he presented the “forgetfulness of language” as well as the importance of the

tradition of language (Grondin, 1994; Moules et al., 2015). Martin Luther's (1483-1546) beliefs regarding written text initiated early hermeneutic interpretation of scripture (Grondin, 1994; Moules, 2002; Moules et al., 2015). Friedrich Schleiermacher (1768-1834) has been called the father of contemporary hermeneutics as he developed three important themes of hermeneutic philosophy: creativity in interpretation, the role of language, and early concepts of the hermeneutic circle (Grondin, 1995; Moules, 2002; Moules et al., 2015; Palmer, 1969). Wilhelm Dilthey's (1833-1911) work focused on the development of a hermeneutic methodology that would allow for the study of human sciences (Moules, 2002; Moules et al., 2015; Palmer, 1969; Smith, 1991). Edmund Husserl (1859-1938), known as the father of phenomenology, is credited with drawing attention to the importance of hermeneutics in contemporary research (Moules, 2002). He made some particularly important contributions to the current understanding of hermeneutics including the belief that we are all innately connected to the world by introducing the notion of the *Lebenswelt* or "life-world" (Moules, 2002; Moules et al., 2015). Husserl understood phenomenology to be a scientific method which required the bracketing of one's own prior knowledge in order to discover the essence of a phenomenon. Martin Heidegger (1889-1976), Husserl's student, did not believe in the practice of bracketing as he believed that "we are in the matter and not simply enclosed in ourselves" (Gadamer, 1984, p. 59). Heidegger introduced the notion of *Da-sein* or being-in-the-world (Moules, 2002; Moules et al., 2015). He understood people to be situated in the world as well as being an essential part of the creation of that same world (Moules, 2002).

Gadamer's Hermeneutics

It is the philosophy of Hans-Georg Gadamer (1900-2002), a student of both Husserl and Heidegger, that guides my research. Gadamer is considered to be one of the most influential

philosophers of the 20th century (Grondin, 2003). He has been credited with providing the most compelling and coherent interpretation of the philosophy and study of hermeneutics to date (Grondin, 1995). Gadamer's seminal work, *Wahrheit und Methode* first published in Germany in 1960, then translated into English in 1989 as *Truth and Method*, has significantly influenced current understanding and application of hermeneutics. Gadamer's particular contributions to philosophical hermeneutics include that interpretation is closely bound to both language and history as "we are situated in a history articulated in linguistic tradition" (Grondin, 1994, p. 106). In addition, he contributed to the further development of the notions of prejudices, fusion of horizons, and the hermeneutic circle.

Increasingly, nurse researchers are guided by the contributions of Gadamer's hermeneutics in exploring topics relevant to the profession of nursing. For example, Gadamer's philosophy has guided the seminal work of Nancy Moules in understanding the art and mystery of therapeutic letters (Moules, 2000); Lillian Rallison in understanding the experience of families caring for a child with a life-limiting illness at home (Rallison, 2009); Graham McCaffrey in exploring nurse-patient relationships in mental health nursing from Buddhist perspectives (McCaffrey, 2012); and Catherine Laing in understanding the meaning of children's cancer camps (Laing, 2013).

Central Tenets of Gadamer's Hermeneutics

Address

"Understanding begins...when something addresses us" (Gadamer, 1960/2006, p. 298), but it is important to remember that address is only the beginning. "Something awakens our interest—that is really what comes first!" (Gadamer, 2001, p. 50). Address occurs when our

usual world is interrupted and this causes us to change how we see and understand it (Moules et al., 2014).

For some, address occurs in a single moment in time: “There is often a *suddenness* about it that makes us say that a question ‘comes’ to us, that it ‘arises’, or ‘presents itself’” (Dunne, 1993, p. 135). However, for others (like me), address does not occur suddenly. It is rather experienced as a niggling feeling over many years that is not always consciously detected (Moules et al., 2014). Topics that address people this way have been described as a “pebble in my shoe” (Corcoran, 2013, p. 7) or a haunting (Moules, 2002). Over time the topic draws attention to itself through generating questions:

Questioning indicates the existence of an unsettled issue, a difficult matter, an uncertainty, a matter for discussion. It also invites a reply, a dialogue, a searching out of opportunities and similarities. It opens possibilities and leads, in some sense, to uncertainty, for it throws what may have been thought secure into dis-equilibrium or imbalance. (Bergum, 1991, p. 57)

Interestingly, when a topic reveals itself, it is only partially revealed and requires us to approach it carefully with “both curiosity and suspicion, suspense, and intent, discipline and free play” (Moules et al., 2014, p. 2). The topic asks that we respond to it by doing the right thing by asking ourselves what *should* be done, rather than what *can* be done, which is often the approach of the natural sciences (Moules et al., 2014). What is more, the topic appeals to our sense of obligation to explore it: “obligation is like the cry of a small child who has lost his way on the beach calling for help” (Caputo, 1993, p. 246). The response to the sense of obligation is not about choosing a method to aim at the topic, but rather cultivating the topic as it already exists (Moules et al., 2014). Address is the joining of a conversation that has been going on long before

my arrival (Gadamer, 1960/2006). “If there can be no last word in philosophical hermeneutics, there can be no first. The question is how and where to join a continuing ‘conversation’” (Davey, 2006, p. xi).

History and Tradition

Hermeneutics is interested in understanding topics within their historical context: “*Understanding is to be thought of less as a subjective act than as participating in an event of tradition, a process of transmission in which past and present are constantly mediated*” (Gadamer, 1960/2006, p. 291). Hermeneutics recognizes that we are historical and that we belong to history (Gadamer, 1960/2006; Moules, 2002; Moules et al., 2015): “In fact history does not belong to us; we belong to it” (Gadamer, 1960/2006, p. 278). Furthermore, we are connected to the past and its traditions through a continuous thread through time (Moules, 2002). We exist in a world where we live forward, but understand backwards (Madison, 1988) where we need to remember, recollect, and recall our history (Moules, 2002). History, our inheritance of knowledge, both personal and professional, constitutes a fundamental piece of hermeneutic understanding. Hermeneutics is interested in “what it means really *to live with* that which comes down to us” (Gadamer, 2001, p. 55).

Gadamer believed that history was at play in all hermeneutic work (Gadamer, 1960/2006). “The historical consciousness has the task of understanding all the witnesses of a past time out of the spirit of that time, of extricating them from the preoccupations of our own present life and of knowing, without moral smugness, the past as a human phenomenon” (Gadamer, 2008, p. 5). As such, we cannot step over history in order to understand the present as the present is inextricably linked to the past (Moules, 2002). We live in a world of tradition where we are “always already affected by history” (Gadamer, 1960/2006, p. 300).

Aletheia

The complexities of the everyday world are often hidden from view in their normalcy and commonality (Jardine, 2012). Hermeneutics seeks to examine the ordinary and to uncover what is concealed in our day-to-day world. Hermeneutics, as Gadamer described it, is the practice of aletheia (Gadamer, 1960/2006). It urges us to look for what is veiled, to look behind that which is obvious (Caputo, 1987/2000; Grondin, 1994; Moules, 2002; Moules et al., 2015). In hermeneutic inquiry, this concept is described by the notion of aletheia. Aletheia is a Greek word meaning to seek to uncover that which is hidden (Rodgers, 2005). In Greek mythology, Lethe is a river in Hades where drinking or swimming in the water causes one to forget the past and, consequently, it is referred to as the “river of forgetting” (Moules et al., 2015, p. 3, cited Hoad, 1986). Lethe is about the hidden, the concealed, and the amnesia of our everyday world (Jardine, 2012; Moules, 2002). Therefore, aletheia asks us to remember what has been forgotten, open up what was once closed, and enliven that which is dead (Gadamer, 1960/2006; Jardine, 2006; Moules et al., 2015). Aletheia reminds us to look for what is hidden, look beyond the obvious, to question, and to recapture the original difficulty of life (Caputo, 1987/2000; Grondin, 1994; Moules, 2002; Moules et al., 2015). However, “for every opening there is closure and some things are necessarily left behind” (Moules, 2002, p. 6). Therefore, no topic can be fully revealed all at the same time. Furthermore, “truth, in this hermeneutic sense, is a dance between revealing and concealing, between opening and closing off” (Jardine, 2006, p. 15). Truth is not about discovering how things “really” are rather truth is aletheia (Jardine, 2006).

A hermeneutic approach to a topic encourages us to pay attention to the dominant discourses and try to look behind their often smooth surfaces. Hermeneutics is the “discipline of thought that aims at [the] unsaid life of our discourses” (Grondin, 1995, p. x). For instance,

Western culture promotes the denial of illness and death of children. Increasingly, children die in acute care facilities surrounded by medical equipment and hospital staff. This trend influences the experience for nurses where the dominant discourses involve the expectation for nurses not to express their emotions, or perhaps not even to have any, to be strong for their patients, and to be ready to accept care of the next patient as soon as the previous one has died. It is time for these discourses to be examined, looked at, and turned over in order for other voices to be heard (Abram, 1996).

Language

Gadamer believed that people are “language beings.” Clearly language is one of the things that set us apart from other earthly creatures. Our ability to communicate by using language allows us to connect with others. What is more, Gadamer asserted that it is essential to be knowledgeable about all aspects of a language such as idioms, play-on-words, and jokes (Binding & Tapp, 2008; Gadamer, 1960/2006). He used the German word *auskennen* to describe this need to know something thoroughly and applied it in the context of language (Binding & Tapp, 2008; Gadamer, 1960/2006).

Hermeneutics was originally conceived as a way to interpret written texts. The tradition of hermeneutics is the understanding parts of text in relation to the whole and understanding the whole as represented and understood through the parts (Gadamer, 1960/2006). Gadamer (1960/2006) rejected the view that the author’s intent in writing was the primary importance: “Not just occasionally but always, the meaning of a text goes beyond its author” (Gadamer, 1960/2006, p. 296). Once created, text separates from its author and begins to take on new meaning based on its historical context and changing circumstances of the present/future. When trying to understand text, not an attempt to understand what the author really meant, rather “we

try to transpose ourselves into the perspective within which he has formed his views” (Gadamer, 1960/2006, p. 292). Hermeneutics involves the reading of a text as the answer to a question that could have been answered differently (Gadamer, 1960/2006).

Humans are social creatures and we use language and conversation as a fundamental way of being with others. It is through conversations that we conduct ourselves in the world (Binding & Tapp, 2008). “In a conversation, when we have discovered the other person’s standpoint and horizon, his ideas become intelligible without our necessarily having to agree with him” (Gadamer, 1960/2006, p. 302). Therefore, a conversation is not about understanding the individual, but what he says; a conversation is about coming to an understanding (Gadamer, 1960/2006). Therefore, it is the language we use in conversation that allows for interpretation. Interestingly enough, while interpretation is located in language, its meaning can also be bound by those same words. As soon as we name something, we deny some other meaning or interpretation (Moules, 2002). Therefore, Gadamer (1960/2006) encouraged us to carefully examine the words (meanings, etymology, history, and tradition) we use for he believed that a word is as much about what it is, as what it is not. Furthermore, language and the words we use often mean more than we mean them to mean; language outruns our ability to corral it.

Nevertheless, there are times when language simply fails us: “We are all familiar with the strange, uncomfortable, and tortuous feeling we have as long as we do not have the right word” (Gadamer, 2008, p. 15). Furthermore, there are times when words simply cannot adequately capture emotion, pain, and suffering (Moules, Simonson, Fleiszer, Prins, & Glasgow, 2007). These fundamental human experiences often evade description and defy articulation (Moules et al., 2007). When trying to describe such emotions and experiences, people often resort to poetic language in an attempt to express the inexpressible (Moules et al., 2007). This is where the use of

hermeneutic interpretation can begin to reveal an understanding of the experience and, most importantly, the topic at hand. Hermeneutics allows for the examination of “what is said, what is uttered, but at the same time in what is silenced” (Grondin, 1995, p. x); it allows us to peer behind language and venture into the unsaid (Moules, 2002). “To understand...hermeneutically is to trace back what is said to what wishes to be said” (Grondin, 1995, p. 32). It offers the opportunity to open up language that is closed and for us to recognize what has happened when we use certain language (e.g., calling the experience “compassion fatigue” and not “traumatisation”). This is where the use of hermeneutic interpretation can begin to reveal an understanding of the topic at hand. It is something that is never quite definable and seems to lie between words (Moules et al., 2007).

Language and Nurses’ Experiences

In coming to a research question based on my topic of interest, I spent time exploring the question of whether or not nurses have grief. I wondered if the debate was primarily based on semantics. Perhaps the word “grief,” for whatever reason, does not resonate with nurses and that a new word to capture the experience was needed. There are already a variety of terms offered to nurses such as moral distress, compassion fatigue, and professional bereavement. I could not imagine that yet another term would somehow identify the complex experience of working with dying children. I was uncertain if it were even possible to capture such a complicated experience in a single term. Furthermore, I wondered what the purpose and benefit in doing that would be. I thought back to the hermeneutic message that “[t]hings should not be captured in the writing, not imprisoned by it, but set free within it” (Moules, 2002, p. 15). It seemed to me that labelling the experience as “grief” (or something else yet to be named) was not setting the experience free for nurses, but confining it and limiting it to a particular definition and denying anything that fell

outside of that categorization. Certainly it is not simply grief, or moral distress, or compassion fatigue, but a combination of things that all play a part in the experience for nurses.

At first I wondered if we were living without a word to describe the experience for nurses because of the limitations of the English language. In one of my undergraduate linguistics courses, the professor suggested to the class that if a word did not exist in a language, then those language speakers were unable to experience it. However, I would now argue that that is likely not the case. As Moules (2010) discovered, there is not a word in the Portuguese language equivalent to the English word grief. Nevertheless, the Portuguese people certainly experience the complex phenomenon of grief (Moules, 2010). So while nurses are experiencing something, perhaps our lack of vocabulary to describe it does not prevent us from experiencing it, rather it impedes us from labelling it.

Yet this then led me to wonder if perhaps there were no words in any human language that could adequately describe this experience for nurses. It seemed as though any term captured only part of the experience and somehow denied the rest. That any one label used to describe the experience for nurses was merely a piece of the puzzle. I was drawn to the work of Ludwig Wittgenstein (1889-1951). Wittgenstein's interest in the philosophy of language also built on the philosophy of Kant. Kant explored the limits of knowledge by asking what things will forever lie outside of human understanding and proposed that many problems in philosophy arise because we fail to recognize the limitations of our ability to comprehend (Scruton, 1995). Wittgenstein proposed that the limits of language are what limit our world (Keith, 2012). As a result, everyday language is inadequate for speaking clearly and precisely about the world. Wittgenstein believed that the most important problems of the world cannot be put into words—these things exist even though we cannot speak of them. Therefore, we actually cannot talk about the most important

problems in our world. In fact, according to Wittgenstein what cannot be expressed in language, must be passed over in silence (Keith, 2012; McGuinness, 2002). I wondered about that for a while thinking that perhaps in the context of grief (for lack of a better word) for nurses means that we are living without words. By virtue of the fact that we simply do not have words to describe our experiences, we are, therefore, forced into silence.

Prejudices

“The recognition that all understanding inevitably involves some prejudice gives the hermeneutical problem its real thrust” (Gadamer, 1960/2006, p. 272). Other methods require the researcher to remain objective throughout the data collection and analysis. Hermeneutics, however, not only acknowledges a researcher’s subjectivity, but also welcomes it into the research process. Gadamer referred to this as “prejudices,” although Gadamer’s predecessors, Husserl and Heidegger, referred to this phenomenon as “preunderstandings” or “forestructures.” In fact, when it comes to prejudices, hermeneutics asserts that understanding is only possible when the researcher brings his or her own prejudices into play (Gadamer, 1960/2006). I should point out that the word “prejudice” in this context does not mean “preconceived opinion that is not based on reason or actual experience” (Merriam-Webster Dictionary, 2015), but rather the notion that prejudices are the previous experiences, knowledge, and opinions of the researcher prior to entering into the research topic (Gadamer, 1960/2006). In fact, when it comes to prejudices, hermeneutics asserts that understanding is only possible when the researcher brings his or her own prejudices into play (Gadamer, 1960/2006). These prejudices arise from our life experiences, our clinical work, and our familiarity with dying children and their families (Chesla, 1995) and represent a starting point of understanding (Smith, 1991). In fact, Gadamer asserted that “[p]rejudices are biases of our openness to the world” (Gadamer, 2007, p. 82). According to

Gadamer, in order to conduct sound hermeneutic interpretation, the researcher must recognize the influences of such prejudices, apply them to understanding, use them to uncover meaning, and offer new interpretations (Gadamer, 1960/2006). Prejudices situate us within the topic such that we “see” and “hear” things that we may not have been able to otherwise (Moules, 2002). Prejudices need not be put aside, but brought into play in order to deepen and further understanding.

This notion of allowing prejudices to enter into the research arena has not been adopted by many other research approaches. While Gadamer’s philosophy suggests that a researcher should never attempt to set aside previous knowledge, experiences, ideas, or opinions, other phenomenological philosophers, such as Husserl, disagreed. Husserl argued that, in order for new ideas and knowledge to be formed about a phenomenon, the researcher’s own beliefs need to be held in abeyance (LeVasseur, 2003). Husserl described the concept of suspending one’s own prior knowledge and understanding as “bracketing.” Gadamer, on the other hand, believed that we are not separate from our prejudices and rather than trying to suppress them, we should openly examine them. In fact, Gadamer believed that to try to eliminate one’s own prejudices is not only impossible, but also absurd (Gadamer, 1960/2006). All understanding is in the light of our own prejudices (Grondin, 2003) and it is impossible to separate oneself from one’s own prejudices (Gadamer, 1960/2006). “Prejudices are merely the conditions by which we encounter the world as we experience something. We take prejudices....with us into the research process and these assist us to understand” (Koch, 1996, p. 177).

According to Gadamer, we all have prejudices that are superficial as well as ones deeply hidden. Interestingly, he believed that those hidden prejudices, the ones that we are not even aware of, are the ones that influence us the most. In order to begin to reveal these prejudices, we

must continually search and question ourselves about what is influencing us. Reflecting on prejudices allows us to see “something that otherwise happens ‘behind my back’” (Gadamer, 2008, p. 38). It is through this process that prejudices slowly begin to reveal themselves (Geanellos, 1998).

We do not, however, know all of our prejudices, for they are intricately woven into the fabric of our lives, our beliefs, and our behaviours. In hermeneutic research, we need to keep our prejudices within view, but also submit that we are most influenced by the ones we have no idea we possess. A declaration, even to ourselves, of our prejudices does not serve to shed them, but to acknowledge that our prejudices move with us and stand in front of and between us and the world, filtering our perceptions and interpretations. (Moules, 2002, p. 12)

As a researcher, I hold certain prejudices that I bring to my research through my own personal history, my education, and my nursing experience. “Hermeneutics is not founded upon the separation of researchers from the earthly life they live or the lives that are the topics of their research” (Jardine, 2000, p. 105). The prejudices I carry through my experiences as a pediatric nurse working in acute care with children with PLSIs help me to understand the topic and allow me to recognize the topic when I encounter it. I am a member of the group I want to study; therefore, I bring to the topic insider knowledge about nurses’ experiences caring for children with PLSIs in the acute care setting in relation to not only my professional experiences, but also my intimate knowledge of nursing culture, practice, and expectations. My experience is not a barrier to the topic, but rather a point of access to the hidden world of nurses. I am an acute care pediatric nurse who cares for children with PLSIs, alongside those with curable and transient illnesses, and their families in the hospital setting. This provided me with advantages that

enhanced my understanding through the research process, such as my experiences of working with dying children and my understanding of how the acute care system cares for these children. However, I was also aware that my own knowledge and life experiences also impose limitations. Therefore, hermeneutic inquiry reminded me to approach this research with an open mind in order to extend my understanding, but also to challenge it. What I needed to be particularly cautious about is that my prejudices did not become my conclusions. I needed to remain open to hear what the participants had to say, rather than listening to confirm what I already believed to be true. I frequently asked myself what I brought to this research. How does my experience as a pediatric nurse and a researcher influence my prejudices? What is lurking in my understanding of illness and death of children? What are my expectations around the role of the nurse when caring for dying children and families?

Fusion of Horizons

Prejudices, belonging both to the researcher and the participant, are brought into conversations on the research topic. In the context of a conversation, these prejudices are referred to as “horizons” or “range of vision” which is what each participant understands based on their history, their experiences, and their prejudices (Koch, 1996). Gadamer (1960/2006) described the meaning that occurs in conversation as a “fusion of horizons.” Fusion of horizons “...happens continuously. Horizons are not rigid but mobile; they are in motion” (Gadamer, 2001, p. 48). The notion of horizons also includes the belief of what lies beyond ones’ limited understanding (e.g., spiritual beliefs, thoughts on the meaning of life; Rallison, 2009). A horizon is that which can be seen from a particular vantage point, but it also shifts as positions change (Palmer, 1969). As we move to see another’s horizon, our own horizon travels with us, bringing what we know and question to what we attempt to understand. In meeting and understanding another, there is not a

termination of either participant's horizon, but rather a joining of horizon takes place (Moules, 2002; Moules et al., 2015). Therefore, horizons are in a constant state of flux: changing as we learn, grow, achieve, think, remember, and incorporate the present and the past. Through conversation, the participants and their horizons of understanding, reveal the topic to be different, more extensive, and more thoroughly exposed than either participant could have understood the topic to be on their own (Binding & Tapp, 2008; Gadamer, 1960/2006). When a researcher and a participant engage in a conversation on the topic, it is the combining of understandings and interpretation of the conversation—a fusion of their horizons—that leads to a different understanding of the topic (Koch, 1996).

Hermeneutic Circle

The notion of the hermeneutic circle is a metaphor for understanding the process of interpretive analysis rather than a method for uncovering meaning: “The hermeneutic circle is the generative recursion between the whole and the part” (Moules, 2002, p. 15). To interpret the whole is to interpret the parts and in order to interpret the parts, it is essential to interpret the whole. The circle shape of this concept, where there is no beginning and no end, suggests fluidity and repetition through the interpretive analysis process (Moules, 2002; Moules et al., 2015). There must be a tracing of movement between the whole and the parts, continually expanding the circle as new understanding emerges (Moules, 2002; Moules et al., 2015). According to this, interpretation takes place within this circle for there to be no loss of background meaning. David Abram (1996) used an analogy of how the hermeneutic circle works as a method of interpretation. He wrote about examining a clay bowl. He described how he is unable to examine all parts of the bowl at once. In fact, he is unable to even see the entire bowl at the same time. Furthermore, if he were to break the bowl in order to examine each part individually, he would

no longer be able to understand each piece within the larger context of an intact bowl (Abram, 1996). This is an effective analogy that helps to illustrate how the hermeneutic circle works: it is simply not possible to understand everything at the same time, nor can the whole be understood simply by examining its parts. It is through understanding the parts within the context of the whole that interpretation can take place. So when a researcher is in conversation with a participant, any part of what he or she hears from that participant can only be understood within the larger context (Gadamer, 1960/2006).

The Philosophy of Gadamarian Hermeneutics Guides the Interpretation of Data

Hermeneutics does not offer a step-by-step method to guide researchers. There is no strict method to adhere to, no recipe to follow with carefully delineated steps to navigate the interpretive research process. It is rather the central tenets of hermeneutics that are used to guide the research of those engaged in this form of inquiry. However, hermeneutics does ask that researchers be guided by the topic that has addressed them. Gadamer argued that the nature of understanding in hermeneutics transcends the concept of method (Gadamer, 1960/2006). Even though “philosophical hermeneutics does not constitute a system or method, its critical procedures have a clear style and a discernible signature” (Davey, 2006, p. 18).

Complex Landscape

When we are met with highly complex topics, we have a tendency to want to simplify them in order to make sense of them. There are certainly times when this is appropriate. However, with a topic such as this one, trying to simplify it would deny the topic its true nature and how it exists in the world. This is a topic that I have spent a lot of time considering both in my practice and through my work in graduate studies. Nevertheless, the more time I have spent with this topic, the more complex and difficult it has revealed itself to be. Therefore, I do not

have a clear and simple explanation to present. However, I will welcome the complexity of the topic and stay true to hermeneutics that asks us not to try and disentangle life and its complexities, but rather “stick with the original difficulty of life” (Caputo, 1987/2000, p. 1).

The Research Process

Research of any kind is laced with challenges. While I had anticipated some of the challenges I might encounter in this research project, I never expected to be faced with difficulty in recruiting participants. Over the past few years, as I worked through my coursework and candidacy, I talked about my research with many nurses working directly with patients at the bedside. I was surprised at the number of times I met nurses and within seconds of hearing about my research, they shared with me very personal stories of distress and pain from their bedside practice. They could recount in excruciating detail moments in their practice that changed them forever. I heard stories from nurses who could recount in exact detail their experiences with terrible deaths and the need for on-going counselling for PTSD in order to manage their enduring symptoms. Nurses openly talked about having to quit their jobs and even choosing not to have children of their own based on what they had seen happen in acute care.

Therefore, it came as a shock to me when I announced that I had received approval from the Conjoint Health Research and Ethics board at the University of Calgary and that I was now able to recruit and interview participants, suddenly no one was talking to me. A shift had taken place: I was no longer simply a colleague with her own stories of trauma and pain, but rather a researcher and, therefore, an outsider. Those nurses who did talk to me informally about my research made it clear that they would not share their experiences on the audio-recorder. At first this was frustrating and, admittedly, heartbreaking for me. Years of preparation and personal sacrifice to get to this point in my graduate education to suddenly be faced with silence was

difficult. As participants slowly began to come forward, I discovered that their reasons for not participating were surprising and not quite what I had assumed.

Admittedly, many felt they did not have the time to be interviewed in their busy lives of work, raising young families, and caring for aging parents. Others said they did not want to “fill out forms” and were clearly not familiar with qualitative research and were not open to learning what was involved in a qualitative study using interviews. Another barrier was the memory of how other researchers have treated inpatient nurses in the past. As bedside nurses, we are often involved in data collection. We are required to collect samples, complete paperwork in addition to our regular charting, attend training/information sessions on the research, and even to introduce the research project to patients and families. This increases our workload significantly. Yet once we are no longer needed, we rarely hear from the researcher again. We are seldom acknowledged for our contribution to the study, nor are we informed of the results or outcomes of the study.

Of all the reasons I became aware of for nurses to choose not to participate in my study, the one I found most distressing were the nurses who said, “I would love to participate, but I am afraid that what I have to say will get me fired.” While I could assure those nurses that I would do everything in my power to protect their privacy and confidentiality, this group said that they just could not take the risk. To those nurses who did come forward, I am forever thankful for their willingness to share what their experiences have been caring for children with PLSIs in acute care and for their willingness to be vulnerable in the face of a difficult topic.

Process of Data Collection: Conversations with Participants

A hermeneutic study often requires text to analyze as language is a vehicle for expression, interpretation, and understanding. Conversations (interviews) with participants were

conducted, then the audio-recording was transcribed verbatim in order to obtain a text to analyze according to the tradition of hermeneutics. However, these were not arbitrary talks about any subject, nor were they highly structured interviews. Rather the conversations with participants in the context of hermeneutic research were about the topic under study. Kvale (1996) described interviewing from a hermeneutic perspective, using the metaphor that the interviewer is a traveller on a journey during which he wanders with participants as they enter into conversations that allow stories of experience and meaning to emerge (Kvale, 1996). The purpose of these conversations is to bring forth the topic, to enliven it, to breathe new life into it (Moules et al., 2014; Moules et al., 2015). Such conversations are an opportunity to put the topic on the table and talk about it; an opportunity to open and maintain a space for the topic to be engaged (Gadamer, 1960/2006). Gadamer wrote, “to reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one’s own point of view, but being transformed into a communion in which we do not remain what we were” (Gadamer, 1960/2006, p. 371).

Recruitment of participants. “Hermeneutics seeks the best participants on purpose” (Moules et al., 2015, p. 90). Those who undertake hermeneutic research should engage in conversation with are those who are best able to cast light on to the topic and help to further unconceal it (Jardine, 1992). Therefore, I recruited nurses who work (or have recently worked) in pediatric inpatient acute care where a large population of children with PLSIs frequent. Recruitment of potential participants took place on two inpatient units at a large children’s hospital in western Canada. Recruiting ensued through displaying a poster (see Appendix C) in staff-only areas (e.g., report room and staff room). The poster was also included as a PDF attachment in the “weekly update” e-mail sent out to all nursing staff from the managers of the

two units. The posters outlined the inclusion criteria for participants: nurses working on inpatient units with children with PLSIs with a minimum of two years of experience in the area.

Number of participants. Hermeneutics is unlike other methodologies, especially in quantitative research studies, where a representative sample from the larger population is recruited and included in the data collection and analysis. The reason is that, unlike other types of research, the goal of hermeneutics is to achieve a deep understanding of a topic. Consequently, a large number of participants is not required to fulfill this mandate (Smith, 1991). Therefore, only willing participants who had particularly relevant experience of, knowledge about, and insight into the topic of interest were interviewed. “Hermeneutic inquiry is not validated by numbers but by the completeness of examining the topic under study and the fullness and depth to which the interpretation extends understanding” (Moules, 2002, p. 14).

In consultation with my supervisor, recruitment concluded after eight participants had been interviewed, which was the minimum number I sought to interview. While three potential participants expressed interest in being interviewed, they failed to follow up when I attempted to book an interview time with them. Despite recruiting on two units, all the participants were nurses who were employed on a single inpatient unit at the hospital. Interestingly, news of my research spread as I was contacted by administrators in other parts of the health region as well as nurses and social workers from other areas as they were interested in participating, but they could not be included for they did not meet the eligibility requirements of the research project.

Early in the recruitment process, it became apparent that a number of nurses who had recently left the unit wanted to participate. My supervisor and I had to consider this carefully as I did not want to interview nurses who could not offer a deeper understanding into the topic.

However, I was seeking participants who had something to contribute to an understanding of the

topic. In the end, I included those nurses who had recently left the inpatient unit. As it turned out, interviewing nurses who had recently left was a wise decision as they offered important insights and allowed for extending the understanding of the topic. Therefore, of the total of eight participants, five were currently working on the unit and three had left the unit less than a year before the date of the interview.

Interviewing participants. Prior to conducting interviews for my own research study, I had had the opportunity to conduct research interviews through my various research assistant positions. I had learned about the use of “essence of the question,” as proposed by Gadamer (1960/2006), where questions are asked with curiosity and from a position of not knowing with the intent of truly engaging in genuine conversations (Binding & Tapp, 2008). I was prepared with a list of guiding questions (see Appendix D). I had practiced the art of redirecting questions to keep participants focused on the topic for which we were trying to gain a new understanding.

Despite this prior theoretical knowledge and practical experience, I found the interviews for this topic more difficult to conduct than I had expected. It is perhaps not surprising that it was difficult for me to listen to participants as they recounted their upsetting experiences as it led me to revisit my own traumas. More than once I found myself gripping the edge of the table in the hopes it would provide me the strength to remain present, and not run away, as a participant waded into a detailed account of a trauma that mirrored one of my own. However, it was the falling into old communication patterns I learned in my years as a bedside nurse that posed the greatest challenge as I interviewed the eight participants. I had not been prepared for that occurrence and had not expected it, although in retrospect I perhaps should have anticipated it. I was challenged to remain the researcher in the interview, rather than engage in a conversation with a colleague the way we would have at the break room table. There were many times where I

noticed I lapsed into old patterns only once I transcribed the interview. However, even when I was able to maintain my position as the researcher in the moment the interview was taking place, it sometimes created an awkwardness as the participant/research relationship was artificial while interviewing nurses I had worked with in the past: *“She died. Anyway, this was back in the day when babies with short gut died. Babies (pause) should I be explaining all this for the tape?” (Jeanie)*. In addition, I found it could be difficult to persuade participants to elaborate on key points as there was an element of strangeness for me to be asking certain questions: *“And, you know, there’s bells ringing and the vents are going off [the ventilators are alarming] and the kids (pause) Well YOU know!” (Isla)*. There was the assumption that because I was familiar with the work environment and culture, or in many cases I had been present during the incident they were describing, that it seemed senseless to describe it further. This was particularly true for stories or experiences that the participant and I had previously discussed at length at the time of the incident and in the years following.

This highlights how intimately I know this population and the work—making me, perhaps, the ninth participant in some ways. I was not separate from the data and the experiences as I had been in other studies I have been involved with. While hermeneutics does not ask that researchers distance themselves from the research or bracket their prejudices, it does ask that we be aware of them.

Introducing the participants. Eight nurses from one inpatient unit agreed to participate in this research study, met the inclusion criteria, and were interviewed. The world of pediatric nursing is small; therefore, in order to heighten participant privacy and confidentiality, I will provide only a brief overview of the participants. The participants, both RNs and LPNs (Licenced Practical Nurses), had between two-and-a-half and 35 years of nursing experience in

pediatric acute care. Two nurses have worked outside of Canada and, with the exception of one participant, all the nurses had received their training in Canada. Two nurses were originally diploma prepared RNs, but completed their degrees more than 15 years ago. At present, three participants have left the unit: Sarah, Jeanie, and Trina. Five participants remain actively employed on the unit: Meg, Lily, Heather, Isla, and Rachel. Of those who have left, two have continued to work with children in other areas of the health care system. All participants were female with ages ranging between mid-twenties to early 60s with varied cultural, familial, and spiritual/religious backgrounds. For the purposes of this research, the pseudonyms Sarah, Meg, Jeanie, Lily, Heather, Isla, Trina, and Rachel were used.

While every participant contributed to furthering the understanding of the topic, two participants in particular (Sarah and Isla) were exceptionally thoughtful and articulate in their understanding of the topic and its complexities. As a result, throughout this dissertation, Sarah and Isla were quoted more frequently than the other participants. Hermeneutics is about the unconcealment of a topic and seeking out those who can further understanding. In this case, it was Sarah and Isla who were exceptionally well prepared to do this at the time the interviews were conducted. I chose to include a greater number of quotes from Sarah and Isla because I wanted to capture their insights into the topic. This was not intended to silence or dismiss the other participants.

Hermeneutic Analysis

Hermeneutic analysis begins immediately. The researcher, through the process of entering into conversations, transcribing those conversations from the audio-recordings made, reading and then re-reading the transcripts, writing and reviewing field notes and journals, and reflecting on the entire process, develops interpretations of that data which will then be analyzed

using the concepts of philosophical hermeneutics (Gadamer, 1960/2006; Grondin, 2003; Moules, 2002; Moules et al., 2015) such as seeking understanding, extending understanding, finding resonance, and kinship. It is through examining the whole and the parts that interpretations are created. This is further expanded and extended through including relevant literature from multiple sources that resonates with the topic, but the intention of that is not simply to validate or confirm the findings (Jardine, 2006). The intention is to have this topic situated within the broader domain of nursing. Most importantly, it is about *aletheia*—about remembering something that was forgotten, enlivening something that was dead, and offering a portal to understanding anew (Moules et al., 2015). Through this practice, the researcher will be fully engaged in the process of interpretation: looking at the particulars, then stepping back again to examine the whole. It is through the movement in and out of the data that the researcher is given the opportunity to see things anew and further develop his or her understanding of the topic. Unlike some other qualitative research methodologies, hermeneutics does not require that the interpretations made by the researcher be returned to the participants for verification (Moules, 2002; Moules et al., 2015; Smith, 1991). Furthermore, issues such as data saturation are not relevant in interpretive analysis. Instead attention is paid to “the instance, the particular, the event of something that does not require repetition to authenticate its arrival” (Moules, 2002, p. 14). Strong interpretations are those that extend understanding of the topic and can be recognized to be “true” of it.

Trustworthiness of the Research

Issues of Rigour and Trustworthiness

Qualitative research is judged on its credibility using criteria that is different from other types of scientific inquiry (Koch, 2006). A conversation on evaluating issues of trustworthiness

and rigour has been ongoing in the realm of qualitative research (Emden & Sandelowski, 1998). Madison (1988) understood rigour for interpretive research as being evaluated on its coherence, comprehensiveness, penetration, thoroughness, appropriateness, and potential. Rigour and trustworthiness is about “fidelity to the spirit of qualitative work” (Sandelowski, 1993, p. 2). In interpretive work, researchers must find a balance between over-interpreting the data where unjustifiable findings are presented and under-interpreting the data where no new ideas are offered to the reader (Sandelowski & Barroso, 2002). The results of hermeneutic research can always be re-interpreted and explained in another way. Consequently, there are many possible interpretations to any given topic, although some interpretations will clearly be better than others (Gadamer, 1960/2006). As a result, even if the reader does not accept the interpretations presented in the study, the reader should be able to follow the researcher’s logic that led to that particular interpretation and understanding (Koch, 2006). It is the responsibility of the researcher to demonstrate how he or she has interpreted the data by providing examples from the data and explaining the interpretation, but it is up to the reader of the study to decide if the interpretation is believable (Koch, 2006). In order for this to happen, the researcher must provide evidence of credibility, transferability, and dependability (Koch, 2006).

Credibility and Dependability

Hermeneutic research is credible and dependable when those who are confronted with the experience can recognize that experience (Koch, 1998). In order to illustrate the interpretations I have made throughout my research, I used direct quotes from my participants. In addition, I made transparent my thought processes that led me to my conclusions (Koch, 2006). Through this process of supplying an audit trail where I have provided documentation and reflective writing throughout the project, I endeavored to achieve credibility and dependability in my

research. As I worked through my analysis, I met with my supervisor and other members of my supervisory committee. I talked about what findings I saw emerging from the data and shared with them my transcripts, field notes, and journals in order to gain feedback on my interpretations and how my understanding of the topic developed over time.

Transferability

In quantitative studies, researchers aim to achieve generalizability of their findings. Qualitative research, on the other hand, especially research based on hermeneutic philosophy, does not have the number of participants, random sample size, or statistical backing for their results to be considered generalizable to others. However, this does not mean that hermeneutic studies are not highly valuable and cannot be extended to other contexts. Hermeneutic research endeavors to achieve transferability, rather than generalizability, and this occurs when “its findings can ‘fit’ into contexts outside of the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences” (Sandelowski, 1986, p. 27). Ultimately, it is the reader who will decide if the research findings are transferable or not (Streubert & Rinaldi Carpenter, 2011).

Ethical Considerations

Consent

Nurses who were interested in participating and learned of the study either through seeing the poster on the unit or through an e-mail from the unit manager contacted me through e-mail or by phone. An interview was arranged at a mutually convenient time and at a location chosen by the participant. With the exception of one interview, which was held in a quiet cafeteria, the interviews took place in the participants’ homes. Basic information of the study was communicated to participants through e-mail or over the phone, but a full explanation was

completed at the time of the interview. The written consent form (see Appendix E) was reviewed and I answered any questions participants had. The written consent was signed by the participant and a coffee card given. In addition to this verbal explanation, a written copy of the consent was provided, signed by both participant and researcher.

Risks and Benefits

Part of the process of informed consent involved the review of risk and benefits involved with participant participation. Participants were reminded that their participation in the study was completely voluntary and that they had the right to withdraw from the study at any time. No participant was overcome by undue stress. No one expressed the desire to withdraw from the study. None of the participants indicated that they experienced any distress either during the interview itself or afterwards; therefore, no follow-up counselling support was needed. Several participants said that the opportunity to share their experiences and talk about distressing experiences from practice as well as the joys of their work was helpful to them and remembering what they love about their work.

Summary

While it would certainly be possible to take up other research methodologies in order to explore the topic of pediatric acute care nurses' experiences caring for children with PLSIs in the acute care setting, hermeneutics is a good fit for this topic. Gadamerian hermeneutics allowed me to explore the topic of pediatric nurses' experiences caring for children with PLSIs in the acute care setting: cultivate the address of the topic, incorporate my prejudices to further understanding, and acknowledge the history, tradition, and language of the context and topic. Through taking up the central tenets of hermeneutics, unconcealment of the topic was possible.

Participants were recruited from an inpatient pediatric acute care unit. Interviews with participants were audio-recorded and transcribed verbatim. All efforts were made to protect participants' privacy and confidentiality throughout the research and analysis process.

In the next chapter, the landscape of pediatric acute care is described in terms of the work environment, nursing responsibilities, patient acuity, and the philosophy of care. Mapping the landscape of the work environment of participants as they care for children with PLSIs and their families is important in order to contextualize the findings in subsequent chapters.

CHAPTER FOUR: MAPPING THE LANDSCAPE

You are encountering a family who have a child who will not survive and...it's a pretty massive thing, but because you're there, day-to-day it becomes part of the natural landscape of what you're doing. (Sarah)

When Sarah described the pediatric acute care unit as a landscape, it made me consider the fact that part of effectively communicating the findings of this study is through a better understanding of the topic. The topic is tethered to the physical layout and activities of the unit, the population of children with PLSIs, and the philosophy of care known as Family Centred Care. Therefore, before presenting the interpretive findings, I first take the time in this chapter to map the landscape.

In our day-to-day lives, we all become familiar with our usual environments of home, work, and community. The landscape of our lives becomes ordinary due to its familiarity and our comfort in the context. It becomes such familiar terrain that it can be difficult to recognize and remember that others are not acquainted with the landscape. For the participants in this study, the common context is the pediatric acute care setting. A part of the philosophy of hermeneutics is to appreciate the common, the ordinary, and the everyday and appreciate how it is also uncommon and extraordinary: akin to White's (1993, p. 35) notion of "exoticizing the domestic" (Moules et al., 2015). What is more, "hermeneutics accomplishes...bringing of something out of one world and into another" (Gadamer, 2007, p. 44); in this situation, bringing truths out of the acute care context and into the greater world.

In an initial writing of this chapter, I relied on words such as busy, acute, and stressful to capture the experience of what it is like to work on an inpatient unit in the context of pediatric acute care. I had succumbed to the taken-for-grantedness of the acute care context, forgetting that

this environment is strange and unfamiliar to many, even other nurses. Therefore, in order to come to a better understanding of the topic of pediatric acute care nurses' experiences of caring for children with PLSIs, it is important to not only understand the patient population of children with PLSIs, but also the physical setting, the responsibilities, tasks, and interventions undertaken by staff nurses, and the governing practice philosophy where nurses come to know these children with PLSIs. "It is impossible to divorce the question of what we do from the question of where we are" (Berry, 1987, p. 51).

Sarah's use of the word "landscape" is a lovely way of describing the work environment of the participants. The word "landscape" describes "an area of land that has a particular quality or appearance [and] a particular area of activity" (Merriam-Webster Dictionary, 2015), which is a useful way to explain the layout of the inpatient units, the staffing, and the patient population. It also has the meaning of "all the visible areas of countryside or land; a portion of territory that can be viewed at one time from one place" (Merriam-Webster Dictionary, 2015). While I describe the physical layout of the unit and the readily observable parts, the point of undertaking this research is to have a look at some of the areas that are not readily visible and perhaps offer a different vantage point, the point of view of participants, who see and understand the horizon over this landscape differently. It was through my conversations with participants, that the topic and the landscape revealed themselves to be more complicated, multi-faceted, beautiful, and difficult than I could ever have anticipated.

I begin by mapping the landscape, offering a description of the physical environment and presenting a glimpse into the daily work of pediatric acute care nurses through briefly explaining their work responsibilities before moving on to unconcealing the topic of what it is like to work and care for children with PLSIs in the context of acute care. Reading a map is a good way to

begin a journey even though a map can only provide an idea, a superficial glimpse, of the landscape. I will begin with the map and recognize that my work does not stop there as a map only begins to tell the story of what trekking through that landscape is like.

Mapping the Physical Landscape of the Pediatric Acute Care Setting

In the interest of protecting the confidentiality and privacy of the study's participants, I do not divulge the name of the hospital where they are currently employed. However, in order to have a better understanding of the landscape, I will briefly describe the physical layout of the unit. The unit was designed to accommodate a maximum of 26 patients; however, what was originally intended to be a procedure room is currently being used to accommodate a 27th patient. The unit is at full capacity most of the time. The hospital is large and inpatient units are equipped with spacious private rooms that spread out along four hallways. It was built with the comfort of families in mind. Each patient room is equipped with its own bathroom including a bathtub and shower as well as a built-in bed for parents of patients and closet space and drawers for the storage of parents' personal items. Ensuring that families are comfortable in the acute care environment is a positive intent. However, the layout is highly problematic for nurses trying to care for very sick patients. The long hallways and centrally located medication rooms and medical supply rooms are not conducive to easy monitoring of young patients who are very ill and often alone, while at the same time obtaining the supplies required to provide them with the care they require.

While nurses work hard to avoid having to move patients to different rooms, it is not unusual for children to occupy a variety of patient rooms upon a single hospital admission. At one point, it was routine to move a patient to a room closer to the nursing station when they became more acutely ill, which allows for closer supervision of the patient by nurses. Yet, in

recent years, nearly all the patients have been highly acute and only six of the patient rooms are adjacent to the nursing station. However, because of the location of the medication rooms behind the nursing station desk, it is not possible for nurses working at the desk to see two of these rooms. Patients are moved to different rooms on the unit for reasons other than acuity including infection control and orders from Child Protective Services. Moving rooms is a time consuming activity for nurses and can be distressing for patients and families.

Surviving a Shift as an Inpatient Acute Care Pediatric Nurse

“Practitioners *suffer these things in their practice.*”

(Moules et al., 2014, p. 3)

During the interviews, I asked participants to talk about what it is like to work on the unit on a daily basis. Several participants just gave me a puzzling stare and said something like, “well, you know, it is busy.” As a member of this group, I do in fact know what it is like. Having a participant tell me that “it is busy,” I do know and I feel some anxiety as those three words reveal to me the intensity of the work environment and remind me of my history of working in that context. I would not be alone in that as I would suspect that any nurse who works on the unit, or who has ever worked there, will undoubtedly know what another nurse means with the words: “it has been a busy shift.” Other participants, perhaps with having some time away, could reflect a little on the working conditions: “*I can now see that that unit was extremely busy and extremely stressful and I wouldn’t want to go back to it now after leaving it. I wouldn’t enjoy going back to it*” (Jeanie). It is perhaps the familiarity of the environment that made it difficult for participants to explain what it is like. Two participants did choose to describe the work with the use of metaphors: head above water and over the edge.

Head above Water

“Your head is always just above the water because it’s getting so busy and kids do have such high needs” (Rachel). Rachel uses the expression of your “head just above the water” to describe what it is like to work on the unit. That expression means “to manage to survive” (The Free Dictionary Online, 2015), meaning that nurses are able “to remain alive” (Merriam-Webster, 2015) for the duration of their shift and persevere despite the challenging and life-threatening situations they face. Sadly, this seems to be an accurate reflection of what nurses experience when working on the unit. Nurses are working in a situation where they feel as though they are drowning in the demands of the job in a highly stressful environment.

Over the Edge

“I don’t think you should have more than two patients [at a time] on [the unit] because the acuity is too high. And for one person with two hands and two legs, it’s too much. And if you get that third one [third patient], it puts a lot of people over the edge” (Lily). The expression “over the edge” means to be pushed “into a condition of extreme emotional or mental suffering” and has etymological roots in being at the edge of sanity (The Free Dictionary Online, 2015). From the outside, perhaps the thought of having three or more patients does not sound unreasonable making the statement by Lily about putting nurses “over the edge” and onto the edge of sanity sound overly dramatic. However, these words offer a glimpse into the realities of the work environment and I will describe in further detail the responsibilities and tasks that inpatient acute care nurses have on the unit.

Caring for Pediatric Patients: Children are Not Just Mini Adults

Until the beginning of the twentieth century, children were not considered to be anything more than simply small adults (Anderson, 1956). Following a significant shift in understanding,

western society now recognizes children as creatures unto themselves. Children do not think the same way as adults and have physiological changes accompanied by mental, emotional, and physical development. This is no different for children with PLSIs with the exception that these children often do not meet developmental milestones at the same time intervals as would be expected of other children, and in some cases because of their disease process, children with PLSIs will be unable to meet the milestones at all. Allied health professionals are often involved with the care of children for their physical development in acute care: dieticians, physiotherapists, occupational therapists, and speech language pathologists. Resources geared to supporting children's emotional development in this time are found in the form of Child Life Specialists, music therapists, and professional clowns who integrate play, music, and laughter into the daily routine of hospitalized children. While adults in hospital can also benefit from similar services (Nuttman-Shwartz, Scheyer, & Tzioni, 2010), they are crucial in the pediatric setting where young minds and bodies are developing and growing.

From a physiological standpoint, children are also different from adults in the speed by which they become ill in part because of their smaller reserves. Therefore, quite often, there is very little warning when a child will shift from being in a reasonably stable state into a life-threatening situation (e.g., sepsis, respiratory/cardiac arrest). It is not uncommon to start a shift with a patient who appears stable and who is being prepared for discharge only to have the scenario change quickly over a span of minutes or hours and have a child suffer from a respiratory or cardiac arrest from a fast moving infection or a change in their disease process. This is a scary prospect as it can never be certain that a stable patient will remain stable for very long. This is the nature of working with children, but even more so children with PLSIs whose disease processes shroud their health and future with uncertainty.

Therefore, the need for constant monitoring is essential in this environment. Yet this is a challenge when patients are in their private rooms, often alone. Infants and young children do not push call bells or deliberately alert nurses, nor do children with developmental challenges. As a result, it is up to the nurses to frequently check on patients, particularly when those patients are unattended by family members, which is common particularly during the evening and night shifts.

Perhaps most troubling is the lack of time nurses have to spend with patients attending to their need for positive and unhurried interactions with adults as well as affection, play, and physical contact. Frequently, in a context that is so busy and stressful, the most nurses can do is turn on a children's television program or activate a baby mobile. Children are often left in their rooms unless they have family members visiting, are lucky enough to have a volunteer, or have some contact with the Child Life specialists: *"I think these chronic kids, they stay in their room all the time. I mean, Child Life's good, but it could be better"* (Trina). The inpatient hospital environment is not conducive to support healthy child development.

I acknowledge these kids are developing, but sometimes, most of the time, I don't have time to help them out that way and I always, I feel really sad when my baby doesn't have an active routine and that because I'm not part of it. I find it challenging when I see babies have to lay in their crib or go crib to swing, crib to swing, crib to swing. That's challenging. Or when they're popped in front of a TV. I find that hard. But sometimes you just need that kind of respite so that you can take care of the other ones down the hall.
(Rachel)

Inpatient Units: Characterised by High Acuity

While children being cared for in the hospital setting have always been sick, the acuity is increasingly high and continues to rise: *“The acuity, I would say is 300% heavier than when I started. The kids are 300% sicker”* (Lily). It might seem like an obvious statement that children who are admitted to an acute care facility are acutely ill and even with a cursory understanding that children are getting sicker would be logical based on our “[a]we-inspiring medical technology” (Illich, 1976, p. 13) that can be utilized to sustain life in ways that were inconceivable only a few years ago. The language of “high acuity” is somewhat opaque and does not readily reveal what the experience of it is like out on the unit. Gadamer wrote that, without context, language has no meaning (Gadamer, 1960/2006). Therefore, instead of simply saying that the children are acutely ill and the unit experiences a high level of acuity, I will illustrate the context to enliven what is meant by the language of “acute.”

Nurses who work on inpatient pediatric acute care units care for children with a wide range of conditions. Patients can be healthy children with transient illnesses (e.g., pneumonia), children with chronic, but treatable conditions (e.g., asthma), and children with a PLSI. Increasingly, there are fewer children admitted with only a brief acute issue (e.g., meningitis, pneumonia, gastro-intestinal infection). This has been a shift over the past decade. Children admitted to an inpatient unit have always been sick, but it is becoming rarer for nurses on the unit to have within their care a healthy child with a transitory, curable illness:

We sometimes have babies who are rule-out-sepsis, here’s a healthy baby who maybe had a fever one day and had to have a septic work up and now needed to be here for 48 hours to make sure that they really are healthy even though they are really healthy and for you, you think “whoo hoo, healthy baby is an easy-breezy one.” (Sarah)

While nurses have much to gain from working with the long term patients, specifically children with PLSI, there is a relief that comes with having the opportunity to care for an otherwise healthy child. Nurses in this area spend much of their time with children who cannot be cured, or even effectively treated, to be discharged and sent home to live full and happy lives. Therefore, when one of these healthy children is admitted, it is a special and noteworthy moment.

Because of the ever-increasing acuity and rising demand for inpatient care, even those children with a PLSI can be denied a bed. This is not because the system does not want to help these children, but decisions need to be made as to how best to allocate limited health care resources. Consequently, for patients to even be admitted, they must first meet a set of criteria and prove themselves to be sick enough to be admitted. As a result, the patients who are admitted are sicker than ever.

There's certain parameters that the chronics now have to meet now in order to get in.

Well, first of all, there's no beds, second of all, the acuity is so overwhelming because it's so system-focused and our cardiac history is massive compared to when I started. [It used to be] One kid with a transplant, one kid with heart failure, now every other kid on [the unit] has that and that's if they can get in on our unit. Half the time there's no beds.
(Lily)

Additionally, children who only a few short years ago would have been admitted straight to the PICU because of their level of criticality and the need for cardiac monitors or ventilators, are now routinely being admitted to inpatient units. It is not to say that the nurses on the inpatient units are not knowledgeable and capable of caring for critically ill children, quite the opposite in fact. The problem lies with the fact that in the PICU the care is often a one-to-one nurse/patient

ratio in addition to the fact that a whole host of other resources are available right on the unit:

respiratory therapists, intensivists, advanced practice nurses, and the PICU staff nurses.

Consequently, patients who were previously cared for in a highly staffed and monitored area are now on units where the nurses are caring for two or more other patients at the same time.

Routine Interventions in Pediatric Acute Care

No matter how sophisticated our technical means of treating patient may become, we will always remain bound by the truth expressed in that old saying of medical wisdom:

“surgical intervention is only surgical intervention after all.” The validity of this saying extends far beyond the domain of surgery alone. It is important to be aware of the extent to which our civilization as a whole with its foundation in science and its myriad technical possibilities constantly tempts us to believe that we are able to do whatever we wish. (Gadamer, 1996, p. 129)

Medical intervention is another term that is common place on acute care units, but what that means is somewhat unclear outside of the context. Because the use of medical interventions play a large role in the care of children and require a great deal of energy and commitment from staff nurses, a better understanding of what is meant by this term will help to further un conceal the topic. Therefore, I will take a moment to briefly describe some of the interventions that are routinely being performed on children with PLSIs in the inpatient setting.

Airway Management

Children with PLSIs on the unit often require airway management support including oxygen by mask or nasal prongs, continuous positive airway pressure (CPAP), bilevel positive airway pressure (BiPAP), nasopharyngeal airways, or tracheostomies—both ventilated and non-

ventilated. Patients must be closely monitored as they have compromised airways, which could result in respiratory arrest.

Vascular Access

Patients usually have some type of vascular access either through an intravenous line (IV) to a peripheral vein, a central line (CVC) which is a vascular access port that is surgically inserted either into a superior vena cava, or a peripherally inserted central catheter (PICC) which is inserted through a major vessel such as the femoral vein. These sites require close monitoring and nurses are mandated to check the site every hour for IVs and every four hours for CVCs and PICCs. The fluids that are put through the IV lines include a fluid maintenance solution (e.g., 0.9% NaCl), total parenteral nutrition (TPN), narcotics, and potassium solutions. Depending on what the patient requires, there can be anywhere from one IV line to more than four. The volume of IV fluid administered to patients needs to be carefully monitored as fluid overload leads to complications such as congestive heart failure.

Feeding

If children are able to take food by mouth, either solids or formula/expressed breast milk, they require being fed anywhere from every hour to every four hours. Often patients who are infants require careful feeding with the use of a Haberman Feeder bottle nipple, paced feeding, frequent burping, or side-lying feeding. The task of feeding is often the responsibility of the bedside nurse. If the child requires tube feeding, this takes place either through a nasogastric (NG) or nasojejunal (NJ) tube or a surgically inserted gastrostomy tube (G-Tube) or gastrojejunal tube (GJ-Tube). Care needs to be taken that the NG/NJ tube is not pulled out and care to the G-Tube/GJ-Tube site is important as skin breakdown is common. Feeds can run from continuous to hourly to every few hours.

Monitors and Other Interventions

Patient rooms are equipped with oxygen saturation monitors and cardiac monitors; therefore, each patient is monitored for the oxygen concentration in their blood as well as their heart rate and cardiac functioning. Children may also have chest tubes that need to be carefully monitored as well as the dressing and insertion site. Others have ostomies and mucous fistulas and, by virtue of their tiny bodies, frequent changes to the dressings are required. Increasingly experimental treatments are used, such as “stool refeeding” where stool is collected from the ostomy bag, put into a syringe, and fed back into the mucous fistula.

Medications

Children with PLSIs often require many medications to manage their symptoms as well as manage the side effects of other medication. It is not uncommon for a patient to be on 20 or more regularly scheduled medications as well as a variety of prn medications (prn medications mean *pro re nata* medications, which are drugs to be given only when needed and not on a schedule) to aid with pain and symptom management. The medications often include benzodiazepines, narcotics, antibiotics, and immunosuppressants. In order to collect the medications, check dosages, and prepare the medications for dilution or reconstitution, nurses are required to go to one of the two medication rooms which are located in the centre of the unit and are behind locked, sound-proof doors. Nurses jokingly call the medication rooms Fort Knox. In order to prepare a large number of medications for three patients, nurses must be in the medication room for extended periods of time. However, they also have several patients who need to be closely monitored. Therefore, nurses must often run between the medication room, check on their patients, then run back to the medication room to continue preparing the dozens of medications for administration.

Expressed Breast Milk: A Controlled Substance

It is not only medications that are stored behind locked doors. In recent years, expressed breast milk (EBM) has become a highly controlled substance and requires completing more steps to access than narcotics. Nurses recognize that EBM is a bodily fluid and its handling should not be done casually. Nevertheless, the procedure to getting EBM to feed a baby requires entering a locked room, unlocking a fridge guarded with a pad lock, having another nurse double check the name on the EBM label, and sign off on it in the hospital computer system. This must be completed prior to preparing the feed either by warming it for a bottle, putting it in a syringe or feeding bag for administration through an NG/NJ or G-Tube/GJ-Tube. Interestingly, despite all the checks and controls put in place to mitigate errors for babies being administered the wrong EBM, this has not decreased the incidence of error (Zeilhofer, Frey, Zandee, & Bernet, 2009).

RSV Season

If this were not overwhelming enough, many patients require isolation to protect other patients from highly infectious diseases. This is particularly prevalent during what is often called “RSV Season,” which refers to the months when RSV (Respiratory Syncytial Virus) is prevalent in the hospital as well as the wider community. Worldwide, RSV is the most common cause of pneumonia and bronchiolitis in children less than one year of age (Centers for Disease Control & Prevention, 2010). In Canada, RSV peaks between November and April (Sampalis, 2003). RSV poses a significant risk to all children under the age of one, but is particularly threatening to children with PLSIs particularly those with chronic lung disease, congenital heart disease, immunodeficiency (congenital or acquired), cystic fibrosis, and prematurity (Ogra, 2004; Sampalis, 2003). RSV is not the only infection to severely compromise children with PLSIs. Influenza, pneumonia, and gastrointestinal infections are also frequently managed on the unit and

pose a threat to all children, particularly those children already vulnerable because of their underlying PLSI.

The standard when treating patients with communicable illnesses such as RSV, pneumonia, and influenza is to care for them using contact and droplet precautions (Alberta Health Services, 2014). Therefore, before a nurse is permitted to enter a patient's room, she is required to put on a gown, gloves, mask, and, when necessary, eye protection as well as perform hand hygiene (Alberta Health Services, 2014). This equipment must be removed prior to the nurse leaving the patient's room. In this context, with very ill patients with monitors, feeding pumps, and IV pumps alarming, as well as patients needing to be bundled, fed, or attended to in some way, a great deal of time is spent implementing precautions. This is all the more onerous when all the patients a nurse is caring for are under contact and droplet precautions.

Nurses Struggle to Fulfill Expectations

There is often a great deal of chaos associated with caring for children with PLSIs in the context of inpatient acute care often around the time of admission and post-operatively. They are often under the care of a variety of specialties and the communication is often incomplete. Consequently, when patients are admitted to an inpatient unit, it can be difficult to manage their care effectively. During my interview with Heather, she described her most recent shift on the unit, which illustrates this point:

I felt like I wasn't doing my patient [older child with a PLSI] justice because he was in a lot of pain, but we couldn't get pain meds on board because he hadn't voided and so I couldn't give that to him and then he needed a continuous pump running, like a PCA pump and it was just like a comedy of errors. I asked the unit clerk, she called the recovery room to send us a pump, then they sent a pump with no batteries, then I got

called to a STAT CT, so this patient is screaming at STAT CT because he had no pain meds on board and I felt so bad. Then we got back and got pain meds on board, then I felt better. But then he needed all these pre-op procedures, which included an NG-Tube and a foley simultaneously, so we gave him IV Ativan, which didn't work, twice. And it didn't sedate him enough and he flailed during the whole thing. Then he was so uncomfortable with the foley that we had to take it out and it got stuck on the way out. ... While the foley was stuck, he had to go to the bathroom. And I had two other patients who got assessed once each. (Heather)

It is clear from the long list of expectations nurses are required to fulfill in order for them to survive their shift, along with their patients, there is often little time for anything else. Survival is the focus and the priority. Anything that is not directly linked to the survival of the patient and nurse, like therapeutic conversations with families, playing with children, teaching student nurses, reading work-related e-mails, or supporting colleagues simply does not happen. Even being able to have meal breaks is sometimes a luxury for pediatric nurses in acute care.

Children with PLSIs: Tenants of the Landscape

Such sick kids that could die at any moment. For years, they could die at any moment.

(Jeanie)

As a group, children with PLSIs live with a wide range of diseases and health conditions. As a result, they do not fit easily into a definable category and they are difficult to capture under a single title. Children with PLSIs are precious, important, medically complex, and chronic ill as well as acutely ill. Finding the language to capture children with PLSIs in all their complexity as well as their individuality is difficult. "I would say that when speech deserts us, what this really

means is that one would like to say so much that one does not know where to begin” (Gadamer, 2007, p. 93).

In the past, the language used to capture this population of children has often focused on the limits their bodies impose on them. However, there is a great deal of life to be lived even with a life-shortening illness. Labels such as “children with life limiting illnesses” define children with PLSIs by what limits them and that should not be the case (Rallison, Limacher, & Clinton, 2006). This poem, written by the mother of a child with a PLSI who died in infancy, offers a glimpse into what might be possible, rather than limiting, for children with PLSIs:

If I Had a Voice...

If I had a voice I would tell you so many amazing things,

My family did so much with me before I gained my wings.

As soon as they brought me home we went straight to the beach,

And we often packed up our bags to spend the weekend at EACH.

This is our local Children’s Hospice and they helped look after me,

I needed extra care—some oxygen to breathe, I had a tube to feed me and I couldn’t see.

The nurses sometimes came to our house to look after me overnight,

So mum and dad could get some rest and hopefully sleep tight.

My family took me on holiday not just once but twice,

I’ve even got a picture of me with a snowman in the ice!

I entered a fancy dress competition with my brother and sister, which was fun,

We had our photo taken and were in the local paper because we won!

We did so many other things—to list them all would take too long,

But I know my family have great memories to look back on now I’m gone.

The love and care I had from everyone I shall never, ever forget,

And I hope that my short time being here will help others for a long time yet.

(Taylor, 2014, p. 15)

There is much that is possible for children with PLSIs. Nevertheless, these are often very sick children. While they will enjoy periods of relative health and stability, these periods are typically brief (Rallison & Raffin Bouchal, 2013; Steele, 2000). During periods of acute illness and medical instability, children with PLSIs are usually admitted to an inpatient unit for medical support and treatment (Himelstein et al., 2004; Steele, 2000). Often from birth, children with PLSIs are dependent on medical technology to sustain their lives. For many, from the time they are born, it is expected that they will not survive to adulthood. With surprising frequency, children with PLSIs live without a confirmed diagnosis. For the vast majority, effective treatment options are limited and the burden of those interventions is significant.

Children with PLSIs are Truly Loved

Children with PLSIs are special children. I will discuss some of the challenges that nurses face in caring for this population of children, but I do not want to give the impression that those who work with children with PLSIs do not love them in spite of the challenges.

[Child's name] has severe Cerebral Palsy and is trached and he's a spastic quad. ...he is so lucky to be in this amazing foster family where his foster mother loves this child. He's had countless back surgeries for scoliosis, coming in [to hospital] for trach care and all kinds of things. He has a light in him and he's just funny. He likes when I dance, he thinks it's funny. He likes when I bounce on his bed, he thinks it's goofy. Smiles, he giggles, it's quite amazing to see. ...he's loved, he's so truly loved. (Sarah)

Children with PLSIs are very important to their families, friends, and those privileged enough to work with them. They are deeply loved just like any other child and they play an important role in our world:

Just as rainbows show themselves after a storm, these children bring light and beauty to their families and to our world, as each moves through the rain and storm to reach out and touch their own rainbows. Their lives are an inspiration to us and a blessing to their families and all who provide palliative care. (Marston, 2014, p. 5)

Children with PLSIs are no less worthy of medical treatment and deserve to be treated with the same amount of care and due diligence as a child without a PLSI, even if the care they require is palliative in nature:

Every child should expect individualised, culturally and age appropriate palliative care as defined by the World Health Organization (WHO). Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life. (International Children's Palliative Care Network, 2008)

Furthermore, children with PLSIs are also entitled to access education and play. The International Children's Palliative Care Network has within its charter of rights: "Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities" (International Children's Palliative Care Network, 2008).

Family Centred Care: A Philosophy of Care Embedded in the Landscape of Pediatric Health Care

Family Centred Care is a big concept in pediatric health care and I think it's a real blessing considering where we came from. (Sarah)

The philosophy of care known as Family Centred Care (FCC) is an influential aspect of the landscape of pediatric acute care and heavily influences the care of children with PLSIs. This particular philosophy of care has a great deal of positive influence, but there is much that could be improved upon that warrants critique. Therefore, I devote time to this in other sections. The purpose here is simply to describe the presence of FCC in acute care pediatrics.

Philosophy of Family Centred Care

Pediatric health care, including pediatric acute care, is governed by the philosophy of FCC (Galvin et al., 2000). FCC is something that nurses are often proud of and this is particularly true of pediatric nurses: *“One of the things I most love about our approach to practice is that of Family Centred Care” (Sarah).*

The Institute for Family Centred Care defined FCC as

...an approach to the planning, delivery, and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients and families.

Family centred care applies to patients of all ages, and it may be practiced in any healthcare setting. (Institute of Family Centered Care, 2005 as cited by Shields, 2010, p. 1318)

It is also important to note that “family” is often understood to be whoever the patient says it is, so family would include not just immediate family members, but also extended family and friends (Wright & Leahey, 2000). As for the language of “centred” puts the family, as well as the

child, at the centre of the health care situation. Furthermore, it is meant to be a partnership between the health care team and the child/family (Franck & Callery, 2004).

FCC is a philosophy of care that evolved for a number of reasons including public opinion, better understanding of child development, and the introduction of antibiotics in the treatment of infectious diseases (Jolley & Shields, 2009). FCC arose after World War II at a time when health care was deeply paternalistic (Jolley & Shields, 2009). It was a time when physicians and nurses had absolute control over the health care of patients and their authority was never questioned. Change was needed as the social expectation for the treatment and care of hospitalized children was evolving (Jolley & Shields, 2009) as evidence of the serious and enduring psychological traumatization experienced by hospitalized children began to reveal itself (Robertson, 1970). Prior to this evolution, children were hospitalized with severe restrictions on parents who were in many cases denied any access to their sick child or at most were permitted to visit 30 minutes per week (Jolley & Shields, 2009). The reason for this high level of restriction grew out of the prevailing and firm behaviourist approach to the care of children in hospital in the years leading up to World War II (Jolley & Shields, 2009). Furthermore, prior to the introduction of antibiotics, the threat posed by the easy spread of infectious diseases was real and deadly (Aubuchon, 1958). There was a deeply held fear that parents, if they were to have access to their children, would spread infection (Aubuchon, 1958). In the absence of antibiotics and standard precautions against the spread of infection, the control of infection was given priority over the emotional needs of the children and families (Jolley & Shields, 2009).

Summary

The context of pediatric acute care is a challenging work environment for nurses. There are many demands put on nurses as they care for children who are very ill and require a great

deal of support and medical interventions. Children with PLSIs are a diverse group of children who lead complex lives that are full of challenges. FCC plays an influential role in how care is provided for children with PLSIs and their families. In the next section, the first of the interpretive findings chapters, I present pediatric nurses' experiences of caring for children with PLSIs in the acute care setting, children who are living and dying with uncertainty.

CHAPTER FIVE: CARING FOR CHILDREN WITH PLSIs WHO ARE LIVING AND DYING WITH UNCERTAINTY

The focus in acute care is to seek cures and treatments. Nowhere is this more notable than in pediatrics where life-shortening illnesses and death of children is difficult to accept. Children with PLSIs, for whom cure and effective treatment is not possible, live with uncertainty in their short lives and their premature deaths. Pediatric acute care nurses who work with children with PLSIs become familiar with the uncertainty that shrouds these children and learn to care for children with PLSIs at the limits of medical technology.

Living with Uncertainty: In a World that Values and Seeks Certainty

The epicness of the situation, you are encountering a family who have a child who will not survive and it's not the norm in our world. (Sarah)

Death is the great shadow that darkens every life. It is a huge mystery. Though your future is unknown and its content uncertain, one thing will certainly come: death. It is the only certain and absolutely intimate event. Yet we know so little about it. (O'Donohue, 2004, p. 214)

Death of children, as well as untreatable illnesses in childhood, is relatively rare. It is unusual to come into contact with the death of a child in our everyday lives outside of the acute care setting. As a result, the death of children is not the norm in our 21st century western society where life-prolonging technology exists and a collective death-denying mentality is alive and well:

As William Haseltine, the colorful CEO of Human Genome Sciences, put it a few years ago, “death is nothing but a series of preventable diseases” (Fisher 1999). That statement

verges on the ridiculous, but the international biomedical research agenda has targeted every known lethal disease for conquest. (Callahan, 2009, p. 107)

Therefore, children with PLSIs, who live with the prospect of an early death, exist in direct contrast with our societal beliefs about death. Children with PLSIs live with conditions for which there is no cure and possibly limited treatments to mitigate their symptoms. It is those limitations that highlight the shortcomings of our collective medical knowledge and points to our failings:

...the sayings of the Greek physician Alkmaion runs: “We human beings must die because we have not learnt to connect the end with the beginning again and this is something we can never accomplish.” This is a genuinely disturbing observation for it tells us that it is not something in particular that we lack, but rather everything.

(Gadamer, 1996, p. 97)

Another reality that western society has a difficult time with is uncertainty. We often conduct our lives as though life is certain and death is uncertain. However, it is in fact the opposite that is true as no one is given a guarantee of good health and longevity. Nevertheless, we value certainty to the point that it has us pretending there is more stability and certainty in our lives than there actually is. We are driven to fix what is not fixable, to make stable that which is not.

Children with PLSIs challenge both these societal expectations: death-denial and uncertainty. In the case of children with PLSIs, not only does their early death prove to be one of the only certainties in their lives, but also the fact that they are not wholly healthy seems to pose a challenge for our society at large. Jean Vanier, the founder of the international organization L’Arche, which is a foundation focused on supporting profoundly disabled individuals, acknowledged that those who are disabled or weak struggle to find their place in our society.

What is more, “[t]he image of the ideal human as powerful and capable disenfranchises the old, the sick, the less-abled” (Vanier, 2008, p. 45). As a result, as a society, we turn away from those individuals who are different from us and those who are sick; we turn away from those individuals who live on the margins of our society (Vanier, 2008). It seems to be human nature to “want to turn away from anything that reveals the failure, pain, sickness, and death beneath the brightly painted surface of our ordered lives” (Vanier, 2008, p. 80). Children with PLSIs disrupt this “brightly painted surface” because of their illnesses, their age, and the uncertainty with which they live. Their reality is in conflict with the certainty and predictability that we value as a society. Children with PLSIs and their families live with a great deal of uncertainty (Rallison & Raffin Bouchal, 2013). Children with PLSIs live with uncertainty around diagnosis, prognosis, and even being able to predict death (Rushton, 2005; Steele, 2000; Steele & Davies, 2006). They experience periods of relatively stable health interspersed with periods of critical illness often requiring hospitalization (Steele, 2000). Because of their complex medical conditions that leave them vulnerable (e.g., fragile airway, poorly perfused heart, short gut, increased susceptibility to infection, dependence on many medications) they live close to the line between life and death: *“for years they could die at any moment” (Jeanie)*.

As a result, children with PLSIs and their families have much to teach nurses about how to live with this uncertainty. From very early on in the life of a child with a PLSI, parents must learn to live with the uncertainty around their child’s health and impending death. Often, families do not want to make decisions for the future, but rather enjoy the time they have with their children and remain open to possibilities. Nurses, on the other hand, sometimes struggle with the uncertainty. An example of how this manifests itself in acute care is nurses’ preoccupation with the “do not resuscitate” order (DNR order). While the system has now adapted a classification to

allow for a number of levels of care, it used to be that families would be given the option to sign a form declaring that in the event that their child goes into respiratory or cardiac arrest, that no action should be taken to resuscitate the child. Often families would choose not to sign the form in order to allow the family to make their final decision about resuscitation as the moment arose—even when their child with a PLSI was being admitted to hospital for end-of-life care. Families had learned to live with uncertainty in all aspects of their child’s life and the DNR order was no exception. Nurses, on the other hand, wanted to know beyond the shadow of a doubt what they were to do in the event of a code. It was in moments like this, which could cause a great deal of conflict between families and nurses, which illustrate how families learn to live with uncertainty and sometimes nurses do not.

Caring for Children with PLSIs at the Limits of Medical Technology

“Everywhere we are confronted by limits to what we can do”

(Gadamer, 1996, p. 110)

It is undeniable that the advancement of medical science and technology has been impressive over the past century. However, the successes often overshadow the reality that medical technology continues to have serious limitations in its ability to cure many diseases. There still remains a great deal that we are unable to fix, cure, or otherwise effectively manage. Caring for children with PLSIs for which there are no cures often force nurses and other health care providers to work at the limits of the available technology to offer treatment of disease symptoms. To date, there is no cure for brain injuries; we cannot effectively reverse the consequences of significant prematurity; and we cannot change the fundamental genetic makeup of children with chromosomal anomalies. We might be able to mitigate their symptoms and pain

for a period of time, but a cure remains elusive and will remain beyond our reach for the foreseeable future.

Everywhere it is a question of finding the right balance between our technical capacities and the need for responsible actions and choices. Thus we are forced to recognize that there are limits to what we can do, limits which are taught to us by illness and death.

(Gadamer, 1996, pp. viii-ix)

Fixing the Unfixable

[We are] trying to fix children who cannot be fixed. (Heather)

Children with PLSIs point out our limitations and failures as health care professionals and make it clear what we desire to accomplish: to save lives. The reality is that regardless of the technology we implement, we are incapable of saving the lives of children with PLSIs. As a result we expend a tremendous amount of energy trying to fix that which is not fixable in order to fend off death: “The tools and techniques of modern medicine—antibiotics, vaccines, new kinds of surgeries, transplants, and, of course, machines—allowed us to skirt death, or, more accurately, delay it” (Samuel, 2013, p. xvii).

Although there is a great deal that we can hide and repress, fabricate and replace, even a doctor who is able to help patients survive critical phases of their organic life through the extraordinary means of automated and mechanical substitutes for functioning organs is still, eventually, forced to recognize the patient as an individual human being. This takes place when, finally, the doctor is confronted with the momentous decision as to when the instrumental preservation of the patient’s merely vegetative existence can, or ought to be, withdrawn. (Gadamer, 1996, p. 79)

It seems reasonable that as society members we want to fix what is broken. In this case, we as health care providers are trying to fix health problems that we lack the capacity to fix. The challenges these children face are beyond our knowledge, our technology, and our abilities. To fix means to repair. Something that is unfixable is something that is “incapable of being held in a fixed state” (Merriam-Webster Dictionary, 2015). This definition paints an image of health care providers trying to hold children with PLSI in a fixed state with interventions and treatments. This is a reasonably accurate depiction of the current reality in pediatric acute care. Nurses are trying to hold children’s various body parts together and compensate for the child’s failing body systems as best they can to keep children with PLSIs alive by addressing the failures in their anatomy and physiology. Sometimes this holding together goes beyond what is humane:

...we recently had a patient on our unit that I feel is, it’s not compatible with life and the care that I was doing for him the other day, I felt just like foolish. Because it just seemed wrong and I felt like he was a science experiment.... So I just felt that that was kind of cruel. (Rachel)

From this perspective, it would seem that the treatment of children with PLSIs is an exercise in futility. What is more, in the effort to fix, nurses move away from their role to care for patients and attention is focused on treatment: “*we’re curing for these children, we’re not caring*” (Isla). The question then becomes whether nurses and physicians are being thoughtful about the treatments they are imposing. It would seem that it is because we are living in a time where advancements in medical technology are developing and being implemented at a pace never before seen in human history. We live with a belief that all illnesses should be curable. Furthermore, we are living in a time where we believe we have (or should have) power over all

illnesses (Illich, 1976). However, nurses see first-hand the effect that relentless treatment has on the bodies and lives of children with PLSIs:

I have chronic children come back to us and I'm able to ask their parents and what kind of reaction they have and they have very, if you want, PTSD kind of reaction to the hospital. Some of them freak out when they come near the hospital and freak out with certain things and procedurally they get stressed.... So I know that it has some effect on them. So while I can rationally in the moment say that this is a life-saving measure that I'm taking, I know that on some level that I'm having a long-term effect [on that child].
(Sarah)

Nurses struggle with not only witnessing the suffering of children in their care, but they also struggle with the reality that they are actively involved in causing and extending that suffering. There were times when I entered a child's hospital room and felt as though I was attacking the critically ill child with injections, medications, and catheters. There is a burden to this. What is more, I can only imagine the effect this has on the families of the children. From what I have observed from my own nursing practice, some families struggle to know what the best thing to do for their child as they see the suffering, but they are also driven to keep their children alive:

They [the parents] know these kids are going to die but they're still thinking "Save it! Save it! Do everything! It's my baby!" (Lily)

Furthermore, it must be very difficult for families to be able to broach the topic of pulling back on interventions in the culture of pediatric acute care. *"I don't think parents can bear to say, 'Let her go'"* (Isla). It seems to be a process where it is no longer hidden that the child is actively

dying, but that families need time to let go of the interventions that they have been hanging on to, as they were essential to their child's survival:

And I don't always agree with the treatments, [child's name] was an example that was dragged out and it was heartbreaking to see her deteriorate like that. They [the family] just weren't ready to let her go and she was their princess. I have a princess. I get that. If that was my daughter, I'd probably be exactly the same because they knew she was going to die. She was not going to survive until she was 10 and they had to come around to that idea that she was going to die. (Lily)

Nevertheless, there are children with PLSIs who were treated and adequately managed in order to allow them to lead a life rich in quality: attend school, visit amusement parks, participate in family weddings, and travel with their parents and siblings. However, there is a superficiality when children with PLSIs may be functioning well outwardly with only a tracheostomy, medications, and a feeding tube, but they are not completely repaired and the strain on their small bodies from the number of surgeries, medications, and interventions may not be detectable either on the outside or even with the screening or follow-up tests available today. We are reminded of this when one of our patients dies unexpectedly. In fact, as I was writing this chapter, one of the long-term patients from the unit, who had overcome many, many obstacles, was simply suffering from a gastrointestinal infection and went into cardiac arrest and died. The shock and sadness of this reverberated through the community of nurses and health care providers who had cared for her over her eight years. As one nurse said in the carpool on the way to her funeral, "I don't understand. We had fixed her. She was one of the ones that was supposed to make it." Sadly, we cannot fully repair body parts that are beyond our medical interventions—even our limited abilities to repair have long-term physiological consequences. Children with

PLSIs lead lives that are always filled with uncertainty, but we tend to mask that reality with our medical technology and interventions, which appeases our own desires for certainty and fear of death.

Prolonging Lives

*SM: They just didn't survive [children with gastroschisis before the new treatments],
so what we're doing is actually saving lives.*

Lily: We're prolonging their lives.

Despite my preparation for undertaking this research and having considered the limits of our medical technology, I am still, on occasion, taken by the language and concept of “saving” lives. Lily rightly corrected me and reminded me that treating illnesses that we see every day, such as gastroschisis, is about prolonging lives, and not saving them. While our ability to treat and lengthen years of life in children with PLSIs, we are merely prolonging their lives. By virtue of simply treating children, we are not saving them from their inevitable early death, nor are we necessarily increasing their quality of life. To prolong something is merely “to lengthen in time” (Online Etymology Dictionary, 2015). There is no sense that prolonging is anything more than offering children with PLSIs more time. Children who are put on life-prolonging therapies are not necessarily living rich and full lives—particularly if those therapies keep them admitted to an inpatient acute care unit. The treatments are simply making their time on earth longer.

You could be keeping them alive just as little vessels. And don't get me wrong, there's still an essence, there's still a person, there's a child in there, there's a soul that's experiencing love and suffering and all that, if you really step back and came in at the end stage and you looked at the end stage and you looked at this kid with NG-tubes and everything and who is barely present...and then you think, well, really? Really? But you

have to come in to it at the end of the journey and kind of go, “Well that’s crazy!” And then, how come everyone up along didn’t go, “Well this is crazy!”? (Sarah)

It can feel like a failure when one of these children dies. In fact, it often feels like the ultimate human failure. Perhaps in some cases it is the fear of death and failure that has health care teams press on in their search for more treatments.

Sometimes health care professionals are actually saving lives: when they admit and care for children who have meningitis, septic shock, or pneumonia and treat them with IV rehydration, medications, perhaps even feeding tubes and ventilators. Interestingly enough, those same illnesses may affect children with PLSIs in which case the interventions are the same. The difference is when those interventions, meant for the short-term, become the technology of life-long dependency. Therefore, it is not the technology itself, but rather, the purpose and length of use of that technology that comes into question: “The will to mastery becomes all the more urgent the more technology threatens to slip from human control” (Heidegger, 1954, p. 5).

Wanting to “*Bring the Child Back*” to Life

Lily: We’re human. No one wants to see a child die. No one wants to let a child die.

Doesn’t matter what’s wrong with them, how broken they are. If that kid codes, it’s just human nature to try and bring the child back and...that’s what it is.

SM: I think of us in the report room talking about these kids and saying we need to let them go, but finding that they did go, it didn’t feel any better.

Lily: No. You feel worse!

Lily acknowledged that even when a child with a PLSI is dying, there is still an overwhelming urge to save the child and “*bring the child back*” to life through the use of our technology and medications. This is a conflicting space to be in, as part of the nurse knows that

the child is suffering unbearably by being alive and having so many medical interventions inflicted upon them, but the other part of the nurse is driven to keep children alive. Nurses are frequently the ones to witness the prolonged treatment of children with PLSIs, past any hope of survival (Austin et al., 2009). Nurses are caught between reality and technology and sometimes left wishing that the child with PLSI had been spared the interventions driven by the desire to cure.

...being invasive with oxygen and meds and suctioning and all that kind of stuff. Because a baby or an infant, which usually is the case, they're fighting it, they don't understand. They don't like it. It's traumatic to them and it's just, it makes it a really tough, stressful situation. (Meg)

Heroic Measures

They [physicians/surgeons] are still offering heroic measures and of course they're capable of heroic measures...they are offering unrealistic goals. (Isla)

One of the side effects of being at the cusp of new technology and having ready access to just about any intervention available, is the responsibility to offer the interventions only when it is appropriate: "Our society may have sufficient knowledge to create magic but has not achieved the wisdom to control it" (Goethe, 1797 cited by Austin, 2012, p. 31). This is not something that we do very well within our society. We are capable of sustaining life in ways that were inconceivable only a few years ago. However, what we gain in length of life we will often exchange for quality of life. Isla refers to this phenomenon as "*heroic measures*." In the context of pediatric acute care, where there is a constant search for the next treatment, the health care team along with parents, keep hoping for another intervention to address worsening symptoms or failing current treatments. Many times I have been at the bedside of a dying child with a PLSI

and witness a surgeon or specialist sweep into the patient's room to present another intervention, a new drug, or a proposed surgery to extend a child's life a little bit longer. It is difficult not to be taken by what appears to be a hero rescuing the dying child. However, these proposed interventions are never cures and are often interventions that are painful, prolong suffering, and come with a host of new complications and symptoms to manage. The person who has found the next intervention is seen to be a hero. Yet despite our culture's fascination with heroes, the heroes we have created in this part of the world are not always considered to be such a good thing: "Heroes are dangerous things. Bigger than life, highly exaggerated, and always positioned in the most favorable light, a hero is a beautiful lie" (Williams & Drew, 2012, p. 23). It is this type of hero that is the basis of the expression "*heroic measures*." It is these heroes that often play a central role in prolonging the suffering for children with PLSIs in the acute care setting. Despite this troubling reality, performing the role of this type of hero has a definite appeal for health care providers. When physicians or other health care professionals are able to find another medication or treatment to delay the death of a child with a PLSI a little longer, they feel good about it. This often gets in the way of really addressing the issue and having open and honest conversations about the limitations of the technology available, the financial cost, and the decreased quality of life for the child with PLSI as well as their family.

Perhaps in the context of caring for children with PLSIs, the need is not so much for a traditional hero where saving lives is the ultimate goal, but rather a wise hero. "The hero or heroine is by definition a 'generative' person, to use Erik Erikson's fine term, concerned about the next generation and not just himself or herself" (Rohr, 2011, p. 20). Perhaps what is needed are more heroes who are able to be thoughtful in making decisions about the care of children with PLSIs. These heroes would be aware enough to know when to act and know when to stop

because no one is able to change the course of these incurable and often untreatable diseases. No one can change the ultimate outcome. “True heroism serves the common good, or it is not really heroism at all” (Rohr, 2011, p. 20). It is also about having the wisdom and the ability to recognize and accept what we cannot change:

God, grant me the serenity to accept the things I cannot change,

The courage to change the things I can,

And the wisdom to know the difference.

(Niebuhr, 1940, p. 25)

There is a place for technology. There is a place for intervention...and then there is a place to let go. (Isla)

Isla acknowledged the value of technology. The technology at our disposal allows for health care professionals to perform miracles to sustain life and save lives. There is a time and a place to use the technology at our disposal. While technology, particularly medical technology in an inpatient unit, can simply become part of the ordinary context and begin to appear benign and neutral: “Even if in some literal sense technology is neutral, in the important sense of the way it affects human lives it is anything but neutral” (Callahan, 2003, p. 21). Furthermore, Heidegger suggested that “[e]verywhere we remain unfree and chained to technology, whether we passionately affirm or deny it. But we are delivered over to it in the worst possible way when we regard it as something neutral” (Heidegger, 1954, p. 4). What Isla also recognized is that there is a limit to our technology and a time to allow nature to take its course, to allow death to come for the child. Often nurses arrive at the point of knowing it is time for the child to die sooner than families and nurses often have to wait as families catch up. Often there is a point where it

becomes evident that the technology is no longer prolonging life, but rather it is prolonging death:

A family is more hopeful longer than a nurse. I think they [the nurses] have a better understanding of the disease process or the illness process or whatever you want to call it. But I know I tend to be more ready for change in level of care than the family is. So you know I'm ready sooner, but I know I do go along with the family and I mean as the nurse you are side-by-side with them through the illness process, right? (Meg)

There is a need to be experienced in recognizing when it is time to let go and the need to be experienced to recognize that families may need more time to get to that point as well. There can be a great deal of frustration and anger for nurses as they wait out this period where families must come to learn on their own that the technology and interventions have reached their limits. It is an opportunity for conversation with families and it takes experience, wisdom, and courage to not offer the next intervention. Instead of offering more medical technology, there are times when it is necessary and more heroic action is to simply sit with the difficulty of it—appreciating life in its original difficulty (Caputo, 1987/2000). Perhaps it is about becoming experienced and maintaining the outlook of the thoughtful hero.

Quality of Life

Quality of life is a term that gets thrown around all the time and

I don't know if we really discuss what it means. (Sarah)

It strikes me as extremely significant that in today's highly developed technical civilization it has proved necessary to invent an expression like the "quality of life", which serves only to describe what has been lost in the meantime. In fact this expression reflects a fundamental and immemorial human recognition that each of us has to "lead"

our own lives, that we must decide for ourselves how we are going to live. This is not only true for Europeans, for those whose outlook has been shaped by the scientific world-view. It is a fundamental theme that arises even where religious rites and healing knowledge still determine the care of the ill under the aegis of leading figures and social groups such as wise women or medicine men. Here we are unavoidably confronted with the question of whether the accumulation of such experience has produced practices which have proved themselves in the past and still retain their validity, even if we no longer find them reliable or understand the reasons for their effectiveness. (Gadamer, 1996, p. 104)

The concept of quality of life (QOL) is one that is prevalent in the literature. As it stands, the current definition of QOL is “individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Kuyken, 1995, p. 1403). QOL is a concept that has been well researched in the adult health population. There is even a Quality of Life Scale developed by the World Health Organization called the WHOQOL (Kuyken, 1995). However, the concept of QOL has not been well investigated for the pediatric population. This is particularly true for the population of children with PLSIs. There currently is not a way to measure or evaluate QOL for children with PLSIs systematically. Nevertheless, it is very difficult to evaluate QOL for children with PLSIs appropriately or accurately. Furthermore, acute care pediatric nurses only see children with PLSIs when they are admitted to the hospital and are critically ill. Therefore, nurses lack the perspective of what children with PLSIs are like at home with their families when they are in relatively stable health and are not being poked and prodded both day and night. Acute care nurses see the children at their worst and can make a judgment about their QOL that

is not reflective of the children's lives at home. Even so, there are many children with PLSIs who never go home or do so for only a brief period. Therefore, children with PLSIs often do not enjoy a good QOL and this causes a great deal of distress for inpatient pediatric nurses. The desire to sustain life often means there is an inevitable decrease in the QOL that children with PLSIs suffer as a result:

We forget about quality of life, you know. She's got quantity now, but what quality of life does she have now? Like that's often forgotten. It's not about what's best for her. The parents, I feel, have forgotten about what's best for her. It's about, they're giving her a length of life. They're trying to give her what's best for the life that she does have. Well, true to a point, but there is a lot of pain then that's forgotten about too. (Meg)

While nurses certainly are not the only ones talking about QOL for children with PLSIs, it would seem that nurses are well positioned to understand what life-prolonging measures entail. Nurses are aware of some of the immeasurable costs associated with lengthening lives and are left asking questions. *"We have to ask ourselves when is enough, enough? When is enough enough, right?" (Meg).*

Nurses who work in pediatric acute care often do not come in to the area with preconceived notions of quality of life being more important than the quantity of life. Participants spoke about the experience of entering the profession of nursing with the belief that life should be sustained at all costs and that they highly valued the length of life. Yet over time, they came to realize that their focus is now on the quality of life because of what they have seen in practice: *"I lean more now to the quality" (Meg).*

I always thought [before working with children with PLSIs] that if I had a child that had something terminally wrong with them that I would fight and be so maternal and

protective of this baby, but I see what these babies go through and what these families and these marriages and these other children go through, like the siblings. And that has changed how I feel. That's definitely something that has changed and something that my partner and I now disagree on. I mean, hopefully we won't come down that road, but that's changed and that makes me a bit sad that I feel that way because I thought that I would always have that compassion and that fight for a baby. (Rachel)

It is interesting that Rachel used the language of compassion to describe fighting for the life of a child with a PLSI. Often the language of compassion is used in situations where life-sustaining technology is withdrawn to allow a child (or adult) to die. An example of this would be with “compassionate extubation” when the ventilator of a child who has no hope of survival is removed in order to let the child die.

The experiences nurses have of caring for children with PLSIs who live with much suffering and the burden of painful interventions, deeply affect how nurses come to understand their own lives and how they would manage a tragedy with their own children:

I hope that if I am ever faced in this situation where I have to make the life or death call for my child, I hope that I am strong enough from what I have seen and gone through as a nurse that I have the guts to, as a mom, to let them go. Because it rips you apart! Take them off all the supports. Take them home. Snuggle them up and let them die. I just hope that if that ever is me, like a bad car accident or something, and I am faced with that, that I am strong enough to do that. I think I would. I wouldn't want them to suffer. Seeing what I've seen, it's suffering. That child has no quality of life. They're suffering, you know? (Trina)

Without many burdensome treatments, or preparing and supporting parents to manage their child's treatments at home, children with PLSIs have the possibility of going home. Being discharged home, the family can spend time, even if only a brief length of time, at home as a family and enjoy the chance to be together in a normal environment where life can go on around the child:

I think there's going to be a lot bigger population of chronically ill children in the community, which is good, because I know if it was my child I would much rather, I mean every parent would rather have them at home in a controlled environment you know for bugs and routine and everything. And we do our best on the unit to keep a routine, but it falls apart. You could have a heavy assignment with three children and this one chronic child has been their six, nine months like there is one now, who's a respiratory kid and sometimes routines fall apart because your other patients fall apart. They code, they need to be discharged and you have a new admit, it's two o'clock and he needs his nap and you're in the middle of a code, that ain't gonna happen, right? But if he was at home, she [the mom] would be like, "Okay, I can put him down for a nap." No one is going to wake him up, no one is going to go in and poke and prod him. I would much rather, much rather have him at home rather than in the hospital. (Lily)

Participants described the importance of discharging patients home and seem to believe that children do better at home. Whether or not this is verifiably true is beyond the scope of this topic. It is interesting though that acute care nurses in this area believe that children have better outcomes when they are out of the hospital and at home with their families. Pediatric nurses acknowledge that having a sick child at home is difficult, but believe that it is healthier for everyone involved to have the child at home in a normal environment rather than in the

institutional environment of the hospital. It is important to remember that the participants for this study were acute care pediatric nurses; therefore, their horizon of understanding the experience of children with PLSIs is limited to the acute care setting and their perceptions of the benefits of having families care for their children with PLSIs at home are not from the vantage point of a pediatric home care nurse. Where the child is located does not change the outcome, but a short life lived at home may be more worth living than a longer life in the hospital. One family I worked with chose to undertake minimal interventions and took their daughter home with portable oxygen and NG feeds. The child lived only a few weeks, but at her funeral the family posted up beautiful photographs of her with her two older siblings posing along the banks of a mountain river, eating ice cream at a local shop, at a petting zoo, and even on a speed boat. This is a life lived. If she had remained in the hospital, her life may have been longer, but not necessarily as interventions can lead to other problems including nosocomial infections. Regardless, had she lived out her life in the hospital, it would not have been as rich. I imagine that her two siblings who were aged two and four at the time will have far better memories of their sister's short life than they would had she remained admitted to the unit and lived out her life confined to a hospital bed.

I think it was hard for me to watch other families, parents go through what they're going through [with sick children living out their lives in the hospital] and I feel like...like they're in jail. (Trina)

As the concept and practice philosophy of FCC was emerging, one of the arguments against involving parents in the care of their hospitalized children was that it was believed that “a mother would rather be home caring for her other children than sitting at the side of the bed of a child who would, under normal circumstances, not spend much time with her” (Shields, 2010, p.

2630). These mothers were referred to as “captive mothers” (Meadow, 1969). Interestingly this is what nurses begin to see on the unit when a child with a PLSI has been admitted to the unit for an extended period of time. What is more, it is not only mothers held captive at the bedside, but entire families:

I feel so much empathy for these families, you know, especially when they [the hospitalized child] have siblings and the siblings are at the hospital every day. I feel there's no way my kids would tolerate that, so how their kids do, tolerate playing at the hospital every day, all day, and you know, this family whose baby just turned one, their daughter's been doing it, she's just turned four, so she's been doing it that whole year—from three to four, that's a hard year for children. So to ask your child to be like, you know, contained. Maybe that's why she [the four year old sibling] is obsessed with Frozen [the children's movie], so she'll sit there and watch Frozen over and over.
(Heather)

Heather described a family who found themselves having to manage a sick child in the hospital, but also care for their toddler. It is evident in this example how families are impacted by having their sick child admitted to the hospital for months and years.

Quality versus Quantity

While the conversation is not simply two sided as many factors come into play, participants talked about the debate as often simply a question of quality versus quantity. Quality being defined as “how good or bad something is; level of value or excellence” (Merriam-Webster Dictionary, 2015). On the other hand, quantity: “an amount or number of something” (Merriam-Webster Dictionary, 2015). We can certainly quantify a child's life by counting the number of days, weeks, months, or years a child lives, but that approach severely limits one's

ability to describe a life well lived. As a society, we have a difficult time understanding or valuing what we cannot quantify. This begs the question: How do you measure a good life?

We're doing a lot more intervention, you know. I don't know if it's always where the child is the focus. If it's in the best interest of the child, like I said, they're getting more quantity, but I'm not sure that they're getting always the best quality of life. (Meg)

As a society, we seem to be challenged by the disabled and the sick. We have a difficult time learning to accept this reality. As a society, we have much to learn from those who live on the margins, for instance children with PLSIs in their less than perfect bodies and their families who come to learn how to live with the uncertainty of it all.

The excluded, I believe, live certain values that we all need to discover and to live ourselves before we can become truly human. It is not just a question of performing good deeds for those who are excluded but of being open and vulnerable to them in order to receive the life that they can offer; it is to become their friends. If we start to include the disadvantaged in our lives and enter into heartfelt relationships with them, they will change things in us. They will call us to be people of mutual trust, to take time to listen and be with each other. They will call us out from our individualism and need for power into belonging to each other and being open to others. They will break down the prejudices and protective walls that gave rise to exclusion in the first place. They will then start to affect our human organizations, revealing new ways of being and walking together. (Vanier, 2008, p. 84)

Learning to Live with the Unpredictability of Death

Nurses who work and care for children with PLSIs often struggle with the unpredictability of death. Children who everyone thought would survive did not and vice versa.

The belief in medical science to not only save and prolong lives, but also predict time of death, is powerful. It is difficult and painful when a patient who was expected to survive dies. There is also something distressing about a child who is expected to die and lives. I have cared for patients who were on life support and the family was prepared for the child to die following the withdrawal of life-sustaining ventilators only to have the child survive, although remain highly compromised and vulnerable.

I had also come around to the fact that it's not within my control whether a child lives or dies. Because I've thought that there's been a lot of children that I thought should have died, but they made it. Like they survived! (Isla)

Yet what is equally surprising, and far more distressing, happens when we come to believe that we had “fixed” a child, then to have the child die. Children who overcome many obstacles and challenges related to their PLSI, and then die from something unrelated to their underlying condition, is not uncommon, but is devastating. *“I can accept that when their time is up [and the child dies from their PLSIs] that, you know, this child succumbing to a septic event after all she's gone through was so ultimately tragic” (Sarah).*

As medical professionals, we really have very little control over death, despite our hopes and perceptions. Our beliefs are constantly being challenged around the expected death of children with a PLSI and yet the unexpected timing of death for children with PLSIs in our care.

Death of children within the larger society is considered to be unnatural and against the natural order of life (Jones & Weisenfluh, 2003; Rushton, 2005). However, like it or not, death is part of life and children are not exempt from this rule as much as we would like them to be. Just because we believe that only the very old should die, this is not our reality, nor has it ever been.

Landscape means “natural scene” (Merriam-Webster Dictionary, 2015) and death is part of that natural scene in pediatric acute care where children with PLSIs are cared for:

And when people would ask me, “How did you do that?” I don’t know. You just did it. I liked it. I always thought, somebody has to do it. Might as well be me because I actually liked it. I like doing it. I’m not afraid of that [death]. You had to not be afraid of that.

(Jeanie)

As a result of nurses spending so much time with death and dying in the acute care setting, nurses have become increasingly comfortable talking about life and death of children with PLSIs. Nurses are not afraid of it and can talk about it. They do not hide from conversations about life, dying, and death with parents, families, and colleagues. Despite this, nurses work within a larger culture that cannot accept the fact that children die: “in a society where we have come to see longevity as our right, the death of a child is experienced as outrageous” (Maunder, 2006, p. 27). As a result, nurses often experience a disconnect between what they experience in their work life and what they experience in their lives at home and in the communities where they live every day.

Pediatric Nurses: Acquainted with Death

[For families] to experience it [the dying process] with people who are comfortable with it, they’re not afraid of it, they’re not afraid to talk about it or talk to them about it. And at the same time, remaining present enough to be aware of the fact that it is quite sacred.

(Sarah)

Pediatric nurses working on inpatient units experience the death of patients as part of the landscape of their work and, as a result, become experienced with it. Nurses develop a level of comfort with death and are able to talk about death and manage the symptoms of the dying

process as they journey alongside children with PLSIs and their families. However, nurses are far more comfortable talking amongst themselves about death rather than sharing their views with administrators. It would be misleading to say that nurses are comfortable and at ease with death in the sense that they would want to hasten a child's death or would wish for a child to die. Rather, nurses develop a familiarity with death through caring for many sick and dying children over months and years. Becoming experienced, and learning one's way around situations involving death and dying, makes it possible for nurses to continue the important and difficult work that they do.

While nurses may become familiar with dying, it is also still important for nurses to maintain respect to the sacredness of the events leading up to death as well as the death itself to avoid the routine of the process to overtake the experience: *"remaining present enough to be aware of the fact that it is quite sacred"* (Sarah). Participants used the word "sacred" to describe the work they do with children with PLSIs and their families: *"I'm in a line of work that lets me deal with real life in this way and you know, birth and death are universal...they are sacred events. They are sacred events..."* (Sarah). The language of sacred is traditionally associated with religion. However, in this context, participants did not appear to intend to call forward the formal religious connotations connected with the word sacred. Rather participants used the word sacred as a way of honouring the process of dying where the language of sacredness "connects us effortlessly to all living beings. It lets us discover what is most treasured and transformative in human existence" (Dowrick, 2010, p. 3). It would seem that the use of the word "sacred" intended the sense that "the sacred is a *certain type of relationship that humans entertain with the origin of things*" (Godelier, 1999, p. 171). Nurses who are experienced in this area seem to be able to hold the mystery of death, while at the same time being familiar with the process.

...and they would die. And so that was very familiar. I think we had done, we actually did a survey and we had 26 kids, 26 children die in a year or less. (Isla)

To be “familiar is defined existentially as that which brings us feelings of comfort and security” (Rees, 2003, p. 3). Nurses in this area become familiar and acquainted with death, yet because of the mysterious and unpredictable nature of death, nurses are never in a position to fully understand it. In certain circumstances, for instance when there has been a great deal of suffering for the child, the word “friendly” to describe nurses’ feelings about death might be somewhat appropriate. One can be familiar with something without necessarily liking it.

This familiarity and comfort nurses grow to have with death and dying makes them aware of some of their limitations. Nurses cannot take away a family’s pain of losing a child and they are well aware of that. Nevertheless, they are often prepared to be present with the family and support them as they face the dying and death of their child. Nurses are prepared to help families as they hold the significance of the time of death:

You hug someone because that’s the only way you can and you know that maybe your presence or maybe your kindness or maybe your love for that child means something, but you cannot take away any of that burden of that family and you know you can’t, so you don’t, you know, it’s not like you’re the hamster in the wheel trying to find the way, you just know it. And that’s sad. That’s really sad. And you just have to be with that sadness. You just, you either ignore it and pretend it doesn’t exist or you acknowledge it.... Right? Like, I’m so sad. And I’m so sad seeing your pain. (crying) And I don’t like to see a human being in pain. And I can’t fix that, but I can be with you for it and I hope you know that I’m with you for it. (Sarah)

Nurses are often sad when a child dies and they are hurt having to face the loss of a child. Even though nurses are acquainted with death, nurses may still feel deep pain by the death of a child and experience deep sadness:

Life is about family and your relationships and love and...so, I felt pain from some of those, I felt loss for some of those kids (crying). You know, it's funny, because you see all their little faces (crying)... I've certainly felt loss from some of those children that I think, oh the world is a better place with those beautiful little spirits, but that's life. You know, in life, death happens and it's sadder when it's child and that pain is part of life. And being open to life means you're open to pain. (Sarah)

In the moments leading up to a child's death, it is not only nursing skills that are called for, but also the support nurses can offer as a fellow human being. Nurses cannot fix the situation or alter the outcome when death is imminent, but nurses can remain present with the family. It takes a great deal of courage to be fully present at these difficult and momentous times.

The two greatest liminal experiences, of course, are birth and death. We can't understand such events except through experience. Many people try not to experience them. We use denial or drugs to prevent us from really experiencing what is happening. (Rohr, 2003, pp. 48-49)

Summoning the courage to be present at the time of a child's death and even in the dying process can be very painful. Being fully present to support families as their child dies can be one of the most painful experiences to witness. The deaths of children with PLSIs in the context of pediatric acute care are not usually a quiet and peaceful event with family and supportive health care providers present. Often the timing of death for children with PLSIs is difficult to predict (Steele, 2000). Therefore, children who are believed to be dying and requiring end-of-life care may be

admitted for months where they slip between stabilizing health and worsening symptoms, but are eventually discharged home as they did not die. These experiences are often puzzling to nurses and other health care professionals. Just as puzzling, but often far more distressing, are children who are admitted for a seemingly routine cause, such as a feeding issue, and die unexpectedly within hours in the midst of a full code. In this situation, the death is sudden, unexpected, and traumatic where the nurse is often left to hide her distress and expected to carry on with a heavy work load.

The death of children in the chaotic environment of acute care, even if the death is not sudden and traumatic, often prevent nurses from being fully present and caring for the child and family in the moments leading up to death. It can become a blur of stress as many demands are put upon the nurse as she is responsible for the care of multiple patients and not just the one who is dying:

I vividly remember a shift when I was assigned three patients: two with treatable illnesses (one with a urinary tract infection and the other recovering from a tonsillectomy and adenoidectomy) and one who was actively dying. I badly wanted to be available to the dying child and her family in those last precious moments. I wanted to have the time to try to make those moments count. Yet because of my obligations to the other two children and their families, I kept being called away by those other responsibilities and compelled to respond to the demands imposed upon me. In comparison to the needs of the dying child, the demands of the other families seemed trivial. One father yelled at me for being 10 minutes late giving his son Tylenol. Because of our duty to protect the privacy of others, I could not tell him why I was late. I could not tell him that I was

making hand and foot prints of a dying child. (McConnell, Moules, McCaffrey, & Raffin Bouchal, 2012, p. 6)

The times when nurses are able to be present with the child and family as a child is dying, at a time where the nurse is not trying to juggle the needs of multiple patients, nurses can find that their presence is a gift they can offer the child and family.

You bearing witness requires strength, you're such a great person for doing it; you're, you're, that's the help you can give. That's the gift you can give is to be present; to witness what's happening to them and see that this is sad, that this is loss, but I'm here holding your hand (crying). (Sarah)

In the moments when a child is dying, there is often a sense of obligation to remain at the bedside and witness the noteworthy event.

Etymologically, the word “witness” is related to the word “martyr” (Online Etymological Dictionary, 2012) meaning someone who constantly suffers (Merriam-Webster, 2012). In the current vernacular, being a martyr is not considered to be a particularly good thing; however, if we consider its use as someone who suffers with others, the term is particularly appropriate. (McConnell et al., 2012, p. 4)

Sarah referred to her role as being a witness, as someone who bears witness to the illness and death of a child with a PLSI.

The meaning of “to bear” is particularly appropriate in the context of supporting the dying and the bereaved: “to support a weight or strain” and, with this meaning, it is a synonym for “to suffer.” It would seem that suffering is a fundamental part of bearing witness as both words are linked to the word suffer. Furthermore, the word “bearer” has the historical meaning of “one who helps carry a corpse to the grave” (Online

Etymological Dictionary, 2012). Nurses usually do not literally carry a corpse to a grave. Nevertheless, I do think the work of nurses, and others who work with the dying, carry the patient and family through the experience by way of the care and presence we provide in times of suffering and grief. Interestingly enough, if I take the word “bear” yet one step further and examine the homophone “bare” it further enriches the meaning of bearing witness. “Bare” means “lacking appropriate covering” with synonyms such as “to uncover, to reveal, to expose, to uncloak” (Merriam-Webster, 2012). Not only is “bearing witness” the idea of authenticating suffering, but also revealing the suffering through our presence. I have been a witness to dying and grief, but found I had neither words of consolation nor gestures of comfort. I could simply bear witness—to be present, to carry, to authenticate, and to suffer. (McConnell et al., 2012, p. 4)

The Routine of Death and Dying

Look, let's be very, very honest. Sometimes the day-to-day, I don't know if it's the most challenging...you know what? Some days it's boring. Some days just physically doing care is very boring. (Sarah)

The day-to-day process of the slow dying of children with PLSIs has a certain routine to it. The routine of doing the physical care can be mundane and, as Sarah said, boring. The routine of the work, despite it involving dying, can be slow and tedious. Routine is “a regular way of doing things in a particular order; a boring state or situation in which things are always done the same way; a regular course of procedure” (Merriam-Webster Dictionary, 2015). As with any large institution, rules, policies, and routines must be followed throughout the course of the day.

...then there's the day in, day out where the child is not dying in this particular moment, so there's got to be a breakfast, lunch, and dinner, mundane moments within that because you just can't stay in a hyper state of being aware all the time. (Sarah)

On the unit, there are set times for nurse handover, emergency bedside checks, assessments, medications, coffee breaks, calculating ins and outs, changing over TPN lines, and charting. There are days when this routine feels like a mindless repetition of steps. Even when the unit is chaotic, the same tasks need to be completed and checked off the list. Children slowly die as these routine-filled days pass, but it appears to be just another day; and it is just another day in the context with a child with a PLSI: *"Sometimes it can be, just like a regular, I mean how can you say that it's regular?" (Meg)*. Even as Meg honestly described the work as "regular," she was aware of how insensitive, even callous, that may have sounded. Nevertheless, the experience of caring for a dying child becomes regular through it "happening over and over again at the same time or in the same way" (Merriam-Webster Dictionary, 2015). Pediatric nurses do not think that the life of a child is regular or routine and they recognize the individuality of each child. However, it would seem that when nurses spend their days amidst the life and death of children, there is some sense of repetition: *"It was life and death over and over and over" (Jeanie)*.

Becoming accustomed to death and dying of children with PLSIs on the unit does not happen overnight. It takes some time to acclimatize to the culture of the unit and learn that despite our wider societal and cultural beliefs and expectations around when people should die, working with this population in the context of acute care can transform our previously held beliefs and expectations completely.

When you saw how sick this baby was, you realized that this baby was going to die, it's a bit of a shock to the system to initially see that, then after some time you kind of get used to it. In a strange way. It sounds horrible! (Jeanie)

Gadamer (1960/2006) believed that those who are awake and alert to the lifeworld are capable of becoming experienced in it. It is through having seen death before that nurses can develop a level of comfort in caring for sick and dying babies and children with PLSIs. This is not the sort of knowledge that can be presented in a classroom or training session, it is the sort of knowledge that comes with being practiced. This cannot be taught to student nurses or newly graduated nurses, it must be gained through experience and practice (Gadamer, 1960/2006) as “experience as a whole is not something anyone can be spared” (Gadamer, 1960/2006, p. 350).

The expression “get used to it” that Jeanie used means to “accept that a particular state of affairs is inevitable” which originated in the early 1990s in USA meaning “that’s how things are; accept it” (The Phrase Finder, 2015). It is necessary for nurses to “get used to” and accept the realities of illness and death of children that occur on the unit. It is necessary for nurses to be able to accept that incurable and untreatable illnesses and eventual death of children with PLSIs are an inevitable part of the work of pediatric nurses in the inpatient acute care setting. The turnover of nursing staff on the unit is high and it is perhaps the acuity and intensity of the unit, combined with the death and dying, that drive some nurses away from working on the unit. Perhaps the nurses who leave are not able to “become experienced” in the way that is required of them to survive and thrive in the environment of pediatric acute care.

The truth of experience always implies an orientation toward new experience. “being experienced” does not consist in the fact that someone already knows everything and knows better than anyone else. Rather, the experienced person proves to be, on the

contrary, someone who...because of the many experiences he has had and the knowledge he has drawn from them, is particularly well equipped to have new experiences and to learn from them. ...experience has its proper fulfillment not in definitive knowledge but in the openness to experience that is made possible by experience itself. (Gadamer, 1960/2006, p. 350)

The nurses who become experienced are the ones who stay and learn these difficult lessons by acquiring the experience that allows them to be present with children and families in times of illness and death. Nurses must learn when it is appropriate for them to act and when the moment calls for them to stop and simply be present with a child and family. Regrettably, some nurses are simply not able to become experienced in that way and must move on to other areas of nursing or even other careers. Once a nurse has learned to be experienced, despite the challenges, for many there is something special about the work with children with PLSIs that draws nurses to continue the work:

Like [name of a nurse with 27 years of experience on the unit] did try [to leave the unit] and went to [name of a public health clinic] and came back. Yes, there's something kind of keeps you [working on the unit]. (Isla)

In becoming accustomed to death as part of the landscape of nurses' work there is the risk of death becoming normal: "usual or ordinary" (Merriam-Webster Dictionary, 2015). The word normal takes "on any number of right-minded connotations denoting the regular, standard, usual, routine, typical, average, run-of-the-mill, expected, habitual, universal, common, conforming, conventional, correct, or customary" (Frances, 2013, p. 4). Life is extraordinary and the end-of-life is sacred—"birth and death...are sacred events" (Sarah)—and not usual, routine, or unremarkable.

I think there's a real risk to it becoming...normal. If that makes sense, right? I don't want to say banal or any of that, but it becomes normal which is just a bit of a risk and I think when it's normal is when you're not paying attention to what's actually happening and we often just get wrapped up in the tasks of our day. I think in that situation we can often get wrapped up in the task of what we're doing. We have meds to give or a dressing to change or you know, I've only got so much time to do it in and we're ticking boxes and there's other kids, until you are confronted, generally by either an event that's upsetting or an interaction that reminds you that you're dealing with a family who is going through a pretty unbelievable journey. I think it's a challenge as a bedside nurse to remain present enough to be aware of what you're dealing with and you're dealing with a family who are loving a child that won't be with them forever. (Sarah)

There is a tension for nurses between acknowledging and holding the sacredness of the death and dying of children along with the taken-for-grantedness of death in the landscape in which they work. There is some safety in understanding death as normal and nurses may come to function as though things are normal as a way to protect themselves from something very difficult. Nevertheless, when nurses succumb to the belief that dying is normal, often it takes the arrival of the unexpected to encourage nurses to remember the importance of their work with children with PLSIs and their families. "Things that change force themselves on our attention far more than those that remain the same" (Gadamer, 1960/2006, p. xxii).

The normal routine of caring for children with PLSIs should not dismiss the preciousness of the life of a child or allow a child's life to go unacknowledged for the specialness that it holds. The work of the everyday is very consuming and it can be difficult to remember that the life of a child, even a sick child, is not just about the tasks of care: medications, assessments, and

treatments. Their lives are special and the tasks are part of their care, but it is not all of it. There is a risk that nurses' hearts will be eroded as will the importance of the work they do if children with PLSIs become only the tasks of physical care.

It was such an interesting experience [working on the unit] because you learned a lot and learned a lot about the sick babies. You learned a lot about just life. Dealing with different things. And I think you learn that even in these horrible situation where the babies die, you still carry on.... You just carry on. And do it again. (Jeanie)

The expression "carry on" holds within it the meaning of persevering and continuing without rest (The Free Dictionary, 2015). This is what pediatric nurses in acute care do. They care for dying babies and children and they carry the weight and burden of that work and then they do it again with the next child.

Death as an Option

We don't really, I think enough offer the family the opportunity to accept death and if not embrace it, accept it, and walk that journey as peacefully and as beautifully as possible. And death isn't always beautiful. You know that, right? It's ugly in the last few minutes often and, but the journey, should it be a million surgeries and holes and tubes and drama and fighting and I wonder if we discuss death as an option and not a decision. (Sarah)

Families often choose extreme measures to prolong their child's life and for understandable reasons. However, for nurses, they have been hurt by past experience and as a group they are closely involved with the death and dying process, a process that can be slow and painful with much suffering if interventions are used to prolong their lives beyond a certain point. So, for them "death does not appear to be such a bad option" (Mekechuk, 2006, p. 4). The

word “option” does have the meaning of choice, but it also holds the meaning of “possibility” (Merriam-Webster Dictionary, 2015). To tell parents that they could choose for their child to die is not helpful or kind. No parent is comfortable making the unspeakable choice between life and death for their child with a PLSI. However, to approach the situation not as a definitive choice, but rather as a possibility, is perhaps a better approach. The outcome remains the same: the child will die before adulthood, but the possibility of how that journey might look is not fixed. How the journey unfolds is not planned out in a one-time conversation between the health care team and the family. Rather it should be an on-going conversation among the team members who are in a trusting relationship with the family where the options are presented and not just the heroics.

...he should have died [during the neonatal period]. He was very fragile and he coded several times. Finally she [his mom] took him home and said, “Okay, this is enough. If you can’t make him better and give him a quality of life, then I’m going to take him home to die.” So she did. She was an RT [respiratory therapist] so she slept beside him, slept beside his bed and saved his life a few times, but then his G-Tube got messed up, so they took it out. ...he was four when the worst things happened, and she [mom] said to him, “Okay, little one, if you don’t eat, like you have to eat if you’re going to live.” Now he wouldn’t understand the concept, but she just plugged away and she gave him a quality of life. ...nobody expected that he should live, but at least they took him home and gave him a quality of life. (Isla)

Many children with PLSIs who spend extended periods of time on inpatient units suffer as they receive many interventions to sustain their lives including chest tubes, injections, suctioning, frequent blood work, and TPN. There are many times when they are clearly suffering

and are undergoing interventions that extend their lives, but to a point where they are in terrible pain and discomfort.

...we have trached him, we've vented him, we've cathed him, we've treated every illness he's had. If he breaks a bone, we're going to cast those. You've done everything and the kid is in a wheelchair and hurting probably like there's no hurt. Number 10 is non-existent to him. It's probably 20, you know, but he can't communicate so we just keep going on with life. But do you think he's happy? Unlikely. (Trina)

It is at this point that, death “is no longer always an undesired choice in life. Some deaths are viewed as a release for the child from physical or emotional suffering and a release for the family from the emotional pain of watching their child die” (Rashotte, 2005, p. 37). Nurses struggle with seeing a child suffering and can sometimes feel thankful when the child has died as they see that death has put an end to unbearable suffering:

...it's pretty sad when you hear that a child has died and you're like, “Thank you!” And that's not nice, but that's kind of how I was feeling. ...it's like [patient's name], when he died, I was like, “Good for you. Good for you. You're now an angel.” Even [another patient's name]. That poor kid! Poked so many times. You know. When I heard he finally passed, I was like, “Good for you buddy.” You know? (Trina)

Talking about Death: “Let the Baby Go”

*I really believe in end-of-life comfort is when people are ready to die,
we let them die. (Isla)*

Behind closed doors, nurses frequently engage in conversations about families who need to allow their children to die, to “let them go” as the child’s pain and suffering are tremendously burdensome. The meaning “to let somebody go” is to “to stop holding someone” (The Free

Dictionary, 2015). It is heartbreaking to think of parents no longer being able to hold their baby or child in their arms. I have felt deep sorrow watching parents leave the unit with their child's belongings after the child has died: an empty car seat or a wheelchair without its usual occupant, a suitcase of clothes their child will never wear, and toys that will never be played with.

The meaning of holding is also extended to holding on to a child who is ready to die: "We were keeping her alive until her brother left for vacation. And I had to bag her for an hour to keep her alive...It tore me apart... This poor patient was trying to die and we weren't letting her" (Montagnino & Ethier, 2007, p. 443). Conversations among nurses happen freely and frequently behind closed doors on the topic of allowing children, who are trying to die, to do so. On occasion, nurses will broach this topic with families. Sometimes this is welcomed:

She [physician] went to the family and said, "Listen. There's nothing. She's just going to keep getting sicker and suffering." She was the one that initiated that and the family was like, "What? Really? This is an option? [to allow the child die]" They didn't even know it was an option to let her go, right? So I don't think that families actually know. Some maybe do, but some don't you know and the doctors don't say, "It's okay. We can let her go." (Trina)

In spite of this, what happens with increased frequency is that nurses fear repercussions from trying to introduce the topic of dying and death with parents. Nurses are experienced and comfortable in talking with each other about the need to let children die when pain and suffering outweigh quality of life. Unfortunately, nurses often feel apprehensive broaching the subject with parents. Nurses are equipped to navigate the highly sensitive and emotionally charged topic through their undergraduate education and through ongoing clinically relevant training.

Therefore, it is not from lack of preparation that leaves nurses feeling reluctant to engage parents

in these conversations. Rather, the discomfort and reluctance stem from concerns over repercussions. Therefore, ongoing and open conversations between nursing staff and administration is essential. Isla described how a conversation she had with a family resulted in her being reprimanded:

Isla: It was at Christmastime, just a few weeks, she died a few weeks later, I went up to the mother and I said, "You know, it's okay to let her go." I just did it spontaneously. She [the child] was getting worse and...so I said, "It's okay to let her go. You've done everything you could, she's had a wonderful life, she's lucky to have had you. But I think it's okay to let her go..." And did I ever get in trouble for that one! Whoa! I got called in and the doctors were in a flurry because they wouldn't say that! They wouldn't say it!

SM: What was it that upset them? That you broached it?

Isla: Just having the audacity I think to say that it's not your right to tell, to say this. But it felt right to me! At the time. It was giving permission where, because I don't think parents can bear to say, "Let her go." And the doctors never do. I mean they just sit on the fence something terrible. Anyway, I did it and [the unit's administrator] called me in...and everybody was all upset, but I think it was the catalyst that allowed the next stage to happen.

While it is uncertain how often this negative response from families and administrators happens, the culture is now such that nurses are increasingly shying away from talking about death with families or even with the larger health care team. The wider social culture of fear of death, particularly death of children is perhaps making a larger impact on what is happening inside the walls of the hospital. It may also be attributed to our ever-expanding knowledge of medical interventions and technology that is causing it to become increasingly difficult to talk

about death when there are ever more interventions becoming available. So while it would seem that nurses are prepared to have this conversation, even though it is difficult, it is becoming more complicated for nurses to do so without jeopardizing their employment. The fact that bedside nurses have the most contact with children with PLSIs and their families during hospital admissions (Malloy et al., 2006; Rushton, 2005) positions nurses to engage families in conversations about dying. Nevertheless, for whatever the reason, the context and culture of acute care does not always support these sorts of conversations. In the context of inpatient acute care at this particular hospital, there is no forum for nurses to raise these concerns with the larger health care team. Perhaps the opportunity for nurses to have open and honest conversations with physicians and administrators on this topic would ultimately benefit children with PLSIs and their families.

It is important to keep in mind that nurses do not want to see children die: *“I don’t want to see that. I don’t want this child to die even though he’s in a wheelchair or whatever” (Lily)*. Nurses love these children. They do not want them to die, but nurses struggle seeing children with PLSIs suffer. Nurses want to give parents the information and present the possibilities and options for the life the children do have, knowing the outcome of death is not going to change.

Nurses: Insiders and Outsiders of Death

In *Truth and Method* Gadamer argues that “hermeneutic work is based on a polarity of familiarity with strangeness” (TM, 295) and that “the true locus of hermeneutics is this in-between.” Gadamer has a clear sense of the poignancy of the notion of distance for hermeneutic consciousness. After having stated that the true locus of hermeneutics is “this in-between” he implies that in-betweenness is a fundamental condition of

hermeneutic consciousness. *The true locus of hermeneutics is this in-between.* (Davey, 2006, p. 237)

One of the things that drew me to the philosophy of hermeneutics is the space allowed for me to stand, as the researcher, in the in-between and look at this complex issue within its natural context. As a society, we seem to think in dualities: good/bad, life/death, insider/outsider, healthy/sick (Bourgeault, 2013). The reality is that in this context where life and death roll along side-by-side, nurses find themselves living in the in-between where they are privy to insider knowledge of what it is like to care for a dying child. Yet at the same time, most nurses are outsiders for they themselves have not parented a dying child. Nurses on the unit seem to find themselves in an in-between position where they have to navigate between their knowledge of being both insiders and outsiders to the death and dying of children with PLSIs. This in-between space is a place of knowledge, mystery, and experience. Nurses walk the journey so often that they come to know how things might turn out for the next child. Yet nurses do not know what it is like, first hand, to have a child die: *“we cannot imagine the horror of knowing your child won’t survive” (Sarah).*

Nurses are aware that they do not know what it is like for parents as most nurses have not been the parent of a child who has died of a PLSI. Nevertheless, nurses are still expected to walk alongside families, helping with navigation. Nurses have walked this terrain before and they are familiar with the landscape. In this situation, nurses play a dual role when a child with a PLSI is dying: nurses are insiders who are able to offer information and guidance, but at the same time nurses are outsiders who need to listen to what the families need as they experience the death of their child. An experienced nurse is able to slip between these roles when needed. She is able to offer advice and guidance based upon past experience with dying children, but knowing what

this particular child and their family needs, she must remain open and aware of her role as the outsider. Nurses seem to need to learn how to be agile and know which role is expected or needed of them at any given time.

Bane

Full of strength and laced

with fragility:

the thoroughbred,

the hummingbird,

and all things

cursed

with agility.

(Videlock, 2013, p. 442)

Nurses have knowledge of the terrain, they have been along there before, but they have never been the one carrying the heaviest load, the one with the most investment, or the one who has the most to lose by having to walk this path.

Outsider

But they loved her. They wanted the best for her. They cared for her and they sacrificed whatever they needed to sacrifice for her and in her death they accepted it and asked for it to be as peaceful as possible and loved her through it and let us walk with them through it. (Sarah)

An outsider is “a person who does not belong to or is not accepted as part of a particular group” (Merriam-Webster Dictionary, 2015). Outsiders do not know privileged information, they are on the outside of a group that has special knowledge of something. A few years ago I

facilitated a support group for parents whose children all have a PLSI. The purpose of the group was for families to have a chance to come together to support one another. After the introductions, the families began talking and it was clear that I was an outsider to the conversation and that my opinion had no place at that particular table, at that particular time. I recognized that what these families needed the most at that time was a chance to speak to one another rather than have the input of a nurse weighing in on their conversations. I was fully aware that the specialized nursing knowledge and experience that I brought to the table was not what the families needed in that moment. They needed each other to share the pain and joys of parenting a child with a PLSI. What families needed from me and my presence as a facilitator was to keep my mouth closed, my ears open, and my heart ready to hear and accept the difficult and troubling things families needed to say along with the heart-warming and delightful stories. It is not to say that the knowledge that nurses in this area are not needed, but rather the experience and the wisdom will dictate when it is appropriate to engage families on the topic. There is a time when the health care “expert” is needed and other times when the experienced parent of a child with a PLSI is needed.

When nurses are in their domain on the unit, it may be more difficult to recognize their position as outsiders to the family’s experience as in the context of acute care the roles seem to be pre-determined by the institution. What is more, nurses arrive at work and enter a world they come to recognize as a big part of their lives, but a world that is very different than their home life. Participants acknowledged that their job in the hospital is “*not your real life*”: “*You have to somehow put up a barrier between work and your real life. Because it’s not your real life*” (Jeanie). Once a nurse’s shift is done, she goes home to a very different life and a different reality than the one that the families find themselves in when they live with a child with a

PLSI—either at home or on the unit. While it is clear that the work nurses do affects them, it is a bit like stepping into a different reality where they are not meant to be anything but helpful outsiders to the families' journey.

I become an outsider too. Like as they, as their journey continues, I become an outside player and one who is looked on as being helpful, but not really knowing what's going on. And I kind of respect that, like I find there's a better relationship with me and these families as I have learned to respect the fact that I am an outsider to what is happening to you.... I'm the outsider who says: I've witnessed before and you've got, you've got what I can offer to help you. But knowing a little bit kind of that they are on that journey alone.
(Sarah)

While we can offer families our support, knowledge, experience, and care, it is a solitary and lonely journey for them. Just as we all, in the end, face our own death alone, these families have told me that they believe they are on a solitary and lonely journey, which they face on their own even when there is support around them.

All alone, I came into the world

All alone, I will someday die ...

All alone, I had to find some meaning

In the center of the pain I felt inside

(excerpt from the song "Sand and Water" by Neilsen Chapman, 1997)

Insider

Being through what I've been through, a lot has changed and you know, I see more, you know, the sadness and I just really focus on, you know, the child. I've seen the end parts, you know, and other children and families haven't. So they don't know what it's like

towards the end when it's more of a struggle and more pain and stuff like that. It might be okay in the moment right now for them. But as things get closer to the child passing away, it gets a lot more difficult and they don't know that. (Meg)

While no nurse would pretend to know what the journey is like for the families themselves, nurses do harbour some knowledge and know what it might be like for families as they have seen it before. An insider is “a person who belongs to a group or organization and has special knowledge about it; person who is in a position of power or has access to confidential information” (Merriam-Webster Dictionary, 2015). Insiders have information that is hidden from others and is sometimes coveted by those on the outside. There are benefits to knowing insider information “by becoming not just wiser, but more compassionate, too” (Munson, Furman, & Burton, 2012, p. 7). Inpatient pediatric nurses are their own group: nurses who know about dying and death of children with a PLSI. These nurses have access to information that is not widely available outside the walls of the unit. Their knowledge is limited by their own horizons of understanding, but knowing when they can share their acquired knowledge or be acknowledged as knowing something about it is all part of learning to navigate the landscape—becoming experienced (Gadamer, 1960/2006).

Pediatric nurses are insiders in their knowledge and experience with death. Families know their children and their own journey better than nurses ever will. What nurses have is knowledge about the process of dying for children with PSLI:

I say that I'm an outsider to that journey and I am, but the benefit that I have is the perspective of seeing other peoples' journeys, and multiple journeys, and though I don't know the emotional experience, I do know a little bit about what they are going to face in the future that they may not. (Sarah)

There is a uniqueness to being both an insider and an outsider. It is a privileged position to hold this place with families. It is being with families in a place between dualities, in a place of uncertainty, and a place of both joy and sorrow.

Death of a Patient Can be a Good Experience for Nurses

It would seem counter-intuitive to say that the death of a child was a good experience, but participants talked about deaths that went well, where they felt their nursing skills and their desire to care were put to good use. It was in these instances where the deaths were not experienced as deeply painful, but as a privilege and an honour. Perhaps it was the deaths that were open in the sense that everyone acknowledged that the child was dying and they made it as good of an experience as possible, rather than the child dying after endless painful procedures and trying to conceal or deny what was happening:

Like this little baby, they were from Saskatchewan and they, the baby had Down Syndrome and some severe heart problems and the parents decided not to treat. And it was the most wonderful experience I think I have ever had because I was with them all of the time because it only took a few days. I was always caring for the child. I was with the parents. We were on the same page. They knew what they wanted. They knew what they needed. They knew what was best for this baby and everything went really smoothly.
(Isla)

Standing by and watching a child die would not have been an easy experience for Isla, but clearly one that was rich in meaning. It is the stories of so-called “good deaths” that can hearten nurses to go back in and do it again (Hinds et al., 2005). There is an acceptance that the outcome is an early death and there is nothing anyone can do to change that. Coming to a place

where everyone can accept it and make the best of what time the child has is what give nurses the courage to come back and do it again.

I got that phone call that morning when she was made palliative that day, I got a phone call in the morning, I didn't even have a shift booked and they said, "We want you to come in for an evening." I got two hour notice. Of course I'm going to do it! Because that was their finale. And yet she died right at the end of my shift. I was exhausted. I had done my ultimate best for her. I'd advocated for her. I knew she wouldn't last the night...they [the family] got what they wanted. I gave what I could. (Lily)

Nurses Find Ways to Distance Themselves from Death and Dying When Necessary

Despite nurses' familiarity with death and even good experiences when supporting a family of a dying child, there are ways in which nurses seem to protect themselves from the difficult reality that children die.

Not Always Looking Directly at Death

Just because nurses deal with death on a regular basis, it does not mean that it does not affect them or that they do not find ways to shield themselves in certain ways because they cannot face it relentlessly: *"Sometimes you would have to put up some sort of a barrier.... Because if you looked at it that this baby is going to die, it's too horrible"* (Jeanie).

On the unit, there is a certain acceptance of death that can make it difficult to admit, even if only to ourselves, when what was happening with a patient becomes difficult for us to bear. There are times when nurses should be careful not to work too closely with certain patients because of the parallels within their own lives. For instance, trying to care for a dying child in the hospital and having a child of the same age at home can cause distress. The similarities between children at home and children on the unit can break down previously established barriers. Before

I had children of my own, I admitted a child from one of the clinics. She looked like a healthy one year old. Her parents had brought her in to the hospital for some inexplicable changes in her crawling patterns. Through a series of tests, it came to light that she had a rare metabolic condition and she would die within a few weeks. It was devastating news for everyone, including the nurses. The nurses who had young children at home had an even more difficult time. I can remember one nurse, who had a 14 month old at home, crying at the desk and pleading with others to switch patient assignment with her and she kept saying, “I cannot go in that room! All I can see is my daughter’s face! I cannot go in that room!”

Language of Palliative Care: Expression of Concealment for Pediatric Nurses

Palliative means palliative. (Lily)

During my interviews with the participants, talking about children with PLSIs, dying was discussed openly and participants spoke honestly about it—even somewhat shockingly in what they had to say:

...it would have been a blessing if they [some of the very ill children with PLSIs] had died at birth. Let’s face it. Because they wouldn’t have had to go through all that horrible, horrible treatment...in a sense you knew they were better off dead. (Jeanie)

This is perhaps not an opinion shared by all nurses, but it is the sort of comment that nurses make to one another in the staff room or another private place. Whether this was a way for nurses to make sense of the deaths and feel better about the end of suffering is debatable. I know from my time on the unit, nurses could readily engage in conversations with each other about the process of death and dying. While euphemistic language is often used (e.g., “let her go”), the topic was certainly not taboo. Yet interestingly enough, even though nurses who work in this area are often comfortable talking about death, the use of the term “palliative care” was

avoided. This was true when I worked there, so when the nursing managers warned me to avoid the language of palliative care in my recruiting material as they believed it would deter potential participants, I was not surprised by their warning. While the language of palliative care is not foreign to the nurses, I was aware that by using that language, I would potentially be alienating my target audience: “Whoever speaks a ‘language’ that nobody else understands is not really speaking” (Gadamer, 2001, p. 56). This is not to say that no pediatric acute care nurse ever uses the term “palliative care,” but when it is used, it is used in the sense of “end-of-life”: “*she was made palliative that day*” (Lily). Or the term was used as a measureable state of being: “*she was quite palliative by that point*” (Meg). This is opposed to the community of palliative care practitioners who believe that palliative is not a relative state of being. Perhaps the language of palliative care is used in this manner within this environment because the context of pediatric acute care is directly in conflict with the realities held in the language of palliative care. The belief that no child should die is so pervasive that it penetrates the walls of the pediatric acute care facility and disables nurses from using that language. Nurses seem to recognize that:

People are scared of palliative. Because I think, you know, when children are sick, you want to fix them. Because they're children. You want them to have a life and you want them to grow up and no one ever wants to lose a child. They shouldn't die before, you know, before they grow up. And ya, palliative is a very grey area on any unit in the hospital, but especially when it's peds because no one knows what to do. (Lily)

Palliative care, as defined by the World Health Organization, is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial,

and spiritual” (World Health Organization, 2014). The definition offered by the Canadian Hospice and Palliative Care Association describes a similar philosophy of care “the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness, and grief are lessened” (Canadian Hospice Palliative Care Association, 1999). This is in alignment with the nursing care offered to children with PLSIs on the unit. Furthermore, because children with PLSIs have conditions for which there is no hope of cure (Together for Short Lives, 2014a) much of what is done for them could be considered palliative as nurses and other health care professionals focus on the management of pain and symptoms for children with PLSIs in their care.

The word palliative comes from the word “palliate” whose etymological origins mean “alleviate without curing” and “to conceal” (Online Etymology Dictionary, 2015). The definition of palliate is “to make the effects of something such as an illness less harmful, painful or harsh; to reduce the violence of a disease: to ease symptoms without curing the underlying disease” (Merriam-Webster Dictionary, 2015). Interestingly, the word “palliate” also means “to cover by excuses and apologies” (Merriam-Webster Dictionary, 2015). Perhaps nurses and other health care professionals offer interventions and treatments as a way of apologizing for what we cannot cure and excusing our own limitations and the limitations of the technology we have available to us. The use of the term in this way is not from lack of education for nurses on what palliative care is, but perhaps it is one small way in which nurses in this area protect themselves. Palliative care is care through pain and symptom management, which is really all nurses are doing for children for whom a cure is not possible. Nurses alleviate without curing.

Summary

Pediatric nurses working on inpatient acute units caring for children with PLSIs become familiar with death and dying, but also need to live with uncertainty that shrouds the lives of children with PLSIs and their families. Through this work, nurses must grapple with the issues that come with caring for children with PLSIs at the limits of medical technology. While nurses are comfortable with the dying process, they do find ways of shielding themselves from the distressing reality that some children are sick and die before adulthood. In the next section, I discuss what nurses find to be beautiful and meaningful about the work they do with children with PLSIs.

CHAPTER SIX: MINEFIELD OF BEAUTY

There's a minefield of beauty there to mine. (Sarah)

It is evident that the work nurses do in the area of acute care pediatrics with children with PLSIs is fraught with challenges. Nevertheless, there is much available for nurses to take benefit from if they are open to looking for it and cultivating it. Nurses must practice cultivating the beauty through their practice: “[Kant] speaks of ‘cultivating’ a capacity (or ‘natural talent’), which as such is an act of freedom....among the duties to oneself he mentions not letting one’s talents rust” (Gadamer, 1960/2006, p. 9). Therefore, cultivating the beautiful is something that must be practiced freely and frequently so that it is not allowed to rust and be lost. If the beauty of the work must be mined in the minefield, which is not only an area of land that contains (often hidden) mines, but imbedded in the word minefield is the meaning of danger or risks (Merriam-Webster Dictionary, 2015), then it is a beautiful risk. In spite of the dangers, there is also hope and an invitation for nurses to appreciate the good for the beauty and joy of the work, which is all the more beautiful and remarkable in the minefield. If nurses choose to “mine the beauty” in their work, there is much to be gained.

While writing this analysis, I feared that the findings, the truths about what is it like for pediatric nurses working in acute care with children with PLSIs, would be too difficult for the reader to bear reading. I did not want to overwhelm readers through unconcealing some truths about the experiences for nurses who work with this population of children in an inpatient setting. This can be difficult when there are many ugly and painful truths lurking in hospital corridors, at patients’ bedsides, and in staff rooms. In spite of this, there are also wonderful and beautiful things that happen in this same context. The beauty needs to be mined, to be sought out,

and cherished for its value and importance. Nevertheless, this mining is filled with dangers—landmines known as hidden killers (Cameron, Lawson, & Tomlin, 1998).

The metaphor Sarah used about mining beauty in a minefield is one that for a time seemed to be beyond me. The metaphor seemed too complex and difficult to adequately manage, honour, and present it for the truth that it held. The image is startling, partly because it is a juxtaposition of ideas and images. Sarah is not only referring to the beauty and the joys of the work, which there are many; she is also referring to the inherent danger of trying to find, uncover, and appreciate the beauty that is there to mine. Nurses in this area work in a minefield where deadly explosives exist alongside great beauty worthy of honouring. While mulling over this difficult metaphor that speaks to an even more difficult practice setting, I came across these words that perhaps speak to the complexity of the topic: “The world is more magical, less predictable, more autonomous, less controllable, more varied, less simple, more infinite, less knowable, more wonderfully troubling than we could have imagined being able to tolerate...” (James Hollis cited by Rohr, 2011, p. 25). Therefore, in staying “true to the work of aletheia in unconcealing topics in all of their messiness and richness” (Moules et al., 2014), I offer one way that this complex metaphor can unconceal truth about what it is like for pediatric nurses who care for children with PLSIs and their families in inpatient acute care.

Pediatric Acute Care: A Minefield Seeded with Hidden Killers

“[L]andmines truly are ‘weapons of mass destruction in slow motion’”

(Cameron et al., 1998, p. 13)

As a nursing student, or even a graduate nurse, I never would have expected to find myself writing about the context of pediatric acute care as a minefield. However, the longer I thought about my work in the context of pediatric acute care with children with PLSIs and their

families, the more this metaphor seemed fitting. Working on the unit is filled with unknowns. It is impossible to predict how a shift will unfold and there are always surprises—both good and bad. The more I thought about Sarah’s use of the metaphor about the landscape of the work being a minefield, the more I came to realize that this was speaking a truth, a difficult truth, about the landscape of the work. It would have been much more straightforward for me to write my dissertation about only the negative and the troublesome parts of the work. Nonetheless, what makes the work all the more challenging, and rewarding, is that the difficulty and beauty come together. The metaphor of the minefield offers something to better understand the nature of the work of pediatric nurses in this area.

Stepping onto the unit with its bright colours and cheerful artwork covering the walls, it can appear seemingly safe. The cheery exterior attempts to conceal and mitigate the hidden horrors that go on: “*No one knows where the mines are buried*” (Winslow, 1997, p. 13). As a new graduate nurse, I knew difficult things happened and that there were dangers—I had attended lectures on compassion fatigue and burnout. Yet I had not fully realized the existence of “[t]he risks of both known and unknown dangers” (Monin & Gallimore, 2002, p. 144).

Landmines...have ruinous effect on the human body: they drive dirt, bacteria, clothing and metal and plastic fragments into the tissue causing secondary infections. The shock wave from an exploding mine can destroy blood vessels well up the leg, causing surgeons to amputate much higher than the site of the primary wound. (McGrath & Stover, 1991, cited in Vines, 1998, p. 130)

Nurses who are injured by their experiences working in acute care with children with PLSIs and their families do not often recognize the extent of their injuries until those injuries have spread well beyond the site of the primary wound.

Initially, I was distracted by the joys, beauty, and wondrous miracles that came with working in a large pediatric hospital. Yet I had not realized that danger lurked within the beauty—as well as beauty within the danger. Over time I came to better understand that nurses must live with both the constant threat of sustaining a life-changing injury from a hidden landmine, but also grow by enjoying the beauty. For the reality is that laced within the danger is beauty, healing, hope, and love. This metaphor of the minefield is conflicting, but because it is conflicted it highlights what it is like for nurses in this area. There are both risks to be taken when searching for beauty and good of the work. The beauty may be hidden and it may pose dangers to uncover it.

Beauty Imbedded in the Minefield

“Even amidst chaos and disorder, something in the human mind
continues still to seek beauty” (O'Donohue, 2004, p. 14).

Beautiful experiences and the joys of life “occur right in the midst of daily life—far more commonly than is usually acknowledged. C. S. Lewis described these moments as being ‘surprised by joy’” (Bourgeault, 2001, p. 10). To say that the landscape of pediatric acute care resembles the abandoned, overgrown, and contaminated fields of landmines in countries such as Cambodia, Angola, and the Congo, is only telling half the story. The unexpected truth is that buried alongside deadly landmines is beauty. To be open to spotting the beauty when one comes across it is the true gift of the work in pediatric acute care. Furthermore, being able to be “surprised by joy” and even appreciate the routine beauty and perfection of the work is something to be practiced. It is in these seemingly bleak landscapes that the need to spot and cherish beauty is all the more desperate:

In Greek the word for ‘the beautiful’ is *to kalon*. It is related to the word *kalein* which includes the notion of ‘call’. When we experience beauty, we feel called... It unites us again with the neglected and forgotten grandeur of life. A life without delight is only half a life...in the bleakest times, we can still discover and awaken beauty; these are precisely the times when we need it most. Nowhere else can we find the joy that beauty brings. (O'Donohue, 2004, p. 13)

Working with so much sadness can allow nurses to appreciate the goodness of the every day. Feeding, bathing, and tucking in young patients takes on a whole different meaning, a meaning that would be lost if nurses were not present and walking alongside children with serious and life-shortening illnesses. It offers nurses an opportunity to appreciate the good moments at work and also within their own lives. Nurses are able to appreciate the blessings in their own lives. Being able to feel the joy and thankfulness of their own healthy children can be painful, but allowing themselves to be vulnerable enough to allow the pain to give way to joy and appreciation for what they have.

Children with PLSIs: A Kaleidoscope of Beauty

Serious scholars of the classical world have argued that ancient Greek possessed no word that unambiguously signified “beauty” or “beautiful.” The word that is most often translated as “beautiful,” and that has been the focus of almost all studies, is the Greek adjective *kalós* (the root appears in the English *calisthenics* and *kaleidoscope*). (Konstan, 2014, p. 31)

When I read that the word beautiful is etymologically related to the word kaleidoscope, it struck me that this was a fitting metaphor for children with PLSIs: “a mixture of many different things; a diverse collection” (Merriam-Webster Online, 2015) and at the same time fundamentally

linked to the concept of beautiful. Many children with PLSIs do not outwardly look like healthy children due to the illnesses and syndromes that significantly alter their physical appearance.

...as we got to know him, with the good, bad, or what, it was very real...that we came to love him. And he's a very strange looking child! (Isla)

For the Love of the Babies

"And you know, it's also for the love of those babies" (Isla). Nurses love the babies and children with PLSIs for whom they care. Despite the abnormal circumstances, nurses care for them and appreciate normal child care activities and find joy in that. However, nurses must face difficult realities within challenging circumstances when caring for children with PLSIs in pediatric acute care. The wonderful things, the so-called "normal" things are made all the better. The sorrow can heighten their awareness of the beautiful and the good. Nurses are proficient in routine baby care, but do not get to practice it as often as they would like, as patient acuity is far too high. Therefore, when nurses can take the opportunity to perform routine baby care, they savour the moments. There is a real need to be present enough to enjoy the moment.

I really have seen and need to focus on is to be present with what's happening and being present with families...as a human being and right now, I just need to be present and not to take anything for granted. (Sarah)

Tucking in the Babies

I'm a very maternal person and the evening shift works well for me. I like tucking them [patients] in at night. I like the lights going off on the unit. I like putting the music on and you wrap them tight. They know they're loved and cared for.... You do get shifts like that where you have a nice assignment and you have time to cuddle the babies and they look at you and they know that you're going to feed them and take care of them and they're

fast asleep at the end of the shift and they have their little night lights on and they're all wrapped up. The unit is dark and it's calm...that's satisfaction to me...I like that part...but I think with the progression of them being so sick now and so acute, you don't always have the time to do that and I always make an effort around 10 to do that, as long as the unit isn't falling apart, to restock the diapers, you know make sure the pumps are up-to-date and everything...it's an ideal world. It's becoming less and less available to do that because we're so busy, but those people, those colleagues that are the same age as me who had their families grown up and they do the same thing and we look at each other and we're like, "Ya, they're tucked in. They'll be good tonight." And the next day you do it all again, right? (Lily)

It was not until Lily described this that I realized how much I enjoyed that part of the work on evening shift. I would look forward to the second assessment that is scheduled to take place around eight o'clock in the evening. I often liked going for a late supper break so that I could have the bedtime routine done and enjoy that, then go for my dinner break relaxed, knowing that the children were tucked in for the night. In fact, it was Lily who taught me how to bundle babies so they were well snuggled in. I can remember as a new graduate nurse caring for a baby with pyloric stenosis and he was NPO (*nil per os*, meaning nothing by mouth) overnight, so he could not be fed, as he was due for surgery in the morning. I had tried everything I could think of, but I could not get him to settle. Lily came to the room to help me and said, "You just have to bundle him tighter. Then tuck him in for the night." Sure enough, Lily's tight bundling of the baby allowed him to settle and fall into a peaceful sleep.

To tuck is "to put something in a particular place usually to hide it, hold it, or make it safe" (Merriam-Webster Dictionary, 2015) and the etymology is "thrust into a snug place"

(Online Etymology Dictionary, 2015). Perhaps the joy nurses experience when tucking in their young patients is that it is about keeping kids safe. Nurses cannot protect their young patients from their inevitable early death, or even mitigate the pain and suffering they are experiencing, but nurses can offer the children moments of comfort and safety. Nurses appreciate the moments when things are going well: the moments where children with PLSIs are safe and sound and, for a brief moment, everything is okay. Nurses look for those moments and enjoy them as they are moments of satisfaction and perhaps even hope. There is something notable about engaging in normal baby routine in a situation that is abnormal. These moments are not frequent, so it is being able to stop long enough to enjoy the little things. It is important and rewarding to take a moment to enjoy tucking in babies.

This honour and privilege of tucking in babies is so central to the meaning nurses glean from their work, that more than once I have heard nurses include this in their eulogy at a patient's funeral: "We loved caring for this child and loved tucking her in every night she was on the unit. Tucking in the kids is the very best part of our job." It is profound that in moments such as a funeral, that it is the little things about the child that are remembered, but also the little things about nurses' practice that make it worth all the challenges. It is these moments that make venturing into the minefield of pediatric acute care worth the risk.

There is a moment, toward the end of some evening shifts, where everything seems perfect for a brief instant. It is the moment when the patients are tucked in for the night and the hallway lights on the unit go off. There is a moment when everything seems like it will be all right—a moment where chaos, death, dying, lack of resources, despair, and fear slip away and nurses are able to enjoy the moment where the kids are "thrust into a snug place" and the world is as it should be.

I love evening shift because it starts off busy and then you put them all to bed and then they're all tucked in. (Heather)

Appreciating Children with PLSIs as Children: Enjoying a Normal Life when Possible in the Context of Abnormal

In German we find it in words such as *ungeheuer* and *unheimlich*. The word *geheuer* describes a state of being at home, of feeling safe and sound. Its negative counterpart, *ungeheuer* suggests the strange and the uncanny. When we use this word it implies that we do not feel at ease or that something does not seem quite familiar to us.... The expression “making oneself at home in the world” was a favourite one of Hegel’s and he regarded it as constitutive of what it is to be human. It describes the desire to be at home with oneself, secure from any threat of danger, surrounded by a familiar, understood and understandable world where one can feel free of anxiety. (Gadamer, 1996, pp. 153-154)

It is in these moments of so-called normal where there is a sense of safety and calm, that nurses can appreciate sick children as also just children. Children with PLSIs are more than their illness and nurses can appreciate them for the little human beings that they are. It allows nurses to see past the dying, the frailties, and the despair. It makes things seem all right, even if only for a few moments. It seems to be about alertness to the present moment.

Heather: ...it's sort of makes some of our long-term patients, it makes me happy because they're doing a lot more normal things and some of them are older. Like some of the trach patients are older and I get to play with them and you know, sometimes I find the nurses who don't have kids don't really understand how to play with a two-and-a-half year old, so when I get this patient who's a two-and-a-half year old and I have a two-and-a-half year old, then that's great! This is what we're supposed to do! Let's run!

SM: Because you know what's funny—

Heather: Ya, this will crack them up. I know you can't pull that crap with me and if you're going to be naughty, then you can sit in your highchair, you know, right?

Going the extra mile and making a special effort to offer these children a little bit of normal in their abnormal circumstances is what can make for a good day for pediatric nurses. Nurses' expectations are not high and they are not hoping for a cure, but they can add some quality to the lives of the children with PLSIs and particularly those of nurses who have children of their own who are of similar ages, they appreciate giving these children with PLSIs a chance to be children because nurses recognize how different the lives of children with PLSIs can be:

I remember seeing one of our trach patients who happened to be one of my friends' neighbours and he couldn't come outside and play because of the allergens in the air. He was attached to his little, I think he was just on oxygen at the time and not on a ventilator, and it hit me then. Holy cow, he's about the same age as my kid, but his life is so different. (Heather)

Nurses value the normal aspects of what it means to be a child; therefore, nurses want to offer children with PLSIs some normal aspects of childhood. Unfortunately, the time to do this must be searched for in a nurses' busy shift. Nurses are known to stay after their shift has ended in order to spend quality time with patients.

It's the busyness and sometimes because of these kids are so chronically ill, you want to do more for them. You want to make their lives as normal as possible, which means giving them a bath, getting them dressed, and take the time to feed them if they can eat or reading them books. And the days where you just run all day and don't have a chance to do any of that stuff, it doesn't make you feel good. Because part of the reason you work

there is because you do those things that make things normal and if you have time for that, that's great, but when it's a crazy day and you're running around and you feel like you have not accomplished any of those bigger picture things. You get your assessments done, but that's it, then you feel like you haven't had a good day. (Heather)

Even though children with PLSIs in acute care are so sick, they still deserve to enjoy basic and normal baby care and love. Life and its joys are often found in the little things. Nurses enjoy the little things with the children in their own lives and look for moments of normalcy and joy for their patients with PLSIs. Nurses know children with PLSIs may spend months or years in the hospital and they are not living out normal lives: “*They're living out their lives in a hospital setting. That's not normal!*” (Isla). It is not normal, so when children with PLSIs in acute care do “regular kid stuff” nurses feel happy and satisfied. It is recognizing that children with PLSIs may be critically ill, but they are also just kids who are leading abnormal lives and deserve normal things whenever possible. When nurses work with so much abnormal, they come to appreciate the normal of the everyday:

...it's kind of nice to see her having her drama or her hissy fit and you put it [the IVAD--implanted vascular access device] in and a week later she's gone home again and she's back to school and she's doing all the things that teens shouldn't be doing. (Lily)

Walking Alongside Families: Family Centred Care

Nurses appreciate the beneficial aspects of FCC when circumstances allow for the practice philosophy to be used to benefit the patient, the family, and the health care team. Walking alongside a family with a child with a PLSI requires acknowledging the uncertainty of the situation and recognizing that part of the family's journey is to be able to hold off making

decisions or changing their minds. It is through this process that families are empowered to make decisions that are best for their child as well as their family.

I developed my biggest respect for our palliative care team because I really felt that they engaged her [a mother with a child with a PLSI] in a moment-to-moment basis, they honoured her process, they honoured her ups and downs and her changing of goals of care. (Sarah)

Sarah highlighted the reality that FCC is not about the endpoint, the destination, but rather the journey. It is no secret that children with PLSIs will not survive into adulthood. The reality is that unfortunately these children will die within months or years of birth. Therefore, the goal of FCC is to make that journey as positive as possible rather than a focus on changing the outcome:

I was in awe of how they [the hospital's pediatric palliative care team] walked with her through this journey and you know and here's me going on about health care resources and while this child took up a lot of resources, came from a country that they had no health care and you know a lot of work was done pro-bono and a lot of the cost was to us and it was all for not in the end. You knew this child was going to die.... They really saw this mother's struggle and really tried to just...walk with her on it and in any way that they could. (Sarah)

It is about walking alongside patients and families and accomplishing what nurses can to keep the patient the centre of the care, but also integrated into the family and decisions made in alignment with the values and beliefs of the family. In this example, Sarah described her perspective on a situation where the mother was in the centre of the focus and her needs respected and care revolved around her and her sick child.

It is interesting, but also troublesome, that Sarah recognized the contribution of the palliative care consult team for their involvement and commitment to FCC in making this a positive experience for the mother and child. The palliative care team work alongside front line staff, but are not unit staff. Credit for how this story unfolded should also be given to the nursing staff and not viewed as being orchestrated by an outside group. More work needs to be done with front-line nurses, perhaps not in terms of education, but rather through implementing ways for them to be acknowledged in their important role in the process of FCC and including nurses in the decision-making process.

Working with Families is Rewarding

I like the long-term patients. I'm always excited when I have a patient that I know and whose family I have a relationship with. (Heather)

It is in alignment with the philosophy of FCC that nurses build relationships with patients and families that keep them engaged in their work with patients and families in this area of nursing.

...definitely the most rewarding part are the relationships that I make with the families specifically and the children as they get older. I mean, when they're very young, like infant age, there's, the rewarding part isn't there because they can't communicate back to you too well or too often, you know, but it's definitely the family and making those stressful moments for families, like that are having an acute episode with their chronically ill child they are being heard and when they need something and I'm often a good ear for them, so that's probably the best. The most rewarding part. (Meg)

It is when nurses feel as though they are engaged with the family and build ongoing relationships that enter the nurse into the day-to-day struggles the family experiences:

And you know, “Oh your husband lost his job and how’s that going looking for a new job? How’s your older child doing?” So I like, I like developing those relationships. So that’s probably why I stay on [the unit]. (Heather)

Nurses come to know the families very well through the months and years that children are admitted to the unit or have frequent admissions. The continuity is beneficial for everyone involved and nurses appreciate it particularly as they feel included and a part of the precious life of a child with a PLSI. It is about the relationships and the trust that develops over months and years with families with children with a PLSI who come and go through the unit or end up staying for long periods of time. Nurses come to know the child and it makes it a better experience for everyone:

And you don’t have to start from scratch, you just catch up on the latest, the latest episode of why she was in for surgery and it’s nice because they know where you’re at and you know where they’re at and you know your boundaries and the kid was really sick and they don’t get as stressed because they know you’ve got it. They know that you’re going to advocate for the kid and you’ll fight the doctors if you have to and I’ve done that! I don’t have a problem with that! I’ll advocate for the patient always with the parents over the doctor because I know the kid. The doctors change rotations all the time. They don’t know her for 14 years whereas I’ve had her on and off for 14 years. I know the family, I know the child.... I like that too because you have that trust. They trust you. You know, they can go home at night. In the evening, especially the evening shift, and they can go home, you can say, “Go home. She’s going to be fine. You know I’ll call you.” And I will. I will. And I’ll fight the doctor. If the doctor comes in and puts in a weird order and I’ll be like, “No, I’m not doing that. We don’t do that with her. I know

her. ” And a lot of the time they believe you because you’ve got that history. And so, I like that too. You get that more with the chronic families for sure. (Lily)

One of the roles that nurses take very seriously when caring for children with PLSIs in the inpatient setting is protecting their patients. Children with PLSIs are a highly vulnerable population and nurses protect the children with PLSIs in their care and they will do so fiercely. Lily talked about “fighting the doctors” to have the care needs of her patients met. Nurses often take their role as patient advocates seriously and will challenge and disrupt the hierarchy of the health care team knowing that this can cause frustration for others: *“I don’t care who I upset [in my efforts to advocate for my patients]” (Lily)*. While Lily may advocate openly and assertively, not all nurses take this approach. However, it would seem that all nurses find a way to fight to deliver the best care to their patients. This can take the form of ignoring physician orders that they do not believe are appropriate, discussing the issue with the charge nurse or administrator, or submitting their own consults with specialists. Nurses find ways to advocate for their patients even if it means bypassing the system one way or another and breaking the rules.

Gratitude from the Work

I feel such gratitude that being with these families reminds me to be grateful for what I have. To not take what I have for granted. (Sarah)

“Witnessing how others deal with suffering in their lives may have the unintended effect of increasing one’s own gratitude for life” (Emmons, 2007, p. 139). One of the consequences nurses experience when working with the dying is a daily reminder of what they have to be thankful and grateful for in their own lives. Gratitude “is the *acknowledgement* of goodness in one’s life...gratitude is recognizing that the source(s) of this goodness lie at least partially outside the self” (Emmons, 2007, p. 4). The word “gratitude” is derived from “the Latin [word]

gratia, meaning ‘favor,’ and *gratus* meaning ‘pleasing’” (Emmons, 2007, p. 4). The etymology of the word “grateful” comes from the mid-15th century meaning “good will” and “thankfulness” (Online Etymology Dictionary, 2015). Working with children with PLSIs and their families offers nurses an awareness of what they have to be grateful for in their lives. Many people can walk through life without being met with the distressing reality that some children are born very sick and die long before reaching adulthood. That knowledge is a burden and is certainly a painful reality that nurses come to live with. Nevertheless, the benefit to that pain is also the knowledge of what nurses have to be thankful for in their own lives. Nurses with healthy children are much more aware of the gift that they have and they do not take it for granted. Nurses working with children with PLSIs are faced daily with loss and “are reminded to live even more consciously in the face of loss” (Hollis, 2013, p. 66).

I am so grateful that I have not had to walk that journey [of parents who have a child with a PLSI]. And I think that there's an urgency to working in these kind of situations. There's a truth, there's a reality; there's a...the real shit, you know what I mean? What a blessing that I know that this happens and I witness that this happens and I experience gratitude for the fact that quite selfishly that it's not me who's going through it, but it makes me see, it makes me see my healthy children as a blessing...I don't take it for granted as much. (Sarah)

Knowing the pain and suffering that others live with heightens nurses' awareness because they can contrast it with their own lives and experiences: “*I don't take for granted how healthy my children are*” (Meg). They cannot experience deep gratitude without knowing what others must live with—there is a cost to that knowledge. The myth of Inanna, of Heaven and Earth, tells the story of how knowing death first hand changes us. In this myth, Inanna visited her sister

Ereshkigal, Queen of the Underworld, after she heard that her sister was in emotional pain. After she obtained permission to pass through a number of gates and levels down to the underworld, in the end, Inanna ends up being killed, then brought back to life.

In the presence of acceptance and compassion, Ereshkigal's pain and anger were transformed into gratitude, and as a result, Inanna could come back to life. However, as the judges of the underworld informed her, "No one ascends from the underworld unmarked." (Bolen, 1996/2007, p. 57)

As Inanna ascended to the upperworld, and to the safety of her kingdom, she returned not alone, but with demons clinging to her (Bolen, 1996/2007). What are the demons that cling to acute care pediatric nurses?

Nurses are grateful for being part of the lives of children with PLSIs and their families. It is through their work that they are able to come to understand that their presence with children and families is a gift and it is an honour to journey with these patients and their families:

My most heartfelt response to that is that it's a real honour. It really is an honour. I feel so blessed that I'm in a line of work that lets me deal with real life in this way and you know, birth and death are universal, but they're very, it sounds so granola-ish, they are sacred events. They are sacred events and to be a part of that is a gift and a blessing. So with all that other stuff that goes along, I really do want to remain grateful for the fact that I'm with these families. (Sarah)

I know firsthand how important children with PLSIs are to their families, friends, and those privileged enough to work with them. What is more, I feel such enormous gratitude in seeing my own children reach developmental milestones or learn a new skill because I know how lucky I am. This is in contrast with many parents I have met outside of work who seem to

believe that good health is something their children are entitled to (Dominica, 1991; Maunder, 2006). It is for this reason, this fundamental difference in perspective, that nurses who work in this area of nursing are often a cohesive group even outside of work hours. One nurse described her experiences in having her own baby, after spending many years caring for parents who had experienced perinatal loss, as finding it difficult to relate to other pregnant mothers who were preoccupied with wanting a child of a particular gender, personality, or arriving following a particular birth plan, when all she was hoping for is to have her baby born alive (Jonas-Simpson, 2010). Working with children with PLSIs and their families offers us insider knowledge and there is a loss of innocence and an exclusion from other groups in our first-hand knowledge of gravely ill children and death. To call the experience an honour calls the fact that nurses in the context of death and dying are expected to behave in a particular way: "...honour relates to the behaviour expected of members of a particular community" (Gill, 2014, p. 3).

There are times when living our lives as parents knowing first-hand that others have lost their children can be paralyzing. Integrating this reality into our lives can be difficult. However, parents I have talked to whose children have died have told me that they want those parents, who have been fortunate enough not to have a child die, to love and enjoy their children. It would not make them feel better to know that those with healthy children were not out there doing fun things with their kids. For the parents of healthy children to miss out on that opportunity is a double-tragedy.

It is important to keep in mind that the work, while challenging and demanding, is also a privilege and a blessing as it keeps nurses awake to what happens in life that is perhaps hidden from the day-to-day life of most people. It can also help to keep nurses awake to the fact that life is a complex, multi-dimensional experience that requires the tragic along with the joyful.

Sometimes life stinks! (laughs) And sometimes love hurts and it just keeps you more in a real relationship with human beings I guess. So even the crappy parts are still a gift.

(Sarah)

The knowledge and gratitude nurses obtain from their work are a gift. A gift is not something that we obtain through our own means and efforts; it is not something we purchase. Rather, a gift is something that is bestowed upon us (Hyde, 1983). Gifts are not just something we receive that are desirable, but gifts imply a degree of debt and responsibility (Dodaro, 1999). Therefore, gifts are a mixture of attributes. In fact, the concept of gift is a way in which everything is unified: “It [gift] binds everything together: sacrifice, duty, debt, war and peace, status and prestige. The gift presents itself at once as symbolic form and material substratum of social synthesis” (Berking, 1999, p. 32). From this standpoint, gifts can also be difficult to recognize when they are bestowed upon us. These gifts require thought, reflection, understanding, and dwelling with what is difficult: *“even the crappy parts are still a gift” (Sarah).*

Life is so generous a giver,
but we, judging its gifts
by their covering,
cast them away as ugly
or heavy or hard.
Remove the covering
and you will find beneath it
a living splendor,
woven of love, by wisdom,
with power.

(Fra Giovanni as cited by Soper, 2007, p. ii)

I felt gratitude at being a part of something that challenged me to question myself and my practice, my perspective, and it reminded me to remain present without judging parts of a journey that I don't always understand and that was a gift. Really, at the end of the day, I need to be present and to give and to give something to other people and take the gift that is given to me. (Sarah)

One of the gifts we are given through the work with children with PLSIs and their families is that life is a multitude of experiences. Gratitude is “the heart’s internal indicator when the tally of gifts outweighs exchanges” (Emmons, 2007, p. 6).

This mother is so beautiful. She thanked me for being there [when her daughter died] when I hugged her like, that's a whole ball. It's awful, it's a gift, it's this, it's that, it's a part of life, it's...it's, you know, it's a gift and a challenge. (Sarah)

Creating Safer Landscapes through Manual Work in the Minefield

Dedication by Cameron et al (1998):

“For the thousands of people around the world who worked to ban landmines so that future generations may walk without fear” (Cameron et al., 1998, p. i)

Sadly, completely clearing the landscape of pediatric acute care from all metaphorical landmines is not possible. Difficult and painful experiences cannot be completely avoided in a context where children are very sick and die. However, it is perhaps possible to mitigate some of that pain through better acknowledgement of the inherent dangers, increased attention to the beauty, and tangible efforts made to uncover mines. The ongoing discourse around the topic often mirrors the criticisms of clearing physical landmines:

According to Jefferson the campaign has diverted funds from the real issue: “It enables governments to claim that they are spending money on dealing with the problem of landmines, whereas in fact they are spending money on discussing the problem, on hosting conferences, on carrying out ‘assessment missions’, on promoting ‘mines awareness’ campaigns – on almost anything, in fact, other than the messy business of actually getting the mines out of the ground. (Monin & Gallimore, 2002, p. 7)

As a metaphorical landmine victim myself from my work as a pediatric nurse who will carry the scars and disfigurement of someone who has been deeply hurt from practice, my life’s work with children with PLSIs is making the landscape of pediatric acute care a safer context through exposing some of the hidden landmines and engaging in real conversations about the dangers inherent in the work and some potential solutions to demining where possible.

Technology to clear mines through the use of:

Huge tank-like vehicles fitted with flails or chains can thrash the ground ahead of the vehicle. The flails explode some mines, but leave some behind and beat others deeper into the ground. Other machines push or drag heavy rollers that detonate by direct pressure. As with flails, the rollers fail to destroy all the mines. Vehicle treads can tip a mine up on its edge so that the pressure plate is not exposed; the mine can later right itself. (Winslow, 1997, p. 92)

Yet these large machines are not nearly as effective as the slow and careful work that workers on the ground can do (Winslow, 1997). Managers, administrators, and educators cannot make sweeping changes that will prove as successful as collaboration with front-line nurses. In fact, successful change must be done by those in the minefield. In pediatric acute care, the ones in the minefield are the nurses themselves.

Summary

There are wonderful surprises and benefits to the work of acute care pediatric nurses caring for children with PLSIs and their families. The beauty of the work is inextricably bound to the difficulty and challenges that also exist in the landscape of pediatric acute care. Nevertheless, the beauty is there to be found and honoured by those nurses who seek it out. In the next section, I discuss the difficult truths and troubling memories nurses learn to live with as part of what they experience through their work on the unit.

CHAPTER SEVEN: HOLDING DARKNESS

I think until, we talked about the dark side, until, for me, until I express the dark side, the light doesn't come in and I think we're holding a lot of darkness. (Isla)

Darkness is the absence of light. In order for human eyes to perceive objects and colour, a certain amount of light is required. Therefore, in the absence of light, colour is indiscernible by the human eye. The word light holds several meanings including the concept of spiritual illumination, “having little weight,” and “free from care” (Merriam-Webster Dictionary, 2015). Light illuminates so we can find our way, but it also illuminates our minds and hearts. Interestingly, no matter how much darkness exists, even a minuscule amount of light can dispel the darkness. This is not true in the opposite: a tiny amount of darkness could never dispel a huge amount of light. Therefore, even a small amount of light “shows us the way at night” (Jean Piaget, 1974, pp. 205-206--inconversation with "Vog," age 8;6 cited by Jardine, Clifford, & Friesen, 2003, p. 143).

It would seem that humans have a difficult time holding both light and dark. The overwhelming desire is to have only good things in life, to have only light. It would seem that as humans, we long for it all to be light, but the reality is that we must hold both. Humans seem to think in terms of duality where things are either/or:

Most of the world's ancient metaphysical paradigms are binary systems. That is to say, they function on the principle of paired opposites. Yin/yang is an obvious example. In binary systems the universe is experienced as created and sustained through the symmetrical interplay of the great polarities: male and female, light and darkness, conscious and unconscious, yin and yang, *prakriti* and *purusha*. (Bourgeault, 2013, p. 15)

Life is always much more complex than simply being one side of a duality. Life is about living with both: dark and light, comedy and tragedy, yin and yang. Life is complex where there are many influences going on all at the same time. As a result, hermeneutics is “an attempt to stick with the original difficulty of life” (Caputo, 1987/2000, p. 1).

These words from Isla about holding darkness and needing to let some light in really struck me as a truth about what it is like to work on the unit. Nurses in pediatric acute care hold some terrible truths, experiences, stories, and realities very close to their hearts—carrying “baggage we shall all take to the grave” (Sherwin Nuland as cited by Frank, 1995/2013, p. 94). It is through a willingness to be vulnerable and a desire to heal, that nurses can allow themselves to look at this darkness and thereby let the light in. While it seems to be possible to begin opening up conversations and nurses’ history with darkness and difficult experiences, it seems to change nurses in fundamental ways. It weaves into their very beings. Nurses are changed by their experiences, so completely ridding themselves of the darkness is likely not possible. Even for nurses like Sarah who were not aware until the interview that she carried this darkness:

So far I’ve been quite good in having that [distress from work] be self-limiting. But as I say, it surprises me when I talk to how it’s still there and I didn’t know it’s still there. It exists and I don’t know until half an hour into a conversation that it’s there. What I just said (crying)...I feel like I have been minimally affected and yet...you know, we’re talking about this and there’s that nausea, there’s that wave, and there’s that...so maybe, so maybe I can’t identify how it’s affected me yet. (Sarah)

“Holding darkness,” as Isla described, suggests remaining still or carrying a burden without changing speed. Sometimes, however, the darkness can ignite a response of action, a fight or flight response:

I came on one evening and I [was assigned] ...an infant, very young still, and he had been mutilated by mom's boyfriend. ...I was given this child, I think, because of my age. Because I was one of the older—if you want to put it that way—senior nurses on the floor so hopefully I had the life experience to process this awfulness. And I did have him and I coped with it quite fine and I said “No problem. That's what I'm here for. That's my job. It's my professional responsibility.” And I did feel that at the time that I wasn't overly affected by that child. The police had been in that day and watched the mom leave and she realized that her child was apprehended and I said, “Ya, that's my job and let's just move forward.” I watched myself in retrospect act very strangely with this child...in that...sorry...(crying). And the younger staff were all buzzing around in the hype of the drama and I felt a responsibility to curb that drama. You know it was a big, mass hysteria around it...like we don't need to act like grade seven girls all in a titter about something, we need to be professionals and move on, but I wouldn't put him [the baby] down... (crying) I wouldn't let anyone else hold him....(crying)....and a friend of mine, her son, I heard my neighbour's son's name being called to emerg so I went down to check on him and...(crying)...but I took the baby with me...(crying)...because I didn't want anyone else to take him. And when I got home that night I cried and I cried and I cried and I cried and I hadn't cried at work. But it's only interesting to me in retrospect because my behaviour was so bizarre and it was so visceral and it was so primal and I don't know where it came from. And I remember some of the nurses...and I remember....you know, maybe more prone to the gossipy side of things, and they were pulling out the chart to look at the photographs and I thought that I was going to attack them. (Sarah)

Of all the difficult things I heard from participants through conducting this research, this was one the most difficult pieces of transcript for me to face. This was not only because I too cared for the patient; in fact, I was the one who discharged him into the care of his emergency foster family. It was also because it was not until I heard Sarah recount the incident did I realize that this patient's story had not affected me at the time because by that point in my career I had built such an impenetrable wall around my heart that I was unable to experience any emotion around this infant's situation. I was only able to grieve this through hearing Sarah tell the story. I now recognize my loss of innocence and the cynicism that grew out of the relentless onslaught of such deeply disturbing experiences I had while working on the unit. Probably the most troubling reason why I found this difficult is because it is an experience that rings true and is not particularly unusual. There is a deeply felt sense of failure that we are not able to protect children from the monsters in their lives. It hurts to know that we live in a world where people will do terrible, unspeakably horrible things to children. That is a darkness and a shadow that we carry in our hearts.

I think of all that I give to my [own] kids and I think it's so unfair that these kids are given to that way. But there's no reason. There's just no reason for some things that happen to some kids and it's so fucking unfair. And you are a witness to that too...(crying). But when you're a witness to that horror, you're just a witness to horror, right? And that's terrible. ...the number of times I've wanted to pick up a child and run. And I just want to pick them up and run and run. (Sarah)

There is something primitive to the response nurses have when caring for certain children—particularly those who have been poorly treated: *“there was something very primitive in the response in a human being, especially a female, protects an infant” (Sarah)*. It seems to

affect nurses on a level below their own cognition and seems to bypass their brains and strikes right at their hearts and their instincts. The energy it takes to control those impulses to attack or run is exhausting. Over time, when this darkness is not allowed to see light, it begins to corrode nurses' core beings and leaves them fragmented, broken, and hurt.

Part of my Fabric

She's like a little angel in my mind often and her mom was wailing in ICU and that stays with me. She's a story that is part of my fabric. [When she died] I was just barely able to breathe I was crying so hard. (Sarah)

The metaphor of our lives being fabric and our stories and experiences are woven in is an interesting image. If we think of our lives as fabric, each thread that is added to our fabric represents experiences and knowledge—good, bad, mundane, and memorable. Once the cloth is woven together, individual threads are no longer separable from those around them imbedded with “multiple meanings, ‘interweaving and criss-crossing’ (Wittgenstein, 1968, p. 32) (*textus* originally means ‘to weave,’ like textiles)” (Jardine et al., 2003, p. 56). Our experiences with children with PLSIs become woven into our fabric and nurses can no longer peel away certain experiences or memories as the fabric cannot be transformed into fragments from the whole. This fabric, the fabric that represents our lives, is “not shapely and elegant, but a big crazy quilt” (Le Guin, 1989, p. 212). A quilt, often a patchwork of many colours, patterns, shapes, and designs, is an appropriate metaphor for the lives of pediatric acute care nurses as it captures the variety experiences together in a single life: the poignant, powerful, painful, precious experiences of working as a nurse with children with PLSIs.

After telling the story of a difficult patient death, a senior nurse once told me that she believes the work we do changes our DNA. “What story, told or untold, threads its way through

our DNA, our genetic coding, and plays out a same old, same old?” (Hollis, 2013, p. 13). Research suggests that elements in the environment can permanently alter a body’s DNA (Heijmans, Kremer, Tobi, Boomsma, & Slagboom, 2007). This research was focused on identical twin studies where two people shared the same DNA make up, but had different health outcomes, as did their offspring based on the environmental influences each twin was subjected to (epigenetics) (Fraga et al., 2005). This nurse may be closer to holding a provable truth than merely being dramatic. Experiences shape nurses’ outlook and moods, but some of these traumatic experiences may be fundamentally changing their physiology too. These experiences leave a permanent mark on their physical make up and not just on their hearts and minds.

I mean, you can’t (crying)....it can’t be there without affecting me. It can’t be in my fabric and not be hurting me (crying). (Sarah)

Hurt

If I have that patient that I’m assigned to and I’m on a stretch of five or whatever, it’s kind of like, how am I going to get through these five days because being in that room makes me hurt? (Rachel)

It is not a new trend to describe emotional pain as hurt. In fact, it has been used that way since the 13th century (Online Etymology Dictionary, 2015). However, the idea of caring for children with PLSIs as actively causing nurses pain is a startling image. Often for senior nurses seeing a new patient living out a familiar story reawakens past hurts. As a result, nurses often need to push down hurt in order to get through their shifts. Nurses do this in a variety of ways, but it is sometimes done by trying to protect themselves through distancing (Papadatou, 2009). The grief nurses can experience from the death of a patient has been described as being hidden behind a curtain of protection where a nurses’ feelings are hidden, which causes “the nurse to be

fraught with guarded anguish” (Gerow et al., 2010, p. 127). What is more, “[h]urt can be so painful that some victims create thick walls to protect themselves from more pain” (Vanier, 2008, p. 143). There is something about the context of pediatric acute care that allows nurses to avoid the need to recognize the hurt as it is a space where they do not have to acknowledge it. The chaos can help to cover and distract from the hurt. It is in the times where nurses step back from the situation, that they come to realize what it is that they are doing and question it. I did not realize this until I took a step back from acute care. It was only then I was able to reflect on this reality. I wrote the following as part of an assignment during my Master of Nursing practicum at a children’s hospice where I first recognized the “safety” of chaos in acute care:

The Safety in the Chaos of Acute Care: I am an acute care nurse. I understand the chaos and dysfunction of the inpatient acute care system. I am comfortable in that chaos.

Despite the frustrations, limitations, and inefficiencies I find comfort in the familiarity and safety in the acute care system. I didn’t realize that I felt this way. I thought that all the noise and busy-ness of the inpatient setting made it harder for me to cope with grief, but in fact, I seem to base much of my coping in the chaos. My time at [name of hospice] has...revealed my dependency on chaos to cope with emotions that make me uncomfortable. The thought of sitting with death and not looking at a cardio-respiratory monitor or charting or doing something frightens me. (McConnell, 2012, p.

2)

The chaos and busy nature of acute care where there is always noise, tasks, and responsibilities, the difficulty of the work, the distress, and the hurt that nurses feel can be hidden in this setting. Avoiding the quiet spaces, where emotions can come to the surface, can help to mask the hurt that threatens to overwhelm acute care nurses.

Haunted by Horrible Ghosts

...(crying) when I talk about the ones passing and their little faces come up...you know and I see them all and I feel sadness for their loss...(crying) when I talk about the other ones, whether they died or not, that weren't treated well...their little faces come up too and you know what it's like. It's like horrible ghosts that come around (crying). (Sarah)

Ghosts, “the soul of a dead person, a disembodied spirit imagined, usually as a vague, shadowy or evanescent form, as wandering among or haunting living persons” (Dictionary.com, 2015), tell us something about ourselves and how we conduct our lives. “In all the tales of ghosts who want to be set free, what holds them back is memory. They continue to remember what physical life was like, and the unfinished business of those memories has a grip” (Chopra, 2006, p. 87). Perhaps the ghosts Sarah referred to are present in order to remind her of “unfinished business.”

The idea that ghosts serve as a reminder, an incentive to remember the deceased is a long standing idea in human cultures the world over. Famous (and fictional) ghosts are created to teach us something, such as the ones in Charles Dickens' *A Christmas Carol* first published in 1843. In this story, each of the three ghosts walks Ebenezer Scrooge through his life: past, present, and future. It is through this experience that Scrooge comes to better understand his life and how he has impacted others. Furthermore, Scrooge sees the chains his former business partner, Jacob Marley, carries which are described as “long, and wound about him like a tail; it was made... of cash-boxes, keys, padlocks, ledgers, deeds, and heavy purses wrought in steel” (Dickens, 1843/2003, p. 44). While this is one of the most famous works of fiction in English literature, it also speaks to a truth about the noisy metallic boxes we drag behind us (Hollis, 2013). Perhaps today's nurses carry the weight and the ghosts of generations past as well as their

own: “Those [military nurses] who wrote later of their wartime work described feeling ‘haunted’ by their experiences” (Hallett, 2014, p. 103).

In the context of pediatric acute care, it would seem that children with PLSIs who had a troubling story or death turn into ghosts who haunt nurses’ memories and return to life through the stories nurses tell. However, some children, as Sarah described, are the children who were not well treated by their families who are horrible ghosts—they are a reminder of past horrors.

Suddenly there was rustling in the bushes by the side of the path. Savitri jumped back.

“What was that?” she exclaimed, feeling the return of her anxiety.

“Ghosts.” Ramana had stopped short. “It’s time you met them, for having traveled beyond this life, ghosts and spirits have much to teach.” (Chopra, 2006, p. 81)

Learning can cause suffering, just as suffering can offer opportunities for learning: *pathei mathos*, which means “learning through suffering” (Gadamer, 1960/2006, p. 351). What is more, there is a particular difficulty with these ghosts as they point to a reality that none of us want to live with:

And I’m sure that the people that did these things [harmed/abused] to these kids or neglected these kids, I’m sure there’s a source for that. But I don’t want to live in a world, I don’t want to see that, I don’t want to acknowledge that. I don’t want to it to be true. (Sarah)

It is likely nurses on the unit will be able to recall almost instantly which former patients continue to haunt them. Rashotte wrote about how nurses carry stories that haunt them and how certain deaths will always haunt them (Rashotte, 2005; Rashotte et al., 1997). The “etymological origins or the word ‘haunt’ surprisingly capture the true essence of the *raison d’être* of our need to forever keep sacred our stories of the children’s deaths that haunt us” (Rashotte, 2005, p. 35).

These stories come quite quickly to nurses' consciousness and it does not require more than a few seconds for a nurse to recall these stories. This is true not only for me, but also for the participants as well as the nurses who chose not to participate in this study, but recalled their haunting stories in the grocery store, at a local coffee shop, and in the hospital cafeteria. "Stories survive and haunt us partly because they remind us of what we know and partly because they call us back to what we consider significant" (Rashotte, 2005, p. 40). While nurses may not dwell on these stories daily, the stories are never far from consciousness keeping us awake to the present: "We are never finished with the stories that haunt us" (Rashotte, 2005, p. 38).

Nightmares

"Even in our sleep, pain which cannot forget / falls drop by drop upon the heart"

(Hollis, 2013, p. 131, citing Aeschylus in Agamemnon)

No one wants to see a child code or be severely distressed. I mean, I'm a 30-year veteran and I go home and have nightmares about it. I cry. I mean I'm human. Everyone is human. It doesn't matter how long you've been in nursing, it's still hard because it's a child. (Lily)

Nightmares are not only "a dream arousing feelings of intense fear, horror, and distress" (The Free Dictionary Online, 2015), but the term is also used to describe events that happen when people are awake: "an event or experience that is intensely distressing" (The Free Dictionary Online, 2015). Nightmares have a long history dating as far back as the late 13th century as "'an evil female spirit afflicting sleepers with a feeling of suffocation,' compounded from *night* + *mare*" (Online Etymology Dictionary, 2015) and the meaning of the root "mare" has the etymology of "'night-goblin, incubus,' Old English mare "incubus, nightmare, monster'" (Online Etymology Dictionary, 2015). It is interesting that the word monster is etymologically

linked to the word nightmare. “Nightmares have fascinated us for centuries because they are so frightening, so primitive, so unlike waking experience. They are often alien to us, yet obviously ours, too, as though we have given birth to a monster” (Hartmann, 1984, p. 3). Monster is an interesting word as its etymological root of *monere* means “to warn” (Online Etymology Dictionary, 2015). So what do monsters warn us about the work of pediatric nurses working with children with PLSIs?

Interpretive inquiry, in fact, deliberately goes looking for ‘exaggeration’ (Gadamer, 1989, p. 115) and the monsters (Jardine, 1994; Jardine & Field, 1992) such exaggerations invoke, because such monstrosities often contain precisely the portends, the demonstrations, the lessons that are needed to be learned or the warnings (*monere*) that need heeding (Chua-Eoan, 1991). (Jardine, 2000, p. 195)

What is more, “monsters represent experiences of extremity which bring us to the edge. They subvert our established categories and challenge us to think again” (Kearney, 2003, p. 3).

The identifying features of the night-mare are evident in the terms used to refer to it. The etymology of the English word *nightmare*, for example, reveals a great deal about the experience itself. “Mare” comes from the same root as the German *mahr* and Old Norse *mara*, a supernatural being—usually female—who lay on people’s chests at night, suffocating them (Kiessling 1968). The specific terms for night-mare that are used in many contemporary cultures are etymologically related to words for “weight” and “pressing.” (Adler, 2011, p. 13)

The experience of having nightmares when asleep is certainly not exclusive to nurses. Nevertheless, in order to illustrate the feeling of suffocation nurses who work in this area, and

the weight that they carry, here is a description of a nightmare that I experienced a few months ago:

I am sitting in one of the old wooden rocking chairs at the hospital. I am facing a large window that looks out at a solid brick wall. In my arms is my middle child. He is about to die. I am screaming and crying from the depths of my soul—a cry I am painfully familiar with from my work as a pediatric nurse. I am all alone with my son in this state for what seems like a long time. I become aware that my son is moving. He struggles to get out of my arms and stands before me as a healthy five year old. He takes my hand and says, “I’m okay mom. I’m not dying.” He says this over and over. Yet I cannot stop screaming.

This is a nightmare that I had while asleep, but knowing what I know about the work I do, this is also a daily, awake nightmare I must live with. I must live with knowing the pain other parents face as they stand at the bedside of their dying child. In times where I have witnessed great sadness at the death of a child, I have stood there not as a nurse, but as a fellow human being and a mother. As a nurse I was not able to claim the grief and pain I experienced because of the unwritten hierarchy of grief. A mother whose son had been severely injured in an accident, but whose companion had been killed in the accident, described living within this hierarchy of grief.

For years I felt like I was standing in the shadow of the other mother: the one whose child was killed in the same accident that injured mine. To even use the word *grief* when talking about Neil’s losses felt fraudulent, like I was hijacking the very word from someone who knew true loss. Whose loss was terminal. (Roy-Bornstein, 2012, p. 198)

I have suffered the loss of children, but since they were not my own offspring, claiming and owning the loss never felt acceptable or appropriate. I have wanted to wail at funerals along with

the mother as I could relate to depths of her loss, but the child we grieved was not my own child. The pain of these parents will forever echo in my heart and relive in my nightmares—both asleep and awake. “I’d always had nightmares, but now the ghosts didn’t wait for me to sleep” (character Frank Pierce in the film "Bringing out the dead" Rudin & De Fina, 1999).

Paying the Price

Not everyone witnesses a child dying, not everyone witnesses a seizure, not everyone witnesses a child turning blue or suctioning a trach or watching a family disintegrate. That is not normal! But it is what our job description expects of us. And we do it well! And we do it well! But I think there’s a price to pay...but what price nurses pay, I don’t know. (Isla)

The expression of “pay the price” has the figurative meaning of “to suffer the consequences for doing something or risking something” (The Free Dictionary Online, 2015). While the nature and impact of the suffering of nurses is not definitive, the fact that nurses suffer is becoming an increasingly inarguable point (Adwan, 2014; Doka, 1989; Feldstein & Buschman Gemma, 1995; Marino, 1998; Morgan, 2009; Papadatou, 2000, 2001, 2009; Rashotte, 2005; Rashotte et al., 1997; Rushton, 2004, 2005; Saunders & Valente, 1994; Wrenn et al., 1999). The nature of that suffering and the cost has yet to be established. Furthermore, how that suffering is manifested varies: “Some of us let the hurt fester inside, creating an attitude of continual dis-ease and discontent with everything and everyone” (Vanier, 2008, p. 136). Isla was not the only one who referred to the burden of our work in terms of cost:

I’m proud that I’ve been able to deal with them [families of children with PLSIs] and have such good relationships, but it, those are the families that costs me the most too. Specifically, when I see my assignment, and I see that I have them, in a way I kind of

dread it too. Because I'm just like...oh, I give so much and then, to them, and then, in the end, like at the end of the day, I'm so burned out, I'm crabby to my family and everybody else who really, that mean so much in my life personally, they get the shit end of the stick—pardon my language. (Meg)

Isla spoke not only of the cost, the price that we pay as nurses for the work that we do, but the need to recognize the price and the toll that has taken on her. The price of the work does not come as one lump sum, but rather it slowly accumulates over time.

I think that's the cumulative that I've experienced and in denying myself that they had meaning for me. But now that they're coming up because I've got time to say, time and safety to say, "Okay..." And this is what it's doing to me. It's not just that they happened. (Isla)

In order to survive the emotional onslaught that awaited me each shift, I would invest energy in numbing my emotions and further concealing the darkness rather than letting in the light. One of my rituals to do this was to listen to angry and offensive heavy metal music, played at top volume, in my car on my way home after a shift. This would help me to forget distressing events from the shift and numb any emotions I had from the shift. By the time I pulled into my driveway, I was sufficiently numb to carry on with my life at home. This worked for many years, although there was a cost to that. I could function outwardly, but I was dying emotionally. "If it weren't for Primal Therapy, I would be dead from drinking and smoking too much and driving too fast. Even if this had not killed me physically, I still would have been dead emotionally" (Arthur Janov, as cited by Vingerhoets, 2013, p. 220).

The cost never seems to fully reveal itself, but rather in pieces over years. I have experienced this cumulative cost as a trigger to my memory, which can cause a reaction that is

inconsistent with the context. That is something I am familiar with and it seems to happen at the most unexpected times. For instance, I was at my son's preschool Christmas concert a year ago. A part of the concert was a slide show with photos of all the children in the preschool. As the photos rolled across the screen, they played the famous song "Over the Rainbow" by Harold Arlen and E.Y. Harburg. Seeing the photos and hearing that song triggered my memories of being at children's funerals, former patients, where the song was played and photos of the dead child were displayed on a screen. I ran out of the performance and into the parking lot in a mess of tears. I could not bear to see my own child's photo in such a way that triggered my memories of other children's funerals. Most nurses who work on the unit have similar stories and find themselves struggling to behave in a socially appropriate way: learning the name of a new baby in the community can trigger reactions or hearing about a friend's plan for a home birth where we fear for the health of the child. "The most primordial mode in which the past is present is not remembering, but forgetting" (Gadamer, 2008, p. 203). We often feel conflicted by both being terrified of forgetting, but not wanting to live with the memory.

Consequences for Not Dealing with the Burden

I think the system has to recognize that they're dealing with complex nursing issues. And there's a fallout for them that nurses are leaving. I mean if you look at the problems, if you look at the nursing magazine about the issues around addictions and dysfunctions, it's there! I think even in general they talk about sick time, there's so much talk about sick time right now and the abuse of sick time. Is it abuse?! Or is it just a coping mechanism? (Isla)

Nurses are not working in a culture that encourages them to deal with their emotions and burden. Stoicism and emotional control are highly valued in this context: "*I want to become as*

smart and efficient and brave as these women [senior nurses] are” (Rachel). The word “brave” struck me as a particularly interesting word. There is certainly bravery required in entering into the space between life and death—the liminal space, the threshold. Being brave is knowing it will be difficult, but doing it anyway. From the tale of Mella and the Python Healer: “[i]t is not that I have no fear,’ Mella replied. ‘I come to you because my love is louder than my fear...’” (McFarlane, 2012, p. 155).

Eventually, if nurses are not dealing with the burden of the work, it will come out in other ways. Isla talked about her desire to deal with her PTSD in order to address her pain, but also “*I don’t want to be that old bitchy nurse who’s mad at everybody and doesn’t function well in my old age, you know? (laughs) Maybe, I don’t know...I don’t want to be cynical” (Isla).* What is more, the cynicism extends beyond nurses’ work and into their homes where it cannot be removed, but rather acknowledged:

I am learning to live with it [the difficult consequences of the work]. But I’m learning to accept that I was vulnerable that my work life was affected and my home life was affected by some of the traumas that I held on to. You know, because I became a bit cynical and I became a bit cold to my family. Like, “What do you mean you’re sick?...You know what I just did today?” (Isla)

Not only would it be impossible to tease out the memories of difficult experiences, but those experiences nurses tend to hold on tightly to as it is through those experiences that they become experienced and learn how to make sense of their world. As Isla mentioned, there is a risk that the work and the distress have their way with nurses and leave them in a state of anger and cynicism: “*I see some really good nurses who stayed there a long time and they are bitter and they are angry and they moan all the time because that’s not the first time they have dealt*

with that” (Sarah). In order to mitigate the stress and distress of work: *“there’s a lot of drinking that goes on for nurses. For sure” (Isla).* This statement by Isla is consistent with evidence gathered by researchers studying substance abuse in nurses. Nurses have been identified as being particularly vulnerable to the use and abuse of substances “due to their typically high stress jobs, frequent contact with serious illness and death, and the accessibility of controlled substances in the workplace” (Griffith, 1999, p. 19). Furthermore, one study estimated that nurses have a 50% higher rate of substance abuse than members of the general public and one in seven nurses are at risk for developing an addiction (Epstein, Burns, & Conlon, 2010). Other studies uncovered similar findings: approximately 5% of nurses are alcoholics and 3% are dependent on drugs (Dittman, 2008); 10% of nurses have a drug or alcohol problem (Talbert, 2009); the prevalence of substance abuse among nurses is as high as 32% (Tariman, 2007). In fact,

Addiction among nurses has been recognised by professionals in the field for over 100 years, and current estimates place rates of substance misuse, abuse and addiction rates as high as 20% among practicing nurses. Unfortunately, fear of punishment and discipline may keep nurses or students from asking for help for themselves or from reporting a colleague or friend who is in need of help. (Monroe & Kenaga, 2011, p. 504)

Nurses need to find ways to help each other start to manage this burden and perhaps facilitating opportunities for nurses to share the burden with each other can most easily do this. The reality is that there are situations in the work nurses do in the care of children with PLSIs and their families that will never be acceptable or even endurable. Nurses need to find healthy ways to live with that unhappy reality. This is not always true, but there are times when the stories we carry of children with PLSIs are left open and raw, scaring us.

You know, the stories, the sharing....so as much as I am burned out and have probably Post-Traumatic Stress for which I am dealing, in my best moments, I look back and say...it's okay. (Isla)

The Dark Side of Family Centred Care

The way we have taken up Family Centred Care is one of the biggest problems that we face with chronic health care. (Sarah)

It was never my intention to address FCC in my dissertation beyond simply acknowledging this practice philosophy as part of the pediatric health care landscape. I did not ask a single question about FCC in my list of guiding questions that I used during the interviews. Nevertheless, every participant introduced the topic of FCC into the conversation for both positive and negative reasons. FCC plays an integral role in the work of pediatric nurses; therefore, I suppose I should not have been surprised that the conversations included some discussion of FCC. I knew from working in practice for many years that FCC was not perfect and I knew there was a dark side to the idealized practice philosophy. However, I had no interest in talking about FCC in my dissertation as it is a quagmire that I was hoping to leave well enough alone. I even considered omitting these findings completely as I did not want to wade into such precarious territory. I wanted to ignore this data because I felt apprehensive about expressing any disapproval of something as treasured as FCC. Nevertheless, it is for that very reason that I needed to summon the courage to open up and expose a side of FCC that is indeed disappointing and problematic. FCC is a powerful discourse, which is just the sort of situation that requires a hermeneutic approach. One of the roles of hermeneutics is to open up a space for other voices, other discourses, to be heard and examined.

If you really step back and came in at the end stage and you looked at the end stage and you looked at this kid with NG-tubes and everything and who is barely present...and then you think, well, really? Really? At what point is it crazy? And teasing whatever that is out that really, that's the Family Centred Care that I struggle with. That's the, it's the doing, it's putting your finger in the holes of a dyke. (Sarah)

It is time to begin an authentic conversation about what is happening with FCC and how it is hurting patients, families, and nurses with the intention of bringing about positive change.

Family Centred Care Causes Nurses to Struggle when Working with Families

Those are definitely the patients and families that are the most taxing, for sure. ...like those are the families and situations that kind of drive me out of nursing. It's just, I feel a little jaded in a way. You know, it takes away...you know, that ideal nursing. (Meg)

As one might imagine, this creates an unhappy situation for everyone. It is unfortunate because what draws nurses to this area of work are the long-term patients and families who they can get to know and work with closely over months and years. Nurses are drawn to the long-term connection with these families. However, it is ironic and disappointing that it is those very families who drive away the nurses who were drawn to that area of nursing by the families in the first place. It is as though the magnet that was drawing nurses to the area flips and instead of being attracted to work with families, they are repelled.

The long-term patients are the ones, like I said, the ones that burn me out the most and I would love to have like emerg or being in a doctor's office where ideally you have no relationship with them because it's less stressful. You help them in the crisis and then it's done. Like those patients that come in with a respiratory illness, I nurse them for two

days, they're gone home. You know what, that's rewarding. They're doing fine and it's the relationship that burns you out. (Meg)

Meg illustrated where she is challenged working with families over months and years when their child is very unwell with a PLSI. It becomes tiring to continually manage families and continue to advocate for the child for which appropriate treatment choices are uncertain. Paradoxically, while nurses are advocating for the best interests of their patients, nurses are sometimes faced with confrontation from families:

I'm her [the patient's] advocate too. I'm on your side [the parents' side]. I'm not against you. If you want her bagged every five minutes, if you think that's best for her, I'll tell the doctors that. Don't fight with me because I'm on your side. (Lily)

In some situations, the best interest of the child is not always being met by the decisions made by parents: *"Are we doing this in the best interest of the child? We are doing it for the family quite often. And all this intervention is it really addressing, you know, giving the best to the patient?" (Meg)*. This can cause a great deal of distress. Sadly, while nurses are fiercely advocating for their vulnerable patients, no one is supporting or protecting the nurses in this. No one is offering a safeguard for the nurses. Nurses also need protection, sometimes from the abuse of families and other members of the health care team. Nurses' vulnerability affects their sense of security and this reality is highlighted by this plea for physical barriers to protect nurses:

Because people [nurses on the unit] have reached the end, you know, like they were, the night staff were saying, "Can we bullet proof the med room?" Why? "Because we're afraid. The dad is pacing the floor on his phone and he's confrontive [confrontational] and abusive and all that." (Isla)

Family Centred Care: Concealing Child Abuse

The hospital environment is like no other in our society. Other institutions have rules and structure that must be followed and while there are areas of our society that would be even more strict (e.g., corrections), some of what goes on in the acute care setting can be difficult to believe. One thing that nurses are continually frustrated by and creates a lot of stress and jadedness is the practice of FCC allowing for not only the abuse of nurses, but also child abuse.

The hour-long conversations about, “Why are we not apprehending that child and she’s neglected and we just keep letting it happen and she comes in here sick all the time, blah blah blah.” It’s hours and hours and nurses bitching and moaning and getting angry and frustrated and questioning and nothing ever changing and parents that are unwell and in crisis and disruptive and causing havoc. And making choices for their children that are horrific...being witness to just the most maladaptive of behaviours and not have it part of their morning, but just you know what, that man is [mentally] sick and unwell and he just happens to have a child that is also [physically] sick and unwell. So because we are caring for the child, we have to be witness to his sickness, but it doesn’t make it okay, like all that kind of stuff.... Like if you were to say that to a person outside of health care, they would be like, “Well that is nuts!” (Sarah)

This scenario in the context of a child care facility or school would not have been tolerated, but because of the context of acute care and under the guise of FCC, abusive and neglectful parents are allowed to continue this behaviour that would be unacceptable in any other area of society. This has serious ramifications for the child, but also the nurses.

Probably the most frustrating was [patient's name] because you sensed that they were abusing her and neglecting her and probably spitting into her IV tube and feeding her meat when she was going for surgery. I mean, they were trying to kill her. (Jeanie)

When you allow a father, who is a child molester, on the unit because he's a father. Family Centred Care! He's a father! So he gets priority over the child molesting part. A little wrong. A little wrong. (Trina)

Summary

Through the work pediatric nurses do on inpatient units, they carry with them difficult and painful memories. Learning to live with distressing truths about the world is a struggle with significant costs and consequences. In the next section, I discuss the need for nurses to be present at meetings where decisions are made regarding the fate of children with PLSIs in their care.

CHAPTER EIGHT: BEING INVITED TO THE TABLE

We're not invited to the table! And I think that's the difference too is that the expectation is that you will care for this child without knowing necessarily what the plan is. Maybe they don't know either, but to be heard I think is as important as it is knowing an end result. (Isla)

Re-awakening Past Anger

I wrote three iterations of this chapter because what started off as using the participants' words to further unconceal a truth about what it is like for pediatric nurses in acute care quickly became a rant. The space that was opening up to allow the nurses' words to come out became filled with my own anger and frustration fueled from difficult memories from the past. I was so wrapped up in letting out my frustrations that I could not even recognize that this was happening. So through much re-thinking and re-writing, this version came to stand. I had to keep at the forefront of my thoughts that the work is by me, but not about me (Smith, 1991).

Being at the Table

The expression "being at the table" can be understood as having a place at a table to eat, to participate in decision-making, or to be simply as an included member of a group. There is a long-standing familial tradition of all members of a family congregating around the dining room or kitchen table to share a meal at the end of the day (Visser, 1991). This time has traditionally been a time for talking, sharing, and learning. It is in this context where children learn manners, family values, and socially acceptable behaviour. What is more, decisions affecting all members of the family are shared as well as advice imparted, stories told, and traditions and values taught. The ritual of sitting down at the table

...helped give rise to many basic human characteristics, such as kinship systems (who belongs with whom; which people eat together), language (for discussing food past, present, and future, for planning the acquisition of food, and deciding how to divide it out while preventing fights), technology (how to kill, cut, keep, and carry), and morality (what is a just slice?). (Visser, 1991, pp. 1-2)

With the introduction of television and other technology for entertainment, the overscheduling of children's activities, the lengthening of the work day, as well as an increase in the number of people employed in shift work, this is a dying tradition that used to play a central role in a family's daily life.

The expression "not at the table," or more positively, "at the table" in this context is not referring directly to the eating rituals and table manners of families. In this context, it relates to consensus building and decision-making and is used in human resources and business literature (Hoffman, 2007). The language of table is prevalent in this pocket of literature: negotiating table, bargaining table, and round table discussions. This is perhaps related to the discourse and interest this group has with negotiating and bargaining tables (D'Amico & Rubinstein, 1999) and the idea of "round table" discussions where there is no head and everyone is on equal footing. When Isla said that bedside nurses are "not invited to the table," she is referring to the decision-making family conferences that take place periodically for long-term, complex patients with PLSIs. At these meetings, health care providers, usually the hospitalist, resident, clerk, social worker, clinical nurse specialist, dietician, and the family, come together in a conference room and discuss the plan of care for the child involved. On occasion, the charge nurse or perhaps the unit manager will be in attendance. As a bedside nurse, and even as a charge nurse, I was included in only a handful of team meetings. When I was present, my role at those meetings was primarily as

someone to answer questions about patient care (e.g., medication times, feeding schedule); I was there to carry the patient's chart and look up information as required to move the meeting along. It is a shame that bedside nurses, the ones who spend the most time with the patient and family, are not routinely invited to join and actively participate in these meetings—they not invited to the table.

When health care teams do not include bedside nurses at decision-making meetings it is perhaps not with the intention of being exclusionary. It perhaps has to do with the fact that the logistics of having a staff nurse present is perhaps challenging. The unit is a busy place and nurses are stretched to and beyond capacity because of patient load and acuity, so in reality a bedside nurse cannot often be spared. What is more, the unit does not staff primary nurses for patients and with requiring 24/7 coverage, the nurse caring for the child that shift, may not know the child very well or at all. So, perhaps, it is evident that nurses are not always invited to the decision-making conferences for the reason of sheer logistics and practicality alone. Nevertheless, whether it is because of logistics or perhaps that bedside nurses are simply overlooked, there are some serious consequences to excluding the voice of an entire demographic of health care professionals who have something important and meaningful to contribute to the discussion and should have their knowledge and experience weighed in the decisions that are made. "Everyone brings their crumb of information to the table.... If they are not at the table, we don't benefit from their crumb" (Cohen, 2011).

I want some bedside experience in care and understanding [represented at meetings].

I'm educated. I have an educated mind and I want to express my opinion about the situation. Like I just, mine is never really considered, which is really irritating. (Meg)

The consequences for nurses to be excluded from important meetings and denied a place at the table is that nurses are left feeling powerless, voiceless, and silenced. They often fill the role of the task-doer, the puppet, and the waitress. Decisions are made regarding patient care without key stakeholders present. Nursing brings a unique perspective and come to know the family and patient very well. What is more, bedside nurses are better positioned to understand the emotional ramifications on their nursing colleagues, which is beyond what others can guess in terms of workload and time commitment for certain interventions.

I think it would be nice if they just asked us our opinion; not just what it's going to take for our time and our physical efforts. It's more than that. How do you feel? I would like my feelings to be acknowledged too. (Meg)

Participants used different language to describe what it feels like not to be invited to the table. The words are similar, but not enough to collapse them together into a single section as there are some important differences among the concepts. Therefore, powerlessness, voicelessness, silenced, and fear are presented in individual sections.

During the interviews with participants and during my analysis of the transcribed interviews, I was struck with the language nurses used to describe aspects of their practice leaving them feeling powerless, voiceless, and silenced. At first I assumed that this experience was somewhat unusual. It was not until I had fleshed out this finding that it was drawn to my attention that there is a growing body of evidence that indicates that the experience of powerless, voiceless, and silencing for nurses was not new, but rather further supports the findings in the work of others. Studies that report nurses who describe their sense of powerlessness and voicelessness in their practice (Erlen & Frost, 1991; Hamric, 2012; Holly, 1993; Kelly, 1998; Pauly, Varcoe, & Stroch, 2012; Woods, 2005) and have documented the experience of being

silenced (Austin, 2012; Varcoe, Pauly, Webster, & Storch, 2012; Wall, Austin, & Garros, 2015). What is more, not only did participants for this study describe a familiar phenomenon, but the identification of these problems dates back decades (Booth, 1983; Champion, Austin, & Tzeng, 1987; Katzman & Roberts, 1988; Prescott & Dennis, 1985; Sands & Ismeurt, 1986).

Powerlessness

I think powerlessness is probably the word that says it most. (Isla)

While it is evident that nurses hold some power at the individual patient level, bedside nurses do not have a lot of power to influence big decisions (Erlen & Frost, 1991). Nurses may be able to exercise their power in terms of one-to-one interactions, but in terms of being able to effectively inspire change and influence decisions that impact patients, families, and nurses, it would seem that nurses are in a position of powerlessness. Powerless means “the inability to get what one needs or wants (the social desiderata) and the inability to influence others effectively in ways furthering one’s own interests. ‘Powerless’ is a shorthand expression for ‘low index of power’” (Parenti, 1978, p. 64). As a group, nurses are educated, resourceful, experienced, and knowledgeable. Even considering the size and power of nursing unions would indicate that nurses are an influential and dedicated group. Therefore, if bedside nurses feel powerless and find that their voices are not heard, it makes me wonder how nurses are able to effectively advocate and help vulnerable patients and families. It would seem that advocating for patients is not being adequately accomplished as participants reported being powerless to stop ill-advised decisions from being made and from being implemented. What is more, bedside nurses are even powerless to stop abusive parents from continuing the cycle of violence with their children. There was a patient on the unit a number of years ago whose father was a pedophile and the mother was abusive both emotionally and physically:

...a lot of nurses were very upset about [name of patient], knowing she was going home to an abusive, neglect, abuse, and a pedophile sort of thing. That was the hardest case.

(Jeanie)

With the exception of one participant (Rachel) who was not working on the unit at the time, every participant spoke about this particular patient and the terrible situation bedside nurses found themselves in trying to protect the patient from a deeply disturbing cycle of violence in a highly abusive family situation. Isla described the powerlessness nurses felt because of their inability to put an end to the abuse or even influence the situation in order to protect the child:

We tried to do something about it because it was also the time that not only was the guy a pedophile, he was harassing nurses...and people were just terrified. Terrified! And nothing was done. I don't understand. I don't understand a system that would allow for that. I mean, today, this day in age...I just think we became so jaded you know by that by that experience and the only thing we were told to do is document. (Isla)

The inability for nurses to advocate and protect a child not only vulnerable because of a PLSI, but living in a high-risk situation, is profoundly troubling. Patient advocacy is a moral objective as well as it being mandated by the Canadian Nurses Association: “Nurses advocate for persons in their care if they believe that the health of those persons is being compromised by factors beyond their control, including the decision-making by others” (Canadian Nurses Association, 2015b, p. 11). Yet this mandate does not seem to be always met in the context of pediatric acute care: *“I wish there was more advocacy in that way” (Rachel).*

By virtue of the nurses’ role on the unit, they are in direct contact with patients and families for extended periods of time, which means that nurses have more close and frequent contact with patients than any other health care professional. Therefore, nurses witness situations

that were cause for concern and see evidence that patients were not being well cared for by family members. Nurses witness first-hand the consequences and fallout of poor health care decisions. Yet as a group there seemed to be nothing nurses could do to stop decisions that were already in motion: *“We’d see these things going on, but we’d seem powerless to stop it”* (Jeanie).

What is even more distressing is that there are serious consequences to nurses feeling as though they cannot effectively exert their power on behalf of very sick and vulnerable children: *“I’m getting depressed. I’m feeling powerless. What’s the point? ...I just lost hope”* (Isla). We all lose something when the ability to advocate for our society’s most vulnerable is not exercised. Isla described how disappointed she was when those who held the power (or at least appeared to possess the necessary power) to change the system could not. This lack of power to appropriately and effectively advocate for vulnerable patients in the system may cause nurses to ask themselves if perhaps they should leave the health care system. “Everyone is powerless in some specific way” (Binstock & Ely, 1971, p. 1) and for nurses this powerlessness comes in the form of being unable to change the health care system for the better of patients, families, and health care providers (Erlen & Frost, 1991). However, as Isla acknowledged, there are significant barriers to those who try to change the system from the outside. This situation leaves nurses in a difficult position:

The people that I perceived had the power to change it, couldn’t. And that I was...I had the choice. Was I going to work in the system or was I going to leave it? You know, that’s always a tough call because when you leave the system you don’t have any power to change it. So I don’t know, I don’t know, I just...I’ve had a really, really hard time. A really hard time. (Isla)

Voiceless

We have no voice. (Trina)

Having a voice is something that is a fundamentally human characteristic. “For Aristotle, certain animals produce sound (*psophos*). Others have voice (*phone*). But only human animals have language (*dialéktos*)” (Bourke, 2011, p. 30). Having a voice is the “right of expression” (Merriam-Webster Dictionary, 2015) and “to say what you think about a particular subject, especially to express a doubt, complaint, etc. that you have about it” (Cambridge Dictionaries Online, 2015). In this context, nurses are expected to use their voices to advocate for their patients, but often nurses are denied the use of their voices.

I do find it very frustrating.... At the basis, for me, I often feel like, I don't have much of a say in it as a nurse. The doctors and the families, that's who is there and I'm just listening. It's almost disrespectful that way towards nursing, right? And then...the doctors have all the say and families. (Meg)

If nurses are not at the table, then nurses cannot have their voices heard. Major decisions affecting patient care are made and nurses are never given the opportunity to speak. Therefore, nurses are left voiceless meaning “having no vote or right of choice” (Dictionary.com, 2015) and “without the power or right to express an opinion” (The Free Dictionary, 2015). When it comes to decisions made around the conference room table that affect patients and nursing care: “*we really don't have a say in it*” (Lily).

There seems to be a great deal of information that nurses hold as well as a unique perspective that nurses would like to share with not only other members of the health care team, but also with families. Nurses want their voices to be heard not simply for the opportunity to exercise power or to vent anger or frustration, but rather with a genuine desire to share

knowledge and information with families honestly so that the family can benefit from another perspective: “*sometimes you just...less is more kind of a thing. Cherish each precious moment, which is what I want to say to the families sometimes [but can’t]*” (Meg). In the context of many health care settings, nurses’ clinical knowledge and expertise goes unrecognized; therefore, nurses are unable to affect change or even have their views known (Erlen & Frost, 1991). The consequences for nurses not to be able to voice their opinions and thoughts to families leads to frustration and leaves nurses voiceless to appropriately advocate for patients. For nurses in this situation, they are unable to speak and are in a position of wishing to speak: “‘To understand...hermeneutically is to trace back what is said to what wishes to be said’ (Grondin, 1995, p. 32)—just imagine, things *wishing* to be said” (Jardine et al., 2003, p. 149).

Silenced

“Silence is the real crime against humanity”

(Le Guin, 1989 as cited by Rashotte, 2005, p. 40)

When nurses do find a place to use their voices and feel that they can say what needs to be said, they are often silenced for their efforts. The silence that shrouds nurses’ voices is not empty. Silence is “neither muteness nor mere absence of audible sound” (Zerubavel, 2006, p. 8), but a “state of being forgotten; oblivion” (Dictionary.com, 2015). It is in this state that nurses are prevented from revealing a truth about what is happening for a child with PLSI in their care.

The voices of nurses are not welcomed when they do find an opportunity to speak. Isla recounted an incident where she was reprimanded for speaking up at a staff meeting on the subject of a poorly managed child who had been on the unit for years:

So she [hospital administrator] sat beside me and we started, she started, “really appreciate you guys being here, blah blah blah.” There’s 15 of us who came on our days off, right? “But I really have nothing to tell you...there’s nothing I can say.” I was like, “What!?” She said that she was really sorry that she didn’t know about this situation. And of course... “What do you mean you didn’t know about it!?” I was just lit. I just lit into everything. I said, “This has been going on for three years! How could you not know!?” Well of course [the unit manager] says that nobody told her. So [the hospital administrator] would say that nobody told me that these things were happening. It was like, “What!?” There have been letters written, there have been e-mails, I said, “We should pull up all the e-mails to show that this...” The administration knows about this, otherwise how else did they finance the money to pay for this one-to-one care? Anyway, so...I got really hot under the collar and so other people spoke. But then [the unit manager] called me in the next day and said that I was inappropriate and I dominated the conversation that nobody else was allowed to speak, which wasn’t true and that I had to write an apology to [the hospital administrator] ...I had to apologize to all the people at the staff meeting.... And so I got called in and I had to make all these apologies. (Isla)

Perhaps the conflict arises in part because nurses voice difficult issues with the purpose and expectation that a solution will be found. When nurses state openly and honestly truths about their work with patients and families at meetings sometimes what they have to say is difficult for others to hear. In the famous play, *Waiting for Godot* (originally a French play: *En Attendant Godot*) by Samuel Beckett (1952/1954), one character tries to talk about a dream, but the other silences him:

Estragon: I had a dream.

Vladimir: Don't tell me!

Estragon: I dreamt that—

Vladimir: DON'T TELL ME!

(Beckett, 1952/1954, p. 39)

Here Estragon's "nightmare can and must be suppressed. The unspeakable vision must be silenced, maintaining isolation" (Kane, 1984, p. 25). It would seem that this situation is also true for nurses who try to speak of difficult experiences and problems faced by nurses on the unit, but are forced into silence for sometimes these truths are unspeakable.

Nurses want problems addressed that are complex to fix or find solutions to. It seems to be problematic when nurses attempt to address these problems on their own. Nurses will, on occasion, undertake difficult conversations with families, but that is not always successful:

Isla: Ya and the pain and you know what they were putting this kid through was wrong. It was just simply wrong. Morally, ethically, financially, medically. Um and so...so I did speak up and I paid for it. Not badly. Like I didn't end up having to go to the, you know, higher ups.

SM: Would you do it again knowing or would you not knowing how it turned out?

Isla: That's what it is. If you step out of line, or if I step out of line, and I was silenced. So I talk about it with you and my colleagues and we talk about it over and over and like, let the child go, this isn't fair...and that's what we did with [patient's name]. We keep saying that this is just wrong! Medically, ethically wrong! Like, this is abuse! It's what's happening. And I never, I obviously didn't say a word [to the family or any administrators because of past experience].

Nurses learn that they are not welcome to speak, but then nurses are also not privy to all the information either. There is a sense that nurses are good enough to take care of very sick children and put themselves in harm's way to care for the children, but they are not good enough to be included in decisions, or even decision-rationale, that have been made. Secrets run rampant in pediatric acute care: *"This thing with [patient's name], there were so many secrets and confidentiality things [that we did not know what was going on]" (Isla)*. What is more, nurses put story fragments together and fill in the gaps to the information they are given. They will even invent and exaggerate stories to make them make sense. We are all storied beings: "people by nature lead storied lives and tell stories of those lives" (Connelly & Clandinin, 1990, p. 2). People need to make sense of their worlds and this is no different for nurses. They will make sense of the situation, even without all the information. Sometimes they find out what is really going on through their connections in the wider community outside of the hospital. Nurses may be completely denied the information at work, but there have been situations where parents posted the confidential information about their children on a community blog website for which unit nurses have also been members.

Based on past experience, nurses know that their voices will not be heard and, as a result, the silence grows as increasingly nurses remain silent: "Silence like a cancer grows" (Simon & Garfunkel, 1964). Over time they stop crying out against the injustices they witness.

I once visited a psychiatric hospital that was a kind of warehouse of human misery.

Hundreds of children with severe disabilities were lying, neglected, on their cots. There was a deadly silence. Not one of them was crying. When they realize that nobody cares, that nobody will answer them, children no longer cry. It takes too much energy. We cry out only when there is hope that someone may hear us. (Vanier, 2008, p. 9)

While nurses are often silenced “at the table,” they talk at their own table. However, I wonder if sometimes the silence is filled by words that are not necessarily articulating what the true problems are. Nurses can get angry about things that are not all that important, which is perhaps filling the silence in their hearts as there are things that are too difficult for them to articulate—even to each other.

I mean we all agree with how tough it is on the unit. How tough it is to deal with these families. We are just too busy to deal with, um, [8 second pause] um, to shift bases in order to talk like this [7 second pause] But anyways... (Meg)

“[S]ilence often involves an unspoken conversation. ‘What is she not saying?’” (Zerubavel, 2006, p. 9). Perhaps there are times when nurses say one thing when it really is something else that is causing them deep distress. Some distressing situations are beyond words. The philosopher Ludwig Wittgenstein (1889-1951) believed that the most important problems of the world cannot be put into words—these things exist even though we cannot speak of them. Therefore, we actually cannot talk about the most important problems in our world. In fact, according to Wittgenstein what cannot be expressed in language, must be passed over in silence (Wittgenstein, 1921/2014).

They [the very senior nurses] talk very openly, but they don't talk about their feelings too much though, you know. So, um, ya, for the new nurses and the rest, you just talk about tasks and how emotionally draining it is to deal with a mom who, um [5 second pause] well, you leave it at that. (Meg)

Afraid to Speak Up: Consequences to Stepping Out of Line

Only in conversation, only in confrontation with another's thought that could also come to dwell within us, can we hope to get beyond the limits of our present horizon. For this

reason philosophical hermeneutics recognizes no principle higher than dialogue.

(Grondin, 1994, p. 124)

Participants talked about how they felt powerless and silenced in their work with children with PLSIs and their families in inpatient acute care. Another part of this truth for nurses is the experience of living with the fear that comes with the risk of speaking out. Nurses are afraid to lose their jobs by speaking up for what they believe is right. Nurses are stripped of their morality. They are forced to act in ways that they do not believe are right because they are afraid to lose their jobs. They are afraid of the repercussions of standing up for what they believe to be the better course of action for children with PLSIs. When professionals are demoralized, they become addicted to incentives and they stop asking, “Is this right?” (Barry Schwartz, TED, 2009). Interestingly enough, participants did not use the language of moral distress, but Trina offered an example of what it feels like:

No we can complain all we want [about inappropriate or harmful care of children with PLSIs], but nobody does anything about it. That just does not make you want to go home and feel good about what you did that day. (Trina)

For nurses, who are not in a position to speak up, if they attend meetings they often say nothing: “*I really just wanted to say what I couldn’t say*” (Trina). Nurses know the potential consequences of voicing their opinions. Nurses, particularly those who have low seniority, are afraid of losing their jobs or being ostracized in some way. It would seem that the courage nurses must summon in order to speak up in the face of the threat of losing their jobs or being reprimanded comes when a nurse believes that she has “nothing to lose.”

I felt ignored. I didn’t feel valued. So my self-esteem was pretty much shot down because I thought I’d spoken up and taken a risk at saying, “This can’t go on! This is abuse! This

is clear cut abuse!” And I was the one that was reprimanded.... At this point in my career, I also didn’t have anything to lose...you know, I could quit. And I think that’s very real. I think staff are very, very afraid of losing their jobs or losing credibility or being targeted in some way. (Isla)

The Burden of Abuse

When nurses do speak out about their concerns around the care of patients and families or how nurses are being treated, there is an expectation that the nurse will be then forced to bear a burden of abuse as a result. It can be a difficult decision for nurses to either be forced to endure abuse or live in silence. Often nurses choose to remain silent as the burden of abuse is simply too great of a cost:

I wish there would be, the health region would hire someone to be that person to go to the families and be that, like, [name of a senior nurse] would be a great person that we could hire her because she would be...you know, she’s the one who’s gone to say to [a long-term patient’s name]’s family, “Is this really the best decision? Are you making the best decision?” And she said it once before, but it needs to be said a few times for it to sink in to them. For her to be the burden of abuse because she can also say it because I can’t say it. Because I can’t handle the abuse. (Meg)

Now that I have had some time away from practice to reflect on my experiences working in that context, I find it shocking that nurses are expected to tolerate abuse as part of their daily work. Yet I know that this was the culture and expectation when I was employed as a staff nurse on the unit. As with many institutions, there are policies set out by the health region stating that abuse of staff will not be tolerated. Interestingly enough, the posters stating the policy are found on the unit; however, they are posted in the staff room where no patients or families will ever see

them. It would seem that an abuse-free workplace is not high on the list of true priorities in child health. This tolerance of abuse is not seen in other areas of the health care region:

There's a lot of abuse at the [hospital name]. To nurses. There are signs everywhere in adult care, signs everywhere that abuse won't be tolerated and if someone tells you something that, certain things that we've been told by parents, like, it's not acceptable.... Maybe I just need to suck that part up. It's not fair. It's not fair to have to be abused, but sometimes I think I might just need to suck it up because my heart is in peds. (Trina)

The Result: Be a Puppet

It's like nobody listens to nursing. Like just do your job, follow the doctor's orders, but don't have any feelings. Be a puppet. Be a puppet. Do as I say. Don't ask any questions—of anybody, be it the physician or the parents. (Trina)

Participants described how they felt powerless and voiceless, which are reasonable words that come to mind when describing a puppet. This is a particularly fitting analogy because puppets are powerless with no voice of their own. Puppets say what someone else wants them to. Puppets do what someone else wants them to do. They simply go through the motions. Puppets are given knowledge and wisdom as well as a voice and a personality by those who control them.

The puppet has a long history and there have been records of puppets being used centuries ago (McPharlin, 1949). The use of puppets originally grew out of actors' use of masks to invoke images of other creatures. It was not long before the step to animate the image came into being and so was born the puppet (McPharlin, 1949). Of course, a puppet is known as a “doll that can be moved by wires or by putting the hand inside the body; a small figure of a person or animal, having a cloth body and hollow head, designed to be fitted over and manipulated by the hand” (The Free Dictionary, 2015) . The meaning of puppet seems to be

particularly relevant to this discussion: *“Pretend to be nice and put a smile on your face all the time and really you just want to say is: Go home. Do it your way” (Trina)*. Meg echoed this sentiment:

I honestly feel like a waitress sometimes when it comes to these families. I just do what I’m told from the physicians, from the families, I bring them what they want, do what they want. (Meg)

When nurses’ voices are not heard and they are powerless to change the situation for patients, families, or even for themselves, they just go through the motions. Another person, or perhaps the health care institution, dictates their behaviour and words and they become puppets: *“...it makes me feel like you’re just there to be a task-doer” (Meg)*. While it would be politically incorrect to make this statement today, the history and legacy of the nurse as the task-doer is not far behind us: “The nurse is not a medical practitioner – she is merely an instrument which carries out the doctor’s orders, and should remain so” (Katz, Mathews, Pepe, & White, 1976, p. 49).

The role of the puppet that nurses sometimes find themselves playing is all the more distressing in situations where the nurse knows that the child is experiencing trauma. It is then the nurses’ hands that carry out decisions made by physicians and families. The decisions made by others deeply affect nurses’ work, but they find themselves in a position of being in the middle, overlooked, and unrecognized. They are being asked to do things that do not feel like the right thing to do:

They [the patients] cry the whole time, their sats are going to go down, they’re going to be blue and we’re going to be bagging in the end because in the end is this so necessary? And it’s driven by the parents and the doctors...we’re going to be suctioning and stuff

and do you know the reality of asking this one little thing? I know you just think it's just one little thing, but it's not. It's a huge, it's a huge thing. (Meg)

Acknowledging Others' Perspectives

As I worked to edit this chapter, it became increasingly clear that the topic of nurses being unable to express their concerns about patient care struck a chord within me. I considered deleting this entire chapter as I was not sure I could manage it in a productive way. However, after some careful editing and now a critique of these claims, I have kept this section as it does reveal an important truth about what nurses in acute care come to live with.

Having had the opportunity to speak with advanced practice nurses and administrators, it comes to my attention that nurses are often invited to participate in decisions around unit policy, direction of patient care, and even nurse schedule changes. Be that as it may, nurses often do not show up. Therefore, when the administration learned that I was facing significant challenges in recruiting, they were sympathetic, although not surprised as it has been their experience that even when invited, nurses do not show up.

Learned Helplessness

Learned helplessness, in psychology, a mental state in which an organism forced to bear aversive stimuli, or stimuli that are painful or otherwise unpleasant, becomes unable or unwilling to avoid subsequent encounters with those stimuli, even if they are “escapable,” presumably because it has learned that it cannot control the situation. (Nolen, 2014)

What nurses have to say about the care and treatment of children with PLSIs is important and is needed at the table where decisions are made—decisions that change the direction of a child's life. However, through years of being treated as though their opinions, knowledge, and feelings are irrelevant and unwelcome, nurses have come to believe that they are not needed or

wanted at the table. This seems to have translated into a distrust of anyone who welcomes them to the table. An example of this is the challenges I faced with recruiting participants for this study. When nurses are asked to voice their opinions and tell their story at the table or “on the record,” it is nearly impossible to get anyone to come forward. It seems that there is a pattern where nurses want to be heard, but when given the opportunity choose not to come forward (Roberts, Demarco, & Griffin, 2009).

Summary

Bedside nurses hold a great deal of knowledge that could benefit everyone involved, particularly children with PLSIs, if they are included in the care plan decision making. Not only does that inclusion have the potential benefit of better patient outcomes, but the consequences of being continually excluded from meetings has long-lasting effects on nurses and patient care. In the next section, I discuss the knowledge nurses impart at the staff room table through stories, humour, and sharing vulnerability.

CHAPTER NINE: STAFF ROOM WISDOM—NURSES HAVE THEIR OWN TABLE

Isla: You know, the Kitchen Table Wisdom book was about the physicians and their problems and so I guess the research on the physicians' burnout and dysfunction. They are the highest suicide rate, you know, drinking and drugs...what's true for nurses?

SM: I guess it would be similar, but it's not exactly the same.

Isla: It's almost like, for us [nurses], it's "Staff Room Wisdom" (laughs).

Isla said this as a joke and we both laughed at the play on the title. However, there is an interesting truth revealed in the idea of "staff room wisdom." There is much more to being a nurse than completing a nursing program and passing the RN exam. The wisdom that passes between nurses in the staff room is not theory based, but rather it is the wisdom of what it means to be a nurse, the culture of nursing, how to survive in the profession, and the importance of nurse-solidarity.

...there is that vast wealth of knowledge which flows towards each and every human being in the transmission of human culture—poetry, the arts as a whole, philosophy, historiography and the other historical sciences. To be sure, such knowledge is "subjective", that is, largely unverifiable and unstable. It is, nevertheless, knowledge that science cannot ignore. (Gadamer, 1996, p. 1)

In order to prepare students to enter the nursing profession, students require a great deal of knowledge. The type of knowledge that nursing programs are able to impart is largely theoretical in nature. Undergraduate nursing programs aim to incorporate different ways of developing knowledge through programs such as simulation technology and practical hours in a variety of clinical areas. While the theoretical knowledge that students gain through textbooks,

journal articles, lectures, written assignments, and exam preparation are essential to nursing education, the wisdom and knowledge of nursing includes the intangible.

Nursing Wisdom: Becoming Experienced, *Bildung*

Nurses in practice will half-jokingly say, “You do not start learning how to be a nurse until you have graduated from school and start working on the floor.” The knowledge that student nurses learn in the academic setting is substantial, substantive, and imperative to the development of competent and accomplished nurses. However, for nurses who believe that learning begins once a student nurse has graduated are not referring to the theoretical knowledge, basic nursing skills, or critical thinking abilities that students learn while in a baccalaureate program. The knowledge these nurses are referring to is the nursing knowledge and wisdom that is learned through working as a nurse and learning the skills required for the practice setting, along with learning nursing culture. Gadamer called this *Bildung*:

Gadamer invokes the term *Bildung* for a strategic purpose: to demonstrate that alongside scientific and technical knowledge there exists another body of knowledge that is not the result of proof and demonstration but is laid down by tradition, received wisdom, and practical experience. (Davey, 2006, p. 40)

The word *Bildung* is derived from the concept of cultivation yet “the concept of *Bildung* transcends that of the mere cultivation of given talents” (Gadamer, 1960/2004, p. 10). *Bildung* “is not achieved in the manner of a technical construction, but grows out of an inner process of formation and cultivation, and therefore constantly remains in a state of continual *Bildung*” (Gadamer, 1960/2004, p. 10).

This ability to deftly judge the relationship between established knowledge and the arrival of a new case is itself a type of practical knowledge that does not operate in the

same way as the establishment of that natural scientific knowledge itself. It is, rather, a cluster of contingent practical judgments. One can become practiced in such judgments, but one cannot give a set of rules for how to make such judgments because those rules, in turn, would require cultivating, in practice, an understanding of their application.

(Moules, Jardine, McCaffrey, & Brown, 2013, p. 5)

Over time, nurses become experienced in a particular nursing area. Essentially, it is through time spent in the hospital or other clinical settings where nurses learn to survive and thrive in their work context. Therefore, nurses acquire *Bildung* and develop *sensus communis* through a number of ways. Gadamer understood *sensus communis*, or common sense, as the shared knowledge within a community. The literal translation of the term *sensus communis* means “common sense.” The meaning of “common sense” is often understood to be “the ability to think and behave in a reasonable way and to make good decisions” (Merriam-Webster Dictionary, 2015), although surely what constitutes a reasonable behaviour must originate within a particular group or community. What would be perceived as a reasonable course of action for some would certainly not be for others. Therefore, *sensus communis* is about what a community comes to understand as good sense as well as its collective purpose and direction.

...cultivating character and becoming someone because of what you know and do (*Bildung*), about judgement and tact, about *sensus communis*—the “common sense” that is build up through living in a community, and the moral tone that then comes, about the ability to make a good decision about what the right thing to do might be given the case that asks for good judgment from us. Such knowledge is eminently practical and substantive, but in a particular sense. Such knowledge is gained only through the practice of applying it to the cases and circumstances in which one is called to act, to think, to

carefully consider, and, by such means, becoming practiced in good judgement and in the judicious and careful application of a rule. (Jardine, 2015, p. 159)

Through years of practice where nurses work with many patients and families, they develop a knowledge of how to proceed and best care for patients. This is not learned through textbooks or lectures, but through the act of practicing the art of nursing in the world.

“It’s Just the Way It Is”

It’s just the way it is! (Isla)

There is a sense among the nurses that the nature of the work on the unit is “*just the way it is.*” The culture of the unit is such that the circumstances of the unit simply become part of the normal, ordinary, and taken-for-grantedness of the everyday. Nurses are expected to manage all their tasks and responsibilities without incident, without putting in for overtime pay, and without complaining. It is widely understood by the nurses that it takes some time to get used to the “way it is” on the unit; that “[b]ecoming cultured (*Bildung haben*) is enabled by being rooted in a given culture (*Bildung*)” (Davey, 2006, p. 40) necessarily requires time to be spent on the unit. Often new nurses will arrive on the unit long before their shift starts in order to read patients’ charts and review the patients’ medications and so on. For some, it is the only way they can survive in the fast paced, stressful work environment. Over time nurses either adapt to the work, or they quit.

It was fine [working on the unit] because you were in the swing of it and you’re used to it and you know the routines and I felt like I could handle just about anything. But it took at least a year to get to that point where you felt like you could handle just about anything.... You get comfortable after about a year and after maybe two years you’re

quite comfortable. But before that, it's very, very stressful just learning about everything and carrying on. (Jeanie)

Nurses in this area do their best to support each other and help each other whenever possible. However, more often than not, nurses are left alone to manage their patients as other nurses are just as busy with their own patients and cannot spare time to help their colleagues, as much as they would like to:

I also find it challenging working with other nurses who are also under a high stress assignment as well because you want to do what you can to help them, but sometimes it feels like you can't and I think that can be a challenge in between nursing staff as well, but it's something that our unit is becoming more and more used to. (Rachel)

Nurses seem to simply get used to it. They have learned that things do not seem to change, so they seem to make the best of it. They try their hardest and just keep going. When shifts are unrelenting in their demandingness and nurses do not even have time to do the basics, such as assessments, this leaves nurses feeling deeply dissatisfied with their work: *"When it's a crazy day and you're running around and you...get your assessments done, but that's it, then you feel like you haven't had a good day"* (Heather).

Breaking the Rules in order to Provide FCC

Learn and obey the rules very well, so you will know how to break them properly

– *The Dalai Lama* (Rohr, 2011, p. 137)

Learning how to navigate the system to fulfill unit expectations, but to also meet FCC is a skill many nurses learn through becoming experienced. Participants spoke about how difficult it can be to provide appropriate and supportive FCC to the child and family under the institutional rules, regulations, and expectations. This is not an original finding as it has been documented

elsewhere in the literature (e.g., Rankin, 2014). Research suggesting that tension exists with FCC in pediatric health care is highly controversial. FCC is treasured in pediatric health care: “The concept of family-centred care is such a cherished tenet of paediatric nursing to be almost above critique” (Darbyshire, 1995, p. 31). Nevertheless, there is conflict between being able to provide patients and families with good FCC and the regulations and expectations of the health care institution. Nurses are situated between the routine of the hospital (e.g., medication administration times, physical assessments on a strict schedule of every four hours) as well as the policies and rules (e.g., no co-sleeping, one parent only at the bedside and no siblings allowed to stay overnight), but in order to provide good FCC, it seems to mean that nurses need to break the rules:

I try to tell people to prioritize your assessments on acuity, but also what's happening for each patient. If that mom just fed that baby and just got that baby to sleep and that baby is going to eat again in an hour, don't go and assess them. Or you know, if you feel like, oh it's one o'clock and I haven't assessed your baby and your baby is breastfeeding or is about to breastfeed, don't assess the baby before they breastfeed because you're not going to get anything accomplished. The baby is going to scream and you're not going to have a good assessment. So, it's funny because I guess my advice is to break the rules (laughs). (Heather)

Having the confidence and the knowledge to break the rules in order to offer good FCC is something that develops over time. “Only by exposing oneself to the experiences that the practical acquisition of the facts and skills pertinent to a given discipline expose one to, is it possible to become a good or, rather, a *more understanding* practitioner” (Davey, 2006, p. 39). For instance, Heather talked about breaking the rules of when assessments should be performed

and delaying the obligatory eight o'clock assessment to allow the child and father to sleep. She also violated the strict policies of no co-sleeping and she allowed the child to sleep in the chair with her dad and not in the hospital crib:

My nursing care has changed over time and it's partially because I've had kids, but also because I've worked there for so long. If my chronic kid is sleeping, I don't assess them right away...the other day my chronic kid, I didn't assess until 10:30. She was asleep and breathing in dad's arms and they were sleeping together in the recliner and I thought "Oh, you're okay." And I'm sure lots of people judge me! (laughs) When this is their normalcy, this little girl, she's the one who just turned one and she's been home for two months of her life. And they're from Regina! They live at Ronald MacDonald House. And the dad spends every night at the bedside. And I think that if you're going to be sleeping with your baby in the recliner, I don't care. (Heather)

In this situation she likely provided excellent FCC to a father who spends a lot of time in acute care. Nevertheless, she risked being caught violating rules for which there can be serious consequences including dismissal. She also risked being criticized by her nursing colleagues, particularly those who are primarily interested in toeing the institutional line. Heather is a 10-year veteran to the unit and she developed the confidence to break the rules of the institution over time. Isla had a similar comment on how she is able to provide the best FCC:

Isla: I think I probably broke more rules than I kept...but that came with 25 years of knowing what's important. But a new nurse, it's the letter of the law and it doesn't mean, they're excellent technical nurses and they're also good nurses, but....but it takes time and experience and wisdom. You can stand up and say, "A stable baby doesn't need to be woken up every 4 hours for vital signs." You know, basically common sense. I think that's

partly what I miss, what I will miss is the gift that I brought to families. You know, I really did. (Isla)

This is not the same thing as becoming an expert as being experienced “means becoming more sensitive to the subtle differences and openings and opportunities that new experiences can bring” (Jardine et al., 2003, p. 177). Furthermore, becoming experienced and well-versed in a culture

...does not involve the acquisition of predictable responses to known problems but the accumulation of sufficient practical experience within a discipline so as to offer a spontaneous and yet informed response to a question permitting it to be grasped in a new and unanticipated way. (Davey, 2006, p. 39)

Isla spoke of the experience and wisdom that nurses develop over time and it is this knowledge that allows her to break the rules and provide the care she believes is best for the patient and family. It is about being experienced and exercising her practical wisdom. New nurses bring theoretical knowledge to the practice setting, but it is through the experience of working with patients and families that he or she develops an understanding of how to navigate in this environment and become experienced. It takes time to develop the wisdom to know how and when to break the institutional rules to provide the best care possible to patients and their families. Breaking the rules is not about taking short cuts or cutting corners simply to save time. Rather it is about nurses doing their very best to honour the child and family and their needs by moulding the institutional rules around them whenever possible. There are now so many institutional policies and regulations that it would be nearly impossible to observe them all. What is more, often as the number of rules increases, common sense decreases:

Thus judgement requires a principle to guide its application. In order to follow this principle another faculty of judgment would be needed.... So it cannot be taught in the abstract but only practiced from case to case, and is therefore more an ability like the senses. It is something that cannot be learned, because no demonstration from concepts can guide the application of rules. (Gadamer, 1960/2006, pp. 27-28)

While many of the institutional rules are helpful in keeping patients safe and healthy, rules do not provide patients, families, and nurses the important connections and the joys that can come with caring for other human beings. For instance, for pediatric nurses, bathing babies is one of the most wonderful and enjoyable tasks of the work. One senior nurse breaks the rules not only for the sake of the child to have a pleasant bath and experience a caring touch, but she breaks the rules for her own sake as she delights in the love and care she can offer these children: *“I know [senior nurse’s name], she still bathes those babies. She’s not supposed to use her stuff [scented soaps and lotions], but she does it anyway” (Isla).*

The word “rule” is often associated with the meanings of control, authority, and power (Merriam-Webster Dictionary, 2015). Rules are often presented as institutional policies and guidelines. While rules are not necessarily a bad thing as they are meant to inform the best ways in which to practice, they are not necessarily in alignment with the best ways to care for a particular child at a particular moment. It is through appreciating the particular needs of patients and families within the context of acute care that nurses develop unwritten rules that are not documented in the policies and procedures guidelines upheld by the health region or hospital administrators. These rules are about the best way of going about something—a rule is “a piece of advice about the best way to do something” (Merriam-Webster Dictionary, 2015). Therefore, in caring for children with PLSIs in acute care, bedside nurses are faced with navigating the best

way to approach the care of a particular child through being aware of the institutional rules, but also the rules they have learned through becoming experienced as a nurse.

There are situations nurses are faced with where not only do they violate the regulations of the institution, but also their own personal rules about professional boundaries. However, in the business of caring for sick and dying children, policies are not always appropriate and relying on basic human instinct, is sometimes the most appropriate and ultimately the most healing thing for nurses to do for not only patients and families, but also for themselves.

...she passed away the next morning in ICU and I had one of my children with me. And I went in and I feel that this was unusual as this is a boundary that I usually don't...I would never usually bring a child of mine A, into that environment or B, when a parent has lost a child, they don't need to see my young child, but I had him with me and I just had to go to her [the mother of the dead child] and um....(crying)...I had to hug her and tell her how sorry I was and let know that I knew (crying) that I was in the presence of a really special kid...(crying)...and as a parent it would have been important for me to know that someone really saw my kid, you know, really saw my kid. (Sarah)

Sarah recognized that her need to be with the mom and be with her in the moments following her daughter's death were more important than upholding the professional boundaries that Sarah had developed through her nursing education and practice.

Attention to Language: The Words Nurses use Behind the Staff Room Door

"Understanding is language-bound," says Gadamer, meaning that in and through language we have our being in the world. Language opens up a world, even in a foreign language, in what Gadamer calls the "inner infinity" of a dialogue in the direction of the "truth that we are". Genuine speaking in actual dialogue is what truly opens up a world.

Language is integral to the universality of the hermeneutical experience. (Palmer, 2007, p. 75)

Staff room wisdom also includes an exclusive language that nurses share, which is the language of insiders. The language of nurses could perhaps be thought of as a foreign language to those on the outside. It is behind closed doors where nurses often speak their “foreign language” to each other. One way of establishing and re-enforcing solidarity of a group is through language: an “important aspect of interpersonal relationships related to solidarity and power is that of linguistic accommodation, where speakers will modify their language patterns in interactions to make them more like those of the people with whom they are speaking” (O'Grady & Archibald, 2000, p. 508). The way nurses speak to one another has distinctive sociolinguistic patterns within their speech community, which is governed by rules about the use of particular terms that are not shared with those outside of the community (O'Grady & Archibald, 2000).

In a private setting where nurses are at ease to speak freely, they are more honest than they are in front of patients and families. Nurses engage in the raw laughter of dark humour; they say difficult things that others outside the community of inpatient pediatric nurses might not be able to bear hearing; they use words and language that would be considered politically incorrect, even offensive, outside of the group. Nurses are aware that the words they use to describe children with PLSIs are not particularly kind. Finding appropriate and sensitive language to accurately describe the population of children with PLSIs is challenging—a moment when language fails us (Gadamer, 1960/2006). Children with PLSIs is the term I selected to use for it is the one that is currently used by influential and well-respected organizations supporting the work and care of children with palliative diagnoses (International Children's Palliative Care Network, 2014a; Together for Short Lives, 2014a). Furthermore, the language of “short lives” to

describe children with PLSIs moves away from the restricting idea of “limited” lives. In the academic setting, the term for children with PLSIs was readily accepted. However, using this term in the interviews or in the recruitment process, participants seemed to understand the patient population I was referring to and appreciated the language of “progressive life shortening,” although it was not the language that is used in the context of acute care where children with PLSIs are cared for. Even though I had chosen to use the label of “children with PLSIs,” I felt awkward using that language in the context of pediatric acute care with my nursing colleagues. In beginning the interviews with participants, I often struggled and stumbled over my words trying to explain the patients I wanted them to talk about:

For my research, I'm looking to better understand what it's like for us to care for the, um, (pause) so it's the long-term, chronic kids, I've called them children with Progressive Life Shortening Illnesses, so I'm interested in learning more about what it's like for us to take care of the kids who are chronic, we don't know when they're going to die, technically they're palliative, although I know that isn't always the language that we use in acute care. (SM)

It is in these moments I wanted to use the words, the vernacular, of the acute care context and of my past; however, I was aware of their inappropriateness within the larger pediatric palliative care and academic communities. There is a difficulty with the language as we have difficulty naming children with PLSIs without using politically incorrect language or even stigmatizing, condescending, or language that takes away from the love and affection we have for these children. Nevertheless, the words nurses use to capture this population in language offer something to the understanding of these children: the chronics, the chronically acute, and the broken babies.

The Chronics

I find the chronics are in less [frequently] than they were 10 or 15 years ago, but I think we're getting more chronics [overall] than we had 10 or 15 years ago. (Lily)

A chronic disease “is a long-lasting condition that can be controlled but not cured” (Centre for Managing Chronic Diseases, 2015). Many people, myself included, live with chronic diseases. The language of “chronic” used by participants captures the ongoing and long-term nature of the illnesses children with PLSIs endure as well as the lack of cure available. However, what this language fails to capture is the progression of disease and the eventual early death of the child.

In conducting a literature review for this study, I did not include the search term “chronic” as I wanted to better understand children with illnesses that were progressive in nature and ultimately deadly. I wanted to distinguish this population from children with chronic illnesses such as diabetes, Celiac disease, or arthritis who are generally healthy with a continuing need for medical management for pain and symptoms. The word “chronic” captures the prolonged, unending, and constant nature of the child’s challenging health conditions, and is politically acceptable. However, it does not suggest an early death, which is a unique aspect to appreciate with the population of children nurses care for in their practice. Interestingly enough, participants used the word “chronic” in a variety of ways to describe not only children with PLSIs, but also their families: the *chronically ill*, the *chronic kids*, the *long-term chronically ill kids*, the *chronic-ish patients*, the *chronic families*, and the *super-chronic patients*.

The Chronically Acute

But I also find that I get more satisfaction working with these patients and these families because I feel like I'm part of their journey more. So that's what I like about the chronically acute [patients]. (Rachel)

This is a commonly used term by front line nurses as well as I have heard administrators use this term. It is an interesting term as it is an oxymoron. By its very definition chronic means not acute. However, the reality on the unit is that the patients are ill with conditions “marked by long duration” (Merriam-Webster Dictionary, 2015), but remain in an acute state “demanding urgent attention; very serious and requiring serious attention or action” (Merriam-Webster Dictionary, 2015). Acute lends itself to the image of action, intervention, and treatment, which is usually temporary in nature. Yet children with PLSIs require acute interventions to manage their chronic illnesses over a long period of time. Consequently, children with PLSIs are treated acutely for a chronic length of time. In some sense, it is a long-term state of urgent attention and action. Interestingly enough, nurses become accustomed to caring for children with PLSIs in this state where normally concerning vital signs (e.g., low oxygen saturation, high respiratory rate) become part of the ordinary landscape of the pediatric acute care setting with children who are “chronically acute.” This is a particularly fascinating term, which helps to shed light on the back and forth between life and death and care and cure.

Broken Babies

She was completely broken...ultimately I knew when she died, we'd done our best. And you know...she was broken. (Lily)

One term to describe children with PLSIs, particularly those children with significant failures to multiple body systems, are often referred to as “broken.” It is unusual in every day

speech to talk about people as “broken” for we have many other words to describe people in a state of being unwell: sick, ill, unhealthy, ailing, disabled, and so on. The use of the term “broken” in the context of babies is somewhat horrifying—particularly for outsiders. Objects that cannot be fixed are broken. While it is a difficult reality to accept, children with PLSIs have conditions that we are unable to cure or even effectively treat and manage over the long-term. Furthermore, the way in which the health care system approaches the care of children with PLSIs is to fix, not as a whole, but rather as divided into parts. Healthy children, seen as “whole,” and not “broken,” are often cared for over time by one family doctor. “Broken” children are separated into pieces and not treated as one whole person. Broken means “violently separated into parts” (Merriam-Webster Dictionary, 2015), which is certainly how we come to understand the child in terms of systems. It is not uncommon for a child with multiple system failures to have a whole host of medical specialties caring for them: neurology, cardiology, surgery, gastroenterology, and so on. “Even when we say that we have succeeded in ‘mastering’ or controlling an illness, it is as if we are separating the illness off from the person involved” (Gadamer, 1996, p. 111). Each medical specialty brings a particular skill set and knowledge to help manage the child’s disease process and symptoms. However, these services are siloed and focused on one body part and it is not uncommon for there to be disagreements amongst the specialties in terms of how to treat the child and who should be the primary specialty caring for the child. Often arriving at a consensus of treatment for the patient is difficult for health care professionals and downright terrible for children with PLSIs and their families. Calling children with PLSIs “broken” reveals how our system manages their multiple challenges, but also how they are addressed. Children are treated like something to be fixed, although in the case of children with PLSIs, they cannot be fixed or repaired.

Perhaps, more distressing, is the fact that these children are treated as though they are not a whole person: broken also holds the meaning of imperfect and damaged. As a nurse on the unit, talking about children as broken seemed like an apt, even though controversial way, of describing these children. Nevertheless, it is distressing to call a child, who is a person in a body, a small and fragile body, as broken.

... it is impossible to treat the body without possessing knowledge concerning the whole of being. In Greek the whole of being is *hole ousia*. Anyone knowing this phrase in Greek will also hear, alongside the expression ‘the whole of being’, the suggestion of ‘hale and healthy being’. The being whole of the whole and the being healthy of the whole, the healthiness of well-being, seem to be most intimately related. In German when one is unwell one says ‘Es fehlt mir etwas’ – literally, I am lacking in something.

(Gadamer, 1996, p. 73)

Knowledge Dissemination through Nurses’ Stories

As nursing wisdom is not acquired in a classroom, the dissemination of this form of knowledge is not done through a lecture or textbook. Knowledge dissemination “involves identifying the appropriate audience and tailoring the message and medium to the audience” (Canadian Institute of Health Research, 2015). For nurses, one way that the dissemination of wisdom is accomplished is through nursing stories, which appeals to the audience and is appropriate for the knowledge to be disseminated. What is more, stories are also a way for nurses to support one another.

“I would ask you to remember only this one thing,” said Badger. “The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food

to stay alive. That is why we put these stories in each other's memory. This is how people care for themselves." (Lopez, 1990, p. 48)

When nurses are asked what comprises nursing, nurses are often challenged to explain what it is exactly that they do. Certainly there are assessments, charting, medication administration, and procedures. Yet perhaps an answer to this surprisingly difficult question may lie within the stories that nurses tell each other. A truth about what it means to be a nurse and the way nurses understand the world lies within the stories they tell each other.

I am mindful in my use of the word "story" in this context. The word story has contradictory meanings. The word story embodies the idea of "a fictional narrative" and "a widely circulated rumor" (Merriam-Webster Dictionary, 2015), but the word story also means "an account of incidents or events" (Merriam-Webster Dictionary, 2015). Interestingly enough, the word story has an etymological connection to the word history (Online Etymological Dictionary, 2015): "a chronological record of significant events...often including an explanation of their causes" (Merriam-Webster Dictionary, 2015). In any case, it is the etymological origins of the word "story" meaning "narrative of fictitious events meant to entertain" (Online Etymological Dictionary, 2015) that has given it a sense of being nothing more than playing pretend or wasting time. However, even if stories are not necessarily an accurate representation of events that does not mean that stories, and in this context nurses' stories, are not without value and contain "truth." "Story was originally the way that things were passed on, messages communicated, morals disseminated, teaching embedded, and legacies immortalized.... Parry and Doan (1996) spoke of stories as images of meaningfulness in lives, rather than truthful representations" (Moules, 2006, p. 231). Therefore, the concept of story in this context is

intended to mean both a record of significant events, but also a means to share and advance nursing knowledge.

To say a story is a myth does not mean it is a lie. It may not be literal fact, but it tells a story that is deeper than fact because it holds an important truth about life. We put the truth into story form because humans use stories and pictures to understand what cannot be seen and touched.... Collectively, these stories are part of our global heritage, the wisdom passed down through generations. (McFarlane, 2012, p. xii)

It is through telling and re-telling, listening and re-listening to stories that nurses communicate experiences, clarify understanding, state values, strengthen bonds, and pass on wisdom and tradition. Storytelling for nurses is a way of establishing nursing practice and passing on nursing tradition. We stand within our nursing history and nursing traditions whether we remember and acknowledge them or not. It is through our stories that we are able to disseminate knowledge of what it means to be a nurse.

The format of oral storytelling is beneficial in disseminating knowledge, wisdom, and tradition as well as offers an opportunity for healing through listening and recounting stories. When I think of nurses telling difficult stories of their nursing experiences with death, pain, illness, and suffering, I think of not only the audience, but also the physical place where these stories are told. The context of where nurses tell their stories is an important consideration. In my experience, these stories are generally told to one another on the unit, or at least on hospital property, where the experiences most often occurred. Despite the hustle and bustle of the unit, private spaces to share stories are found: medication room, nursing station, staff parking lot, or even whispered outside patient rooms. There is something about the physical context of the hospital that allows for these stories to emerge. Outside of this context, these stories cannot be

told in the same way. Perhaps there is a reprieve within the bounds of the hospital that protect us briefly from the dominant societal discourses. The discourses that follow the “modernist expectation that for every suffering there is a remedy” (Frank, 1995/2013, p. 80) and that would have us tell a restitution narrative (Frank, 1995/2013) or perhaps the *Chicken Soup for the Soul* version of our experiences. Perhaps because of our presence within the context of the hospital where denying the horror of illness and death is not possible, we are allowed the space to tell the chaos narrative (Frank, 1995/2013). This is the space where nurses can tell stories that reveal, even briefly, that “life sometimes *is* horrible. This horror is a mystery that can only be faced, never solved” (Frank, 1995/2013, p. 112) which is something modernity has a difficult time accepting (Frank, 1995/2013).

At the beginning of this chapter, I included a segment of transcript where Isla referred to a book called *Kitchen Table Wisdom* written by a physician, Naomi Remen. The book is a collection of short stories about illness, hope, and healing. The book also stresses the importance of stories in our lives. Remen believed that stories are an important part of our lives and how we construct our worlds.

Everybody is a story. When I was a child, people sat around kitchen tables and told their stories. We don't do that so much anymore. Sitting around the table telling stories is not just a way of passing time. It is the way the wisdom gets passed along. The stuff that helps us to live a life worth remembering.... We may need to listen to each other's stories once again.... The stories we can tell each other have no beginning and ending. They are a front-row seat to the real experience. Even though they may have happened in a different time or place they have a familiar feel. In some way they are about us, too.

(Remen, 1996/2006, p. xxxvii)

It is through the telling and listening of stories that many nurses on the unit learn about the culture of the unit, how senior nurses manage their experiences, how relationships are built and strengthened. This is where the nursing group continues to define itself and begins to create and teach cultural norms, which include how to conduct oneself in a crisis on the unit and culturally sanctioned “nurse humour.” This does not take place around a kitchen table in someone’s home, but rather around the little table in the staff room where nurses congregate at break time. Nurses have received criticism about their preoccupation with breaks. It is not just because nurses want a chance to sit down, have something to eat, and enjoy a brief reprieve from alarming monitors and crying children, but it is also a time for sharing and communion with nursing colleagues.

Why do we huddle over coffee to tell our stories or hear those of others? Why did I want to gather the stories of grief of my colleagues? When we listen to others’ stories we compare them with our own, to find a sense of communion with others’ experiences, to feel like we are not alone in this journey to understanding. When we listen we learn by trying to understand how others experienced and survived their grief. Can their stories be a lesson for my own survival? (Rashotte, 2005, p. 36)

While nurses may not often feel heard by the rest of the health care team, they do listen to each other. It is through telling, and listening to stories that bonds are developed and strengthened among the nurses: “Telling stories can be healing.... Listening to stories can be healing” (Remen, 1996/2006, p. xix). It is true for nurses that “[s]torytelling is *for* an other just as much as it is for oneself” (Frank, 1995/2013, p. 17). It is important for nurses to not only have their stories told, but to hear others’ stories, is equally healing. Nurses develop tight knit groups who have their own table where stories are shared, troubles tabled, and problems discussed. In

the setting of the staff room, during meal breaks, hierarchies are not as important and all those around the table participate on equal footing. “The kitchen table is a level playing field. Everyone’s story matters” (Remen, 1996/2006, p. xxxviii). Nurses are able to talk about the difficult things that cannot be spoken about at home or with those outside of the group. It is through the sharing and recognition of common pain and suffering, as well as laughter and joy, that nurses are able to move forward in healing and being available to care for the next child with a PLSI and their family: “Human suffering becomes bearable when we share it” (Frank, 1991/2002, p. 104).

I think we just talk through things...I think what’s happening more and more of these kids are chronically ill and require more and more medical support and the effect on the nurses is kind of a critical part of that. (Isla)

It is through talking and sharing stories that we find support, but also learn about the culture of nursing. Nevertheless, it comes with the caveat that we cannot just tell anyone. Patient confidentiality is one issue, but not anyone can handle the stories and bear our pain. I learned this early on in my nursing career. Friends and family wanted to hear the cute and happy stories, but they did not know what to do with my stories of pain, heartache, and death. “Stories survive and haunt us partly because they remind us of what we know and partly because they call us back to what we consider significant” (Rashotte, 2005, p. 40).

Debriefing: Sharing the Burden through Conversations

I went to almost all the debriefings because to me that’s probably one of the ways that I get my voice heard and get my feelings out. (Isla)

On occasion, a pre-arranged meeting is set up where a larger contingent of nursing staff come together to talk about a particularly challenging issue on the unit. These sessions are often

called “debriefings.” I expect its original intention was in alignment with the aim of formal psychological debriefings facilitated by a trained professional: “To clarify the event and make sense of what you recall. To share your recollections with others. To feel more comfortable with what you may have witnessed” (Kinchin, 2007, p. 128). For these debriefing sessions to be successful and helpful for nurses, they need to be conducted carefully by an experienced facilitator and it needs to be done with a clear purpose. Unfortunately, the way debriefing sessions have evolved is in closer alignment with the meaning of “to interrogate in order to obtain useful information or intelligence” (The Free Dictionary Online, 2015). In these sessions, administrators or others higher in the institutional hierarchy than the nursing staff in attendance would use these sessions for information gathering (and potentially to discipline nurses) rather than a sharing of the burden of experience and the emotions associated with the event witnessed. The last debriefing session I attended was facilitated by a physician following the death of a child with a PLSI. The physician dominated the session and spent the entire time demanding to know why the nurses had done such a horrible job, that the child suffered unbearably, and we should be ashamed of ourselves. An informal debriefing session was held in the staff room immediately following, which served as a chance for the nurses to debrief from the formal debriefing session.

Useful and healing debriefing sessions, whether informal or formal, not only allow for an opportunity for nurses to talk about the difficult experience they have come together to discuss, but also to hear others speak. The purpose of debriefing is to share difficult thoughts and emotions within the safety of the group and allow for nurses’ venting and validation of emotions and reactions.

Validation

When I heard other peoples' episodes with the family, when I heard their situations, I liked hearing it more than I actually liked complaining myself, more than hearing my own self, I like hearing others. It made me feel that I'm validated and this is very stressful. Anyways, I liked hearing other peoples' experiences with them [the challenging patients and families]. It validated how I felt. (Meg)

Meg expressed her desire to have her emotions validated: recognized and considered worthy and legitimate. The concept of validity is an important one to appreciate in order to better understand nurses' need to feel their experiences and emotions are "accurate and well-founded" (Polit & Beck, 2012, p. 745). While nurses on the unit work alongside other nurses and health care professionals, nurses are often alone in patient rooms and those interactions are largely unwitnessed by others. Therefore, the opportunity to recount noteworthy experiences and receive validation from the resultant emotions can offer nurses support that is both helpful and healing for nurses. What is more, having emotions validated is "based on an attitude of respect and empathy" (Feil, 2002, p. 28). Therefore, nurses also require respect and empathy from the listener as part of the fulfillment of feeling validated. Meg said that she sought out only certain nurses to have her feelings and experiences validated. It is imprudent to expose this vulnerability to the wrong person as support will not be forthcoming from every nurse. Expressing emotions and recounting difficult experiences exposes a vulnerability and there is a risk that the feelings will not be validated in a respectful and compassionate way by the listener. Therefore, nurses seek out those nurses who will best validate and support them depending on the situation. This was particularly true when dealing with difficult and painful emotions and even more so when nurses experienced emotions that they are "not supposed to have" when caring for children.

Therefore, in expressing these difficult and “unsuitable” emotions to an understanding audience “we are telling each other the human story. Stories that touch us in this place of common humanness awaken us and weave us together as a family once again” (Remen, 1996/2006, p. xxxix). So while there is a risk to exposing vulnerability, the rewards of doing so in the right context can be highly rewarding. For instance, Isla and a few nursing colleagues have developed a supportive and trusting group in order to share vulnerable emotions in a safe and validating context:

I just think the way we handle it is the only way I think mostly is that we talk. And so, [names of nurses who work on the unit] get together and we talk about [what is difficult about the work nurses do on the unit]. (Isla)

Interestingly enough, validation is not just about expressing one’s own emotions. It is also about having the opportunity to hear another speak as a way to have one’s own experiences and emotions acknowledged as well-founded. For nurses to hear another nurse speak about difficult things allows nurses to weigh that against their own experiences and emotions and feel validated through hearing about another’s experiences. There is reassurance to learn that others are struggling too:

We had like 40 people show up [for a debriefing session] on days they were normally not working. And that felt so good...it felt good to have our feelings acknowledged...I’m like, I’m not just feeling this way because I’m in every day, I’m feeling this way because it’s real and that’s what felt so good. And it just felt like a weight off my shoulders to know that other people knew and that these feelings were validated. (Rachel)

In my experience, the nurses I worked with became the support system I needed to validate what I was experiencing on the unit as a bedside nurse. However, as I became angrier

about the work environment and the treatment of nurses and children with PLSIs, I sought out other nurses who were also angry and bitter. I did not seek out nurses who were finding meaning and satisfaction in the work as I did not want someone to dismiss or reframe my experiences or angry emotions; I wanted someone to be angry with me. It was through their anger that my own anger was validated and given permission to exist and thrive.

Venting

...the debriefing, more unit or like venting or a staff meeting where we could all vent or whatever. Those were good. (Meg)

Meg used the word “vent” to describe what she wants to do with her pent up emotions and feelings around caring for a particular child, negotiating with a family, or feeling overwhelmed by the workload. Meg described the importance of being able to vent: “to express an emotion” (Merriam-Webster Dictionary, 2015). What is more, venting is the opportunity to allow emotions to escape: “to allow something, such as smoke or gas, to go out through an opening” (Merriam-Webster Dictionary, 2015). There is a sense that exposing and letting out the frustration, sadness, or other emotions is allowing them to be out in the air and dispersing them through sharing with fellow nurses and as a result lessening the pressure by dispersing the burden.

In order for venting to be an effective means in providing the release of emotion a nurse needs, it must be done in an honest and candid way. In the context of a staff meeting where administrators are present, the frank expression of emotions is not possible because of the possible consequences of naming difficult emotions in front of people who have the power to hire, fire, and reprimand. In this context where nurses are concerned with censoring what they

say is not a true vent and release, but a controlled and edited version of what they truly want to say.

Meg: ...we have these debriefing for the nurses about the palliative kids and stuff and I often feel like afterwards those things that they [the administrators] just give general comments and you really want to lay it out on the line and it never is like that. So you just leave kind of frustrated.

SM: So...you don't find the debriefings are a way to express how you're really feeling?

Meg: No. I feel like I want to talk frankly and I don't feel comfortable enough to do that with the managers present. And I don't hear anyone else talking like that and talking frankly. I'm sure they wouldn't talk like that there [at the staff meeting] like they do in [the privacy of] the med room.

Brief and Immediate Nurse-to-Nurse Support

Being able to talk about difficult experiences in the moment that support is needed is essential. Those who work in this area understand when this venting needs to take place and they seem to find time to listen because they know that they too will need a compassionate audience another time and someone to validate the experience. It is not just anyone who can do this and often the most successful debriefing is with those who work in the area. Taking it outside of the solidarity of the group can pose a problem. Sarah described her attempt to debrief with her own father who was not prepared to accept and validate Sarah's response to the death of a young patient. He told her she needed to "get tougher" because the death of children in acute care is not uncommon:

They [the patients] don't die every time. She [a particular patient] died today. I want to talk about it today. Because she died and I loved her. She died. She got to eight and

survived and then she got an infection and got septic and died. That fucking sucks! And it's not fair and she fought and fought and here now I want to fucking talk about it!

(Sarah)

Debriefing informally is not necessarily a time consuming process. Often these moment are brief—an exchange of a minute or less. It is about having a minute or two to talk with a colleague about what is difficult in that moment. Nurses understand the challenges as they face them together. Therefore, having a moment to talk to someone who has lived through similar experiences with patients and families, allows nurses to share the burden of the ongoing difficult experience in order to continue with the patient assignment and survive the shift. A nurse can walk out of a patient's room, to the nursing station, say a dozen words, and then get back to work with a sense of relief of having shared the burden. It is about sharing the burden and knowing others understand what it is like.

Sometimes I do, and I have to go find a fellow nurse, my charge nurse to vent to, just to...you know, it's difficult and you just need someone who can identify with the situation. ...they can identify and that's all you need to diffuse the situation. (Meg)

Nursing History's Impact on Nurses Today: Calling Forth the Ghosts

One of the ways in which nursing wisdom is disseminated is through stories. The history and traditions of nursing are included although often hidden in these stories. However, this is not the only means by which nurses pass along traditions and history. Nursing legacies are also passed along to the next generation of nurses through the ways in which nurses conduct themselves with patients and families, how nurses talk about each other, and how nurses accept or ostracize nursing colleagues.

Hans-Georg Gadamer (1960/1989) suggested that we cannot step over our shadows; we are connected in a continuous thread with our past, with traditions, and with our ancestors, living out traditions that have been bequeathed to us by others. The echoes of history are always inadvertently *and deliberately* inviting us into both past and new ways of being in the present and, thus, we live in a world that recedes into the past and extends into the future. Rather than pitting ourselves against history, we therefore we need to *remember, recollect, and recall* it. (Moules et al., 2015, pp. 1-2)

Acknowledging history is an integral part of hermeneutic philosophy. The call back to history is particularly important to understand the current landscape of nursing and how it is being influenced by “*the persistence of the past*” (Hollis, 2013, p. xvi). In fact, the “past is not dead; it is not even past. And what we resist will persist—as *haunting*” (Hollis, 2013, p. xix). We are inextricably linked to history where “all sorts of old dead ideas and old dead beliefs, and things of that sort. They’re not actually alive in us, but they’re rooted there all the same, and we can’t rid ourselves of them.” (Hollis, 2013, p. xi). Some of the nursing history that we carry forward is helpful, useful, and important in the work that we do today. However, there are aspects of that history that are preventing us from moving the profession forward. In fact, some of these legacies are hurting us. We need to work at being aware of what that history and those ghosts are doing to us above our wanting and doing (Gadamer, 1960/2006). Not only that, but also to be aware of what we are passing along to the next generation of nurses—not just wisdom and practical knowledge, but it is also the traumas and hurts of the past and how we conduct ourselves in the face of loss, illness, and death of children. There are the ghosts and traditions of the past that glide between our words, in our actions, and in our silences (Hollis, 2013). We will never be able to rid ourselves of the past, particularly when we live in a culture that understands

the past as irrelevant (Hollis, 2013). It would seem that in light of this, “to underestimate the power of that history as an invisible player in the choices of daily life is a grave error” (Hollis, 2013, p. 53).

Military History and Nursing

An important part of the history of nursing, although certainly not the only important influence, is the role of nurses in military history. Nursing’s roots in the military are alive and well in the language nurses use to describe their work: “*it [nursing] is an honour, and there’s a duty to it*” (Sarah). It is also carried forward in our everyday nursing practices. It is thriving and influential in how we conduct ourselves, which reveals the history we carry forward in our beliefs about nursing and our place in the world. Interestingly enough, it is acknowledged that the role nurses played in the military has been largely overlooked by both historians and nurses themselves (McEwen, 2006; Monahan & Neidel-Greenlee, 2003). While the documentation and acknowledgement of this history may not have been done for the history books, nurses are living out the legacy of this every day of their lives.

One of the more obvious ways that nurses carry forward the military legacy is through the display of “‘stiff upper lip’ of stoicism” (Hallett, 2009, p. 104). Even in the world of pediatric nursing, the belief in the importance of appearing stoic and impenetrable is alive and well, which points back to a history and a context where “[h]iding one’s own negative emotions was an integral part of this work” (Hallett, 2009, p. 195). However, the history of how nurses are to conduct themselves is multifaceted. Nurses need to play a dual role can be traced back through nursing history. Military nurses were trained as soldiers, particularly in World War II where “at the end of their training could flash through most difficult manoeuvres like veterans” (Mansell, 2004, p. 161). Ever since, the profession of nursing has continued to carry its tradition of military

service, its femininity, and its responsibilities as a profession (Mansell, 2004). These combined factors are what ultimately contribute to the situation where nurses are expected to be “all things to all people” (Mansell, 2004, p. 88).

Performance of their role required nursing sisters to juggle multiple intersecting identities. They had to challenge prevailing social expectations regarding masculinity and femininity, prove their hardiness as “one of the boys,” demonstrate their worthiness as “officers,” and ensure their respectability as “ladies.” (Toman, 2007, p. 93)

Perhaps this legacy has slipped through in the belief that nurses hold as invincible healers (Hallett, 2009). Nurses continue with this legacy and it has begun to evolve in unexpected ways. The criticism of nurses today is that they lack compassion. On the other hand, nurses are under pressure to maintain professional boundaries so that they are not “caring too much.” As a result, nurses are increasingly pressured to be compassionate robots in the era of McDonaldisation of health care (Bradshaw, 2009; Sturgeon, 2010). The message seems to be: care for your patients, but do not care too much.

Culturally Sanctioned Behaviour for Nurses on the Unit

Nurses often conduct themselves as though the death, illness, and dying of children with PLSIs does not affect them. Upon closer observation it is clear that nurses do express their distress, but through behaviour that is sanctioned by nursing culture. The means by which nurses express their vulnerability in the face of this is dictated by the culture of nursing. Violating these cultural norms can result in the ostracization of a nurse. For instance, one nurse I worked with started crying during a code blue and was pulled out of the room by one of our nursing colleagues. She was still openly weeping at the desk long after the code team had left and the patient had been transferred to the PICU. This violated the unit’s unwritten rule about the

expectation that crying—particularly crying in a public area—is to be avoided at all costs. After that incident, nurses viewed her as a liability and she was never again fully trusted as though her crying was indicative of a fundamental inability for her to be a competent and trustworthy nurse. It would seem that there is a fine line for nurses to walk where crying may be acceptable only under certain circumstances.

Nurses work hard to adhere to the unwritten rules. As one nurse said to me “I do not care how sad I am [over a patient’s death] I would never cry or admit to having grief because I do not want anyone to accuse me of not coping.” The unit has the history of vicious nurse-to-nurse bullying and nurses (particularly new nurses) who “are not coping” can be ostracized from the group.

Nurses’ Vulnerability

Vulnerability is a complex, multifaceted concept. In western cultures, being vulnerable is not often considered to be a good thing as it is closely related to the concept of weakness. This perception is alive and well within the walls of pediatric acute care. “Vulnerability is not a trait that we possess or lack. It is a lived experience that unfolds in novel, stressful, or threatening situations and exists on a continuum” (Papadatou, 2009, p. 93). It is through our experiences we may shift along the continuum. We are all subject to the distorted thinking where “we strive to prove to ourselves and to others that we are the best or the most caring professional who fixes, solves, and manages everything without being threatened by anything” (Papadatou, 2009, p. 96).

Vulnerability is not weakness, and the uncertainty, risk, and emotional exposure we face every day are not optional. Our only choice is a question of engagement. Our willingness to own and engage with our vulnerability determines the depth of our courage and the

clarity of our purpose; the level to which we protect ourselves from being vulnerable is a measure of our fear and disconnection. (Brown, 2012, p. 2)

In nursing, there are cultural expectations that nurses are strong for their patients and that nurses should suppress the urge to cry. There are socially sanctioned ways for nurses to express themselves on the unit—most often through humour or anger.

Vulnerability is not often associated with virtue. Yet, to be vulnerable is central to human experience. Etymologically, ‘being vulnerable’ means capable of being wounded (from its Latin root, *vulnus* or wound). . . . One can know of one’s own capacity to be wounded directly, by experiencing suffering, but may also know it in significant ways in the anticipation of harm, in its likelihood. To this extent, vulnerability concerns not only the present moment, but also the future. (McCoy, 2013, pp. vii-viii)

Crying

...when I got home that night I told my husband [about a distressing incident] and I cried and I cried and I cried and I cried and I hadn’t cried at work. (Sarah)

There is a perception that “[n]urses cry. Nurses *have* to cry in order to deal with the pain they get so close to” (Kottler, 1996 as cited by Vingerhoets, 2013, p. 162). While this is true to a certain extent, there are unwritten rules that govern nurses on when, where, and under what circumstances tears are sanctioned by the culture of the unit. Nurses talked about crying, but rarely is a nurse seen openly crying at work: “*I don’t cry at work*” (Heather). There is a pride in those who can control their emotions and hide them from families and other nurses and some shame in exposing that vulnerability to the nature of the work. There is an assumption that crying means you are not cut out for the job: “*I just wanted to cry about it. I just want to talk about it. It doesn’t mean that I’m not right for this job*” (Sarah). If a nurse does need to cry while on the

unit, it is done in a hidden place away from patients and families and even other nurses. As “tears can be delayed until a more appropriate moment” (Vingerhoets, 2013, p. 93) they are often kept concealed until a moment where a nurse can be hidden. *“And you go into the med room and have a little cry...” (Meg).*

The issue of crying is somewhat complicated as it is not necessarily hidden with the sole purpose of avoiding the judgement from other nurses. There are times when crying is felt to be a burden to the family:

Meg: Oh my god, it was so hard for me as a new mom, that was, I could barely keep from crying right there in the room in front of the family. Oh, I can just think of that lump in my throat. It was so hard not to cry.

SM: Why did you try so hard to keep from crying? What made you not want to show your emotions?

Meg: I really felt I needed to be strong for the family. You could see that they had such guilt because they are the ones who sent her [to another hospital] for her heart surgery and it was generally elective. It was just a small VSD [ventricular septal defect], so they wanted to get it done. It was a normal time to get it done [but the child was neurologically harmed from the effects of the surgery/anesthetic]. They felt very guilty. So I didn't want to give them that emotional burden of me crying too.

Meg was experienced and may have chosen wisely to not increase the family's already heavy burden by crying at the poor health outcome that the family felt they had inadvertently (and indirectly) caused the child. Meg chose a different time to share her sadness and vulnerability with the family:

Months went by and later one night I was talking with her mom and a very tough evening with desatting, and she had finally gone to sleep, and we were in the room, the child was on CPAP and we were just whispering and talking and she let out how guilty she felt about everything and how you know this child's future is totally different than what she once thought, the loss there and I just let it out there with her. I just cried with her because I felt it for her. I felt exactly the same. It's not my child, but you do feel loss for that child and for what her future was going to be. (Meg)

There is a human need nurses have to acknowledge loss. There are times when nurses desperately want to acknowledge the pain and sadness of another as their own pain needs to be addressed. What is more, there are times when nurses want to “convey a sense of solidarity among mankind” (Vingerhoets, 2013, p. 73). Furthermore, there is a danger in becoming hardened and immune to tragedy and to the pain and suffering of others.

Wouldn't it have been weird if I didn't cry? Wouldn't that have been awful if I wasn't devastated by that? Like that would be scary if I just heard her mother's wailing in the hallway and walked home and just went, “Well, that's unfortunate.” (Sarah)

Nurses do not seem to always be honest about those emotions and being vulnerable. There is a fear about exposing their difficult emotions: “Tears are the blood of the soul” (Vingerhoets, 2013, p. 36 cited anonymous). There is an illusion of absolute bravery and stoicism: “I liked seeing people who I think are really stoic and brave, I liked to know that they don't feel okay” (Rachel).

Laughing at the Horror

I didn't actually notice it until my sister had pointed it out and said,

“You're starting to get that nurse humour.” (Rachel)

Nurses laughing and making jokes about the difficulty of the work they do is important for a number of reasons including a way for nurses to express vulnerability and solidarity as well as find ways of surviving difficult experiences through emotionally distancing and shifting perspective. Traditionally, western cultures are disapproving of the use of humour in connection to something tragic. What is more, real life tragedies, or even tragedies on the stage or screen, are often considered serious, while comedy and humour is thought to be light or frivolous. In instances where moments of comedy are imbedded within tragedies, they are usually dismissed as comic relief.

But the ancient Greeks, Shakespeare, and other dramatists took their comedy more seriously than that. They realized that comedy is not “time out” from the real world; rather it provides another perspective on that world. And that other perspective is no less valuable than the tragic perspective. As Conrad Hyers has suggested, comedy expresses a “stubborn refusal to give tragedy...the final say.” (Morreall, 2009, p. 119)

Furthermore, humour often serves an important purpose in human survival in the face of difficult and threatening events. Humour can be found at the epicentre of real life tragedies. For instance, during the Holocaust, prisoners often used humour in order to survive the horror:

First was its critical function: humor focused attention on what was wrong and sparked resistance to it. Second was its cohesive function: it created solidarity in those laughing together at the oppressors. And third was its coping function: it helped the oppressed get through their suffering without going insane. (Morreall, 2009, p. 119)

Therefore, the humour participants identified in the interviews should not be dismissed as frivolous or unimportant. “Nurse humour” (also known as black humour or gallows humour) is not simply about releasing emotional tension from difficult situations in the work environment.

Nor is the humour an indication of a callousness and disregard for human life and death. Rather, nurse humour is important in terms of establishing and fostering nurse-solidarity, coping in the face of difficult situations, and emotional distancing.

Being able to laugh at the horrible of parts of the work allow nurses to manage and to be flexible in the face of person-destroying situations, which may be considered distasteful by society at large, but the use of “sick and twisted humour [is needed] to retain emotional control of a particularly annihilating situation” (Scott, 2007, p. 361). The word humour, which comes from the “Latin ‘umor’, which means to ebb and flow like water, to be fluid or flexible, being the opposite of tight, inflexible and in control” (Thornton & White, 1999, p. 266). Making jokes is a safe way of saying difficult things and allows nurses to vent and air difficult emotions and memories. In the moment, humour is what allows nurses to say what they need to in order to get on with their jobs:

...humour appears to be used as a mechanism to help emergency personnel cope with the often incapacitating, liminal space between life and death. On a purely practical level, humour is an economical aid, almost a ‘gift’ in getting things done. (Scott, 2007, p. 362)

In the face of a busy health care system where a huge number of demands are being put on nursing staff, being able to “get things done” is crucial to the survival of the nurse.

Nurse Humour and *Sensus Communis*

Nurse humour, the kind that Rachel’s sister observed her developing, is learned through spending time in a particular clinical area—through becoming experienced. Nurse humour varies across specialty areas. Regardless of the context, some nurses are more readily predisposed to taking up the humour and some participate in it to a greater extent; however, most nurses will develop an appreciation and understanding for the humour even if they do not choose to

participate in it. The understanding of nurse humour is something that is learned and is a sign of being an insider to nursing culture in a particular area of practice. Understanding and participating in nurse humour, can only be understood and participated in with a thorough understanding of the context and the players in the context (Gadamer, 1960/2006). “When we laugh together, we are in effect acknowledging our membership in a community—a community bound together by the norms presumed by the humour at hand” (Carroll, 2014, p. 77).

Heather: I can laugh about it later. And you know...

SM: It seems to depend on who you're talking to. It seems as though there are some people who just laugh so easily about stuff that happens on the unit.

Heather: Those who get the comedy in it because...when you tell a normal person [someone who does not work on the unit] and they do not understand the comedy, but when you talk about [with unit colleagues], they know...

Nurse humour, among other things, is about fostering relationships, developing a closeness and a familiarity within a group of nurses working in the same clinical setting (Astedt-Kurki & Liukkonen, 1994; Dean & Major, 2008). Sharing a joke enhances feelings of togetherness and closeness, helps to establish good relations, which contributes to the development of a sense of community (Dean & Major, 2008; Tanay, Roberts, & Ream, 2013). It is through the use of humour that solidarity can be fostered and the difficulty of the work can be acknowledged (Scott, 2007). Furthermore, the use of “humour reflexively feeds back important truths about who we are in relation to those around us” (Scott, 2007, p. 352). Furthermore, laughing at the difficult aspects of the work help to acknowledge, within the context of a group, nurses’ deep suffering in the face of illness and death of children: “Mark Twain wrote that, ‘The secret source of humor itself is not joy but sorrow. There is no humor in heaven.’ His

contemporary, Nietzsche, said that humans are the only animals that laugh because they alone suffer so deeply” (Morreall, 2009, p. 130). It is through humour that the community and solidarity of nurses can be nurtured:

Humour expressions contribute to the *sensus communis*, or the maintenance of sentimental order, enabling emergency personnel to function often in situations of sustained or repetitive sudden deathwork. Its value as a cathartic stress-reducing mechanism should not be underestimated and inappropriate responses should be perceived as appropriate, indeed essential, in helping emergency personnel cope with the work they do. (Scott, 2007, pp. 362-363)

Nurse humour and laughing in the face of death, illness, and horror is a socially sanctioned way of expressing very difficult emotions in the practice setting. Nursing culture, as a whole, does not welcome vulnerability in the form of crying: “the use of ‘sick’ humour provides an emotionally distancing response because if you do not laugh you are more likely to cry, countering professional codes that moderate emotional display” (Scott, 2007, p. 361).

Emotional Distancing from Horror

The belief that the use of humour as a way to emotionally distance from the realities of the situation people face was first described by Freud in 1905 who explained “humour as one of the strongest defence mechanisms and one which enables an individual to face problems and avoid negative emotions” (Freud, 1960 as cited by Tanay et al., 2013, p. 2133). In the context of health care, humour is used to help nurses distance themselves from difficult and unpleasant emotions (Dean & Major, 2008; Tanay et al., 2013) as well as help establish a perspective on the situation that is more balanced (Dean & Major, 2008).

(laughs) I keep laughing because what else do you do? It [the things that happen on the unit] is so fucking crazy! (laughs) ... And then there was that [patient's name] whose mother bought the coffin way in advance of, several years before the baby died [and kept it laid out in the family's living room]...What else could you do [other than laugh]?...otherwise you'd go crazy (laugh). (Jeanie)

Some of the situations faced by pediatric nurses in acute care, which are parallel to the horrors faced by other health care providers and first responders, are so horrible that nurses fear for their mental health and sanity (Morreall, 2009). Using humour in order to cope is “another of the soul’s weapons in the fight for self-preservation” (Frankl, 1959/1984, p. 63). It is a release and a relief to laugh about what may be more horrible than humorous. During my interview with Jeanie, someone I had worked with for a long time, we laughed through most of the interview. She said things that were clearly not funny to an outsider, but in that moment (as with many moments in practice), the need to laugh was overwhelming.

Jeanie: Oh God, we had such a range of kids! There was the one who like chips? (laughs) God! Oh my God! The big kids I found hard to deal with because they were physically difficult to move and everything. We had everything from babies to basically to big, huge adults that were high-dependency, going to die (laughs). Why is that funny? I don't know! SM: (laughs)

Jeanie: (laughs) I don't know! (laughs) I tend to laugh...it must be my way to just deal with stuff (laughs).

I asked Jeanie about her tendency to laugh about horrible events she encountered in practice and if she ever felt bad about laughing. She acknowledged that she was careful not to laugh in front

of families or others who might be hurt or offended by the apparent callousness that accompanies the use of nurse humour. However, she also said that:

...even if you're all serious, it isn't going to change it. They [the patients] are either going to live or die and we can't do anything to change it, so you might as well laugh. You might as well have fun. Because nobody wants some moody, sombre person looking after their kids. (Jeanie)

“You Might as Well Laugh”

Laughing at the horror of the work nurses do is an opportunity to find humour in what is sometimes an “overwhelming and thankless profession” (Sheldon, 1996). There are times when the situation presented to nurses is so far beyond what normal people, outsiders, would experience and beyond the nurses’ realm of experience that laughing at the throwness and unexpectedness of the situation is a helpful way for nurses to cope with the situation in which they find themselves:

The basic situation in many Charlie Chaplin films, for instance, is similar to what Heidegger calls “throwness” – finding ourselves in a situation we did not choose but in which we have to act. Without a script to follow, we, like Charlie, make it up as we go along. (Morreall, 2009, p. 130)

Furthermore, the ability to laugh is also an acceptance that we are unable to change the ultimate outcome for these children:

But that made it all fun though. It made it all doable, because whether you laugh or cry, you're still saving the babies and you're still doing your job and dealing with the parents in the best way you can. So you might as well laugh. (Jeanie)

There is a strong sense that nurses might as well laugh at the challenges and difficulty of the work. There are situations where nurses are able to laugh with families, which are a way for nurses to connect with families, help to shoulder the burden of caring for a sick child, acknowledge the shared humanness of the circumstances, and it lightened the weight of the situation:

I remember discharging a little guy and he'd swallowed some acid of some kind...whatever, cleaning fluid or something. And he had strictures. He'd come back in to get opened up every once in a while and you know, the funniest things happen. You know, you do the discharge on them and I said to the dad, "Okay, this is what you do." And he said, "Ya, ya, we know." So I said, "Oh ya, that's right. You guys are frequent flyers." He said, "Well yes, as a matter of fact we're just on our way to the airport." They were from rural Alberta and they had their own airplane (laughs). And I just thought the coincidence...I said, "You're a frequent flyer" and he said, "Well as a matter of fact we are!" (laughs)...That was so funny! But you know, there's those little moments where they're just priceless. You know, the stories, the sharing. (Isla)

Unfortunately, with the dramatic increase in acuity, those nurses who have worked on the unit a long time and have seen an equally dramatic decrease in humour and fun on the unit: *"I think that technology and the criticalness of the kids has become so...has increased so dramatically, that I don't think we have time for the fun that we used to have. People are anxious and worried..." (Isla).*

Belonging: Coming Together in Times of Hurt

"stories...never live alone: they are branches of a family" (Calusso, 1992, p, 9), and a telling story bespeaks a family (a "familiarity," if you will) to which we already

somehow belong. This is why interpretation is often equated with a form of recollection, a sort of family gathering ...where “gathering” takes on anew that archaic sense of a way of deeply *knowing*. (Jardine et al., 2003, p. 58)

Ask any inpatient nurse on the unit and she will be able to tell you about the challenges of the work, the day-to-day hassles, the short staffing, the lack of resources, and the frustrations of working in a large organization. Nurses even complain about each other. However, when there is a crisis, such as the death of a much loved patient, the call goes out and nurses come together through shared understanding and solidarity. The pain I have felt from the death of a patient, most recently the one who died unexpectedly following a gastrointestinal illness, was recognized and honoured within that group. The death of a patient is not a loss that is recognized by others outside of the group of nurses from the unit. I would never expect the same support following the death of a patient as I would following the death of a family member. Nurses understand that particular type of pain, loss, and hurt. Nurses who have long left the unit will come back and join the group in order to attend the funeral. There is a need to come together and when they do, healing can take place.

Coming together also demonstrates courage. Attending the funeral of a child nurses on the unit came to know and love takes courage. Nurses know that attending the funeral will be difficult and painful. Yet coming together as a group and hanging on to each other as they view small bodies in small coffins is important for their survival. The pain of sticking stickers on a small casket and listening to Raffi cheerfully sing *This little light of mine* is profound. It takes courage to do that, but ultimately the staff room wisdom would tell them that it is also healing. “We come together because we feel safe together. We encourage and support each other in the values we consider important and that give us life” (Vanier, 2008, p. 106).

Isla: ...we would of course be going to a lot of the funerals you see because we knew the kids. So we all, a few of us went to a funeral just south of [name of city three hours away from hospital]. A few of us just drove up and I've got letters from that mother thanking us for doing what we did.

SM: Do you feel that it was healing to go to those funerals?

Isla: Yep...ya it was... In fact, we often went out of town. We went down to the [town two hours away from the hospital] for one little guy and a bunch of them went down to the [name of town six hours away] you know. It meant a great deal. It meant a great deal to so many people. Because we went together. We were experiencing the same thing and we were reacquainting ourselves with the family and perhaps recognizing in the end that this had really happened. That we had done it for this child and the family. That we became part of the family. That this was the end, that the child had died.

Staff Room Wisdom: Knowledge for the Next Generation of Nurses

Nursing wisdom carries within it important and essential pieces of knowledge that future generations of nurses will surely benefit from. Nevertheless, not everything that is passed on is helpful, healthy, or healing. Nurses pass along nursing history, tradition, and wisdom whether they are aware of that or not. In fact, today's nurses are sharing the past—both the positive and negative—with the future for “the past is not dead, it is not even past” (William Faulkner as quoted by Hollis, 2013, p. xv). By refusing to acknowledge the problematic aspects of the past we may be simply helping to pass on this legacy to the next generation (Zerubavel, 2006). Until we examine the threads of the past, we will keep passing along unhelpful and hurtful traditions to upcoming generations: “the past calls the shots, at least until it is flushed out into the full light of consciousness” (Hollis, 2013, p. xvi). Nurses today have an opportunity to begin to shift the

legacy of nursing going forward by acknowledging the past and challenging some of those traditions.

Summary

The wisdom that nurses possess is passed on to the next generation of nurses through language, humour, and stories. The listening and recounting of nursing stories and experiences can be healing for nurses. Nurses also can find healing in nurse humour, attending funerals, and finding ways of coming together to support one another. History and tradition of nursing are taught to new nurses through the comportment of senior nurses. Senior nurses should be mindful of what they are passing on to the next generation of nurses through their words and actions. In the next section, I discuss the balance and choices nurses face between the rewards and the challenges of the work.

CHAPTER TEN: THE AVALANCHE SLIDES WHEN THE HORROR OUTWEIGHS THE BEAUTY

When the horror starts to outweigh the beauty, I got to go. I got to go. And it's a self-preservation thing because I can't; I can't live in this horror. (Sarah)

Of the eight nurses who volunteered to be part of this study, three nurses had recently left their positions on the unit and two more were seriously considering resigning. In exploring this, there seemed to be a tipping point when the need to make a decision was forced upon the nurse as to whether she would stay or go. Sarah described the experience as when the horror of what happened on the unit outweighed the beauty. There is both beauty and horror on the unit it has been described throughout these research findings. There is much to be enjoyed and savoured as well as much to be grateful for. However, there are aspects of the work that are challenging, difficult, and undoubtedly horrible.

There's so much crazy here [on the unit]! That's not what gets you in the end. It's the kids left in cribs for weeks on end that are chewing at the bars 'cause we can't take them out because they've got VRE [vancomycin-resistant enterococci] and they can't leave the room. And that's so stupid because last week they could leave the room and their mom is nuts and comes in and does terrible things and... (crying) and then doesn't come in. [Then the mom] Has a funeral [for her daughter] and talks about herself and oh God! It's all that awful, awful awfulness that as that becomes.... I think there's a finite amount of time you can spend on a unit like before the horror starts to outweigh the beauty. (Sarah)

Horror

Perhaps it is a bit shocking to describe the happenings on an inpatient pediatric unit as horror: “an intense aversion or repugnance” (Merriam-Webster Dictionary, 2015). Nevertheless, it is the language used by participants and in many ways, this is an apt and appropriate adjective under the circumstances and perhaps nurses try to normalize the horror for patients, families, and themselves as best they can. Children with PLSIs often become increasingly deformed and disfigured by both their illness and from the interventions used to mitigate that illness. Medical interventions have a way of mushrooming. For example, the relatively simple intervention of surgically inserting a gastrostomy tube has a way of turning into so much more: electric feeding pumps, skin breakdown at the site, allergic reactions, the need for a fundoplication, development of scar tissue, and so on. Dying with a whole host of interventions is not beautiful or peaceful and it is difficult to bear witness to that process. In describing difficult happenings and death scenes to friends who do not work in health care, many have literally turned their bodies away from me in an attempt to shield themselves from hearing about the awfulness: “*horror* suggests a physical revulsion” (Daniels, 1975, p. 2). Sarah described the end-of-life situation for one child:

There was one family that were particularly difficult to deal with and I mean their poor child was you know, like a monster, by the end. Really, she was so gone and we were keeping her alive and dressing her in frilly dresses and putting diamonds on her and it was, it was like something out of a horror movie. It was like something out of a horror movie! (Sarah)

Invasive and disfiguring treatments, treatments that could be depicted as torture in a horror movie, are not particularly new to the pediatric population. For instance, the treatments children received for polio and tuberculosis (TB) in past decades were “horrible.” What makes

the interventions for children with PLSIs today distinct is that the painful treatments for diseases such as TB were life-saving interventions. However, in this context, the treatments are not life-saving, but rather life-prolonging and often with significant and inherent suffering.

Weight, Outweigh, Heavy

Sarah described the cumulative experiences on the unit as horror outweighing beauty. The word “horror” is an unexpected word to use in describing what nurses observe in their work with vulnerable pediatric patients. Nevertheless, the word is brought forward by a participant and it is a point of understanding where a truth is being unconcealed. Regardless, it is one way of understanding and certainly “horror” is not all-encompassing in its ability to capture what is happening for nurses. The experience for nurses also includes sadness, grief, cumulative loss, moral distress, compassion fatigue, relief, and meaning making, as described in the research literature. In order to remain in alignment with the language of participants, I chose to use the word “horror” throughout the chapter to capture the difficulty of the work nurses bear in caring for children with PLSIs.

There is a delicate balance between the challenges nurses face in their work with children with PLSIs and the beauty that they can enjoy. Occasionally the horror becomes too burdensome and outweighs the beauty. This can occur suddenly in the wake of a tragic or distress event. I was in charge one evening when we received a call from the emergency room that one of our long-term patients had died enroute to the hospital following respiratory arrest. News of the patient’s death spread quickly amongst the nurses working that evening. A nurse who had been working for nearly 10 years approached me at the desk. She had worked closely with this particular patient and family while he had been in our care for more than two years. She told me that she had heard the news of his death and then handed me her nursing lanyard with her identification

and said she quit. She walked off the unit and never came back. The pain and horror had become too much and the balance had been drastically tipped in that moment of hearing the news of the death of this much loved patient. With sudden clarity, she knew she could not work there anymore. For others who have left the unit, the tipping is slower and it is more difficult to recognize the shift when the horror begins to overwhelm a nurse. Some nurses describe their last shift as not the worst they had worked, but the one where they recognized that they could not withstand the weight and burden of the work anymore. Sarah described the slow process of the balance tipping for her:

...the benefits still outweighed the cons. But as I said, my inner voice guided me away from the long-term care and the chronic care because I knew that ultimately, I knew on some level, it was affecting me and I knew that the war had started to shift the other way where the downsides were outweighing the benefits. (Sarah)

Sarah's use of the word "war" to describe her inner deliberation of staying on the unit speaks to the violence of the decision she is having to make. She is being forced to choose sides, wishing to remain loyal to the unit, but perhaps unable to survive that choice. Unfortunately, she will have to choose a side as there is no in-between space she can occupy.

Sarah was not the only participant to describe the experience of working on the unit in terms of weight. As children with PLSIs grow, they do become a heavier load to physically transfer, reposition, or carry, but the physical weight of the child is not the problem that the participants described. Rather, it is in the sense of weight as an overpowering burden (Merriam-Webster Dictionary, 2015). The etymology of weight in terms of the figurative sense of burden has been traced back to the late 14th century (Online Etymology Dictionary, 2015). What nurses see and know through the work they do is a burden that they carry from knowing the difficult

work and knowing the horror. Nurses come to better understand how unsafe and unfair the world can be and there is a weight to that knowledge. It is a burden for nurses to witness the pain and suffering of children with PLSIs, then leave the unit after a shift to return to their lives with others who do not know this horror.

You have to somehow put up a barrier between work and your real life. Because it's not your real life.... I mean, it is part of your life...but I would just come home and that was a different world.... Because that's not your real life.... Again, that might sound horrible.
(Jeanie)

It is apparent that the burden of the work can be relieved, at least temporarily, by having time away from the unit. Heather had been away from the unit for two years and described coming back without the same level of burden: *"I was clean and fresh and didn't have the two years weighing on me"* (Heather).

The word "heavy" was also used to describe the work. Rachel described the work as coming with heavy feelings: *"I think they're a very, very cool population [children with PLSIs]. They come wrought with kind of heavy feelings. That's for sure"* (Rachel). The word "heavy" is similar to the word "weight." However, heavy also includes the meaning of "having a high specific gravity: having great weight in proportion to bulk" (Merriam-Webster Dictionary, 2015). Children with PLSIs are small people in small bodies. Their physical weight is not significant—particularly the size of the tiny premature babies who are admitted to the unit. Nonetheless, the weight of children with PLSIs is often greater than their bulk. Children with PLSIs are small beings with difficult lives and difficult things are done to them. It can be challenging to witness. This reality can be detected upon entering a patient's room as Rachel

described: *“There are some, I just feel really, like downhearted about it and you know, going into that patient’s room feels like a heavy cloud” (Rachel).*

Following report, the expectation is for nurses to visit each patient and perform a series of safety checks: oxygen and suction working, suction catheters, oxygen mask, IV rates and solutions, ID bands, allergy bands, and so on. This is the first point of contact nurses have with the patient for the shift. Some patient rooms have a heavier atmosphere than others. In some rooms, it feels like a heavy cloud of sadness, despair, anger, or fear occupies all the available space.

Beauty and Horror: The Snow Metaphor

Once the participant interviews were completed and transcribed, it was time for me to begin analyzing the data. I packed up my laptop, transcripts, and books and headed out to a town nestled in the mountains. I booked myself into a hotel with the intention of getting away from my usual responsibilities for a couple of days in order to focus on writing up some of the findings. As the analysis took shape, I was surprised to find that participants used analogies to describe the work based on the snow. It might seem cliché to use snow as a metaphor for the work of nurses when I am writing in the middle of the winter in Canada. I kept wanting to dismiss the analogy for it felt far too quaint and convenient. However, the more the voices of the participants haunted me, the more I came to understand that the metaphor of snow does tell us something about the work that nurses do in pediatrics with children with PLSIs.

As Canadians, we have a complicated relationship with snow. Across Canada, over the course of the winter, we get a lot of snow. Depending on what part of the country, the snowfall can be upwards of 300 centimetres per winter and winters are often long and cold. As a city dweller, my knowledge of snow is primarily from learning how to live with snow in the city:

shovelling it off the sidewalks, driving in it, and avoiding getting stuck or stranded in it. For many, snow is an inconvenience. However, snow provides us with wonderful recreational activities including skiing, snowboarding, tobogganing, snowshoeing, and snow fort building and it is beautiful when it is not brown sludge on the roads or decaying piles in parking lots.

As I sit here, I can look out the window and see the mountains in the winter. They are stunning and magnificent—large and mysterious with their snow-covered peaks. The snow found in the mountains is not understood the same way as the snow I shovelled off my front steps before leaving home in the city. The snow and how it accumulates in the mountains is a whole science unto itself. While it is beautiful, it is wrought with hidden dangers.

Snow is a riddle, a transitory substance that's hard to get a fix on. Scientists call it a "multiscale phenomenon," meaning that the snow's composition at any one time is a result of the complex interactions of many factors, from weather conditions during its initial earthbound tumble to subsequent recrystallization within the snowpack. As Bob Brown, who studied avalanche for thirty years at Montana State University, told *Wired* magazine in 2003, "When I worked on the Apollo space program, I thought rocket science was the hardest form of physics, but snow science is even harder..." (Bowers, 2003, p. 44)

Those who specialize in snow in the mountains come to appreciate the beauty and the danger. We love to ski and the joys of backcountry skiing are unparalleled for those who enjoy the sport. However, the peace and beauty of skiing in those areas are an illusion as danger lurks below the outer crust of snow. The beautiful outward look of a fresh layer of snow in the backcountry may be in fact a precarious snowpack with buried instabilities.

Snowball of Horror

...eventually the snowball of horror is more, I can't affect it any more. And I'm not going to get snowed under by it. I'm just not. Like, why would I sacrifice myself that way? There's no good that can come out of it. I just eventually will become angry and bitter and not be able to be a good leader or compassionate or open. (Sarah)

You do not need to explain to a Canadian what a snowball is in its literal sense. We have all had the opportunity at one time or another to scrape up a mitt-full of snow, shape it into a roundish shape, and then hurl it at someone. It is an intriguing image of someone holding a snowball that is not snow, but rather is horror—a ball of horror to be held outside of oneself.

The expression for things to snowball is “to increase, accumulate, expand, or multiply at a rapidly accelerating rate” (Merriam-Webster Dictionary, 2015). This is not a new expression: “meaning ‘to increase rapidly’ is attested from 1929, though the image of a snowball increasing in size as it rolls along had been used since at least 1613” (Online Etymology Dictionary, 2015). It would seem that when the horror begins to overtake a nurse on the unit, the horror begins to snowball. Almost like the snowball sits on the peak of the balance and once that balance is tipped, the snowball rolls along, picking up speed and growing in size and nearly impossible to stop.

Illusion of Strength: The Snowshoe Story

One of my favourite winter activities is to snowshoe. The mountains are a wonderful place to snowshoe and there are many trails designed with snowshoers in mind. One beautiful sunny and mild winter morning over the Christmas break, I decided to set out for a snowshoe adventure with my children in tow. The snow looked perfect. As I stepped onto the snowy terrain, my foot (snowshoe and all) went through the cold crust of snow and I found myself

standing hip-deep in the snow. The kids and I laughed at how the seemingly strong surface of snow had given way underneath me. The mild winter temperatures had created an unstable snowpack under the hard crust of snow. Yet from the surface it looked stable, strong, and perfect for walking on with snowshoes. As I drove home that evening, I thought about the trust many of us have in how the snow appears from the outside. We assume that the hard outside layer is indicative of what is going on underneath, but we should not. This is true in other facets of our lives. We live in a culture that likes to maintain a smooth, even surface. Nevertheless, the appearance of the surface can never be fully trusted.

For months before I finally took a leave from my position on the unit, I continued to function outwardly: my charting was finished, my patients' medications were given on time, and assessments completed. Yet on the inside, the only emotion I could not completely numb was my anger. I was deeply angry and cynical about everything. I had no interest in forming new relationships with patients and families. I had been profoundly saddened from the death of children who I had cared for and terribly hurt by the families who were angry and cruel, which made me hate my job. I wanted to leave the profession of nursing. Nevertheless, I worked hard to keep the calm, even surface at work and at home. Therefore, no one could outwardly see what a disaster I was on the inside. What was going on underneath was not visible from the outside. Everyone around me trusted that things were as they always were and seemed on the outside—that the stable outer crust of snow was indicative of the underlying snowpack.

Avalanche

It's like an avalanche coming down and you're going to put your feet in and you're going to hold the, you're going to toe the line and there's a little trickle of snow and you push it out of the way. And you're like, "Uh-huh, get out of my way." (laughs) And you're a

beacon. For the other skier coming down.... But eventually there's more snow and eventually there's more snow and eventually there's more snow.... I can't push it all out of the way. So I either get out of there or I get covered by it. That are the two options that I have. (Sarah)

Before coming to live near the mountains, I had heard about avalanches, but did not appreciate their power and the threat they pose to humans enjoying the mountains in winter. Yet for those who live near the glorious mountains, the threat of avalanches is real, particularly in communities nestled within their magnificent valleys. Avalanche safety is frequently talked about in the mountains and yet the techniques are not fool-proof. Danger still lurks. According to an avalanche expert, there are four stages people can move through in their understanding of avalanche danger, which could be a way of describing the dangers nurses face in their work:

...four stages in the development of avalanche risk awareness. "The first stage would be you're so unaware of the risk you don't even realize you're at risk. It never occurs to you to worry about avalanches, and when one hits, it seems to have come out of the blue. The second stage is where you're aware that there's a danger you should be afraid of, but you don't know how to deal with it, you don't know what to do, and you're totally at the mercy of other people's help or advice. The third stage is where you are starting to learn enough about this phenomenon that you can begin to make judgements." This is a precarious stage, Manners points out; skiers can know just enough to feel confident, causing many to overestimate their avalanche skills, sometimes vastly. "And the fourth stage of learning is where you have enough experience and knowledge that risk avoidance becomes somewhat subconscious. A lifetime is probably an appropriate learning period for that." (Bowers, 2003, pp. 60-61)

In terms of working with children with PLSIs in acute care, we are at risk of being taken out by an avalanche of distress, horror, and hurt. It begins with little unsettling events—perhaps a Child Welfare case, a misdiagnosis, or a distressing encounter with a teenaged mom. It could also take the form of a big event that you have the inner resources to manage and make the necessary changes:

I was in charge one night and this child literally died alone at the end of the hall...there was nobody else there but me. I have never forgotten that moment because we'd had that child for a long time and there was no support. No support what-so-ever! And so to transition from that...I got involved [to help form the first] palliative care committee.
(Isla)

However, most of the time, it is little bits of snow that come down the mountain and seem so small and insignificant, that it is hard to recognize the danger. Therefore, we do not recognize the danger that we are in. Even if we do, we do not know how to manage it: “*And you know, we just kind of added that up and recognized what serious trouble we were in*” (Isla). The context of acute care makes these distressing events appear normal. If some of these events happened in an environment outside of health care, it would be more obvious that a problem or danger was present. For instance, a number of years ago, one of the nurses on the unit had a son die of a brain tumour when he was two years old. His death was talked about and support was offered. We recognized the distress of this situation for those of us who had young children too. We recognized the danger we were in and the vulnerability to the experience because of the parallels with our own lives. This death was understood differently because he was not a patient on the unit.

Recognizing when there is an avalanche risk takes knowledge and experience. This is also the case when the avalanche is not snow, but burnout or other challenges of nursing work. Similar to an avalanche, those without experience do not recognize the danger signs and do not appreciate the risk that they are at by being on unstable terrain. “Avalanches happen at particular times and in particular places for particular reasons. That means they can usually be avoided. In many cases, clues about the avalanche hazard abound for those who know where to look” (Bowers, 2003, p. 36). Those nurses with the knowledge and experience to recognize the avalanche danger, who have seen others be taken under or have been victims of this themselves, can sometimes see it coming. They can spot other nurses who are in danger. During my interview with Rachel, I was struck by some of the things she said as she described a classic avalanche path:

When I'm not at work, I feel like I should be because I'm worried that, what if this baby didn't get his bath, he loves his bath in the morning. So I feel a lot of guilt associated with taking a day off, which I know is necessary, but when I do get called in and I say "no" it follows me all day because I feel like I should be there caring for somebody who is sicker than I am and can't go skiing today or whatever the case is. (Rachel)

What she described is in fact “a classic, classic avalanche path.... An existing avalanche path that had obviously run before” (Bowers, 2003, p. 130). The desire to work all the time and not want to take a day off because of what nurses perceive as their role and calling is almost certain to lead to disaster. To work even full-time on this particular inpatient pediatric unit is unsustainable. In fact, there has not been a full-time nurse working on the unit since I gave up my full-time line and even then I was the only full-time nurse working on the floor for many years as all the other bedside nurses worked part-time.

The discourse around the dangers that nurses face in their work can be overruled by unwise people. For instance, recently I visited a drop-in medical clinic because I was in need of some antibiotics for a sinus infection. During the appointment, the physician asked me about my PhD. When I explained my topic, she stopped inputting her notes into the computer, turned to me and said, “Why would you waste so much time on that topic? It is just part of your job.” Advice can also come from well-meaning friends and family members:

(crying) And that child (pause) I cried over. I remember my father saying...that it was wrong of me to feel this way and that I need to create better boundaries and that if I wanted to work in health care...I was angry because I said that this wasn't the first child I had cared for who had died, or the first child who has died soon after being in my care, but that something (crying) needs to affect you. It's pediatrics and it's different.... Because they're precious. (crying) Children are more precious and it's more tragic when they die, because it is. But for whatever reason I felt that the world had lost something very special, when that child died. And I think it was important that I mourned it and that I grieved it (crying). (Sarah)

New nurses are at the mercy of this discourse and prevailing belief of nurses' invulnerability. Novice nurses often have their distress dismissed and they come to believe that the danger they perceive is imagined.

But I think, the way your feelings can get missed, then can make you feel, I think that's the heavier burden is not knowing or how you feel about a situation is something not appropriate and I don't know maybe that's just me feeling like I need to be perfect. You know in every aspect, sometimes I feel very bad or guilty for feeling a certain way. (Rachel)

Just as with avalanche safety, nurses are at the mercy of the advice and guidance that others offer them. Sometimes the people nurses seek out for support are not equipped with the right knowledge to provide them with the best advice and guidance. As a newly graduated nurse, I had a bad week: my first code, my first patient death, and the first time I had to speak directly to the police about a child abuse case. I had my lunch break with Isla and told her about the challenging week I was having. She acknowledged what I had been through and strongly encouraged me to speak with our manager at the time. I did and the manager told me to ensure that my charting was well done. There was no acknowledgement of the difficulty I had been through as a new nurse. There was no acknowledgement of the danger I might be in and would continue to be at risk for—with no helpful safety equipment at my disposal. This sort of response to distress is common: *“I just think we became so jaded you know by that by that experience and the only thing we were told to do is document” (Isla)*. This is inadequate and inappropriate advice. I never spoke with an administrator again about distressing experiences I had on the unit. I learned to seek out my peers, those on the unstable snow pack with me. Rachel described a similar experience, although she did not realize how dangerous the advice was:

But when I get home, I’m like, “What am I doing? Why am I doing this?” And that is something that I have talked to my educator before about and how do I go through this and go home and feel badly about it? What can I change when I’m at work? [The educator said] “Nothing really because you still have to care for that patient as is ordered.” (Rachel)

Those who have experienced being overwhelmed by an avalanche warn other nurses, but often the warning falls on deaf ears. I can remember attending lectures as an undergraduate student about burnout and compassion fatigue, but had this notion that those things happened

only to overly sensitive people or nurses who were unprofessional: “suffering among health care professionals is largely disenfranchised and neglected despite its integral role in their work.

There is a widespread belief that suffering is not supposed to happen to experts” (Papadatou, 2009, p. 92). There is the belief that if you cannot handle situations with patients without tears, then you are unfit to do the work:

And I actually, I had a few nursing instructors, believe it or not, tell me that I shouldn't go into pediatrics because I take things too personally. And I remember specifically one saying, you know, I was tearing up about some case and she said, “I don't know if pediatrics are for you. If you're going to take everything this personally.” (Sarah)

Being caught in an avalanche is difficult to imagine unless it has happened to you or you have witnessed it happen to someone close to you. In truth, no nurse working with children with PLSIs in acute care is safe from the avalanche danger. When a senior nurse who has worked on the unit for many years is taken over by the avalanche and leaves her position on the unit, there is sometimes surprise from other nurses. Nursing colleagues will often talk about how the nurse who left was “so strong” and they believed she would never leave. When those senior nurses did leave, it was often because they could not face the horror anymore. When nurses see this over and over, they begin to better appreciate the danger. One avalanche witness said:

I didn't really understand that until I saw it.... The size of the trees that it pulled out! I think that was one of the most powerful things to me—the depth, the power and the destruction of an avalanche, and to know it can happen to anyone. (Bowers, 2003, pp. 196-197)

This observation could be echoed through the halls and rooms of the unit—perhaps even the hospital. At first it is hard to believe, but once nurses have seen the destruction of an avalanche a

number of times, they begin to realize that the distress and horror will have the power to wipe out even the strongest and the most dedicated of nurses. The truth is that no one is safe and nurses need to monitor the distress in each other as well as themselves. Nurses walk the same terrain and need to acknowledge and talk about the dangers and how they can avoid them. Furthermore, nurses need to become better aware of the point at which they need to get away completely from the path of the oncoming avalanche.

I think of [senior nurse's name] and I think she really tried to stay with two feet on the ground, present with what it is, questioning things, emotionally and intellectually connecting. But I really do believe that she just was there and she eventually knew she had to leave. (Sarah)

It seems that people either do not know of the dangers or know the dangers and enter into it anyway. I think of the work nurses do, not just in pediatrics, but all areas of the health care system. It is difficult work and nurses know it will be hard, but they do it anyway. I noticed that awareness at conferences for health care providers who work with children with PLSIs. I would sometimes want to talk about what was hard about the work and others would readily join me in that conversation. However, at the end of the day, they would nod their head as if to say, "Yes, we all know it is hard, but you do it anyway." Nurses take risks just as skiers do. Skiers are committed to keep skiing and, despite the risks, they seem drawn to the activity regardless of the potential danger. Just as nurses in this area are drawn to the work and the joys, they can be deeply harmed when an avalanche strikes. Nurses work on a shifting and unstable snow pack. Some nurses are aware that the danger lurks, but do the work anyway. Others, on the other hand, are oblivious to the danger. Some nurses recognize the signs of a slide and leave before being taken under. Some nurses stay and must live with the consequences of that decision. It might not

kill nurses, but they are changed, scarred, and different. Nurses' DNA has changed and they are no longer the same people after working on unstable ground. Nurses watch avalanches come down around them. Sometimes that means that they feel invincible, that they will not be swept away. However, most nurses will be taken over at some time or another if they do not get out first. Survival is in recognizing when the terrain has become unsafe and knowing when to walk away:

If you lack compassion. If you get frustrated with the humanity. If you're not capable of loving them [the children with PLSIs and their families] through these times, I still say you should leave, but now it's because that's a big red flag. It's a warning sign. That's saying that there's something happening here that you need to acknowledge. And it's not because you are the wrong person for the job, now I realize it's that you're not in the right place to do this job. (Sarah)

Spotting the Signs of an Avalanche Coming: Knowing When to Get Out

Most nurses enter the profession because they want to care for people. Nurses are told that they will do good work and make a difference in the lives of others. Many who work with children with PLSIs in acute care do it because they love the kids. They adore these children and find great rewards working with families. It is an honour and a privilege and they are thankful for the opportunity. However, there comes a time in most nursing careers when nurses need to step away from this type of work. Often what drew nurses to the area in the first place is also what repels them:

When I chose to start to leave the unit, I acknowledge that ICU would probably be a better fit for me in terms of my interests and my abilities and my way of nursing. And I purposely didn't move in that direction. I purposely chose to go to emerg where there's

less long-term interaction and less interaction with families in the same way. All the flag ship things that I said what I loved about nursing I'm purposely moving away from it. So there must be some survival mechanism that says that over time this will destroy you. You need to walk away from it. (Sarah)

It is often difficult for nurses to turn away from the work they once loved in order to find safer terrain. The help and support for this is not widely available, but hopefully will be. In the mountains, avalanche training is widely available and recommended. While many training organizations admit that no amount of education and safety gear can guarantee someone will not get swept away by an avalanche, their chances are significantly improved with the right gear and the right knowledge. Nurses are put in harm's way every day they walk on to the unit. Their safety could never be guaranteed, but perhaps with the right gear and training, they could help to keep themselves safe as well as those around them. If nurses know how to recognize colleagues in trouble, they are well-positioned to offer help by throwing a rope or digging them out of the snow. I can remember sitting in the staff room not long before I took a leave of absence. I said that I no longer wanted to have any relationship with families and that I was not going to make the effort anymore. Instead my focus would be on the tasks. A nurse I had worked with for years just said smugly, "If that is the case, you should not have wasted your time and money getting your RN. You should have just been an LPN." I wonder if I could have been rescued had she heard my comment not as an invitation to be condescending and judgmental, but as a cry for help—a signal emitted from an avalanche beacon buried under the snow.

Summary

Nurses who work on inpatient units with children with PLSIs walk on unstable terrain and can be overtaken by the challenges and horrors of the work. Being aware of the dangers that

lurk and how to recognize that an avalanche is approaching could better help nurses to stay safe.

In the final section, I discuss the implications that have come from this research project.

CHAPTER ELEVEN: RETURNING TO THE RESEARCH QUESTION

With a complex and multifaceted topic such as the one for this dissertation, it can be difficult to know when to draw it to an end. The topic is deeply imbedded and intertwined in not only the work of nurses, but also health care systems, societal expectations, and fundamental questions involving life and death. Nevertheless, there comes a time when it is important to stop fleshing out and uncovering further truths in order to pause and take stock of what has been revealed thus far.

I started out with a question that I could never have understood to be as difficult, complex, and rewarding as it has been. *How might we, as nurses, understand our experiences when caring for children with Progressive Life Shortening Illnesses (PLSIs) and their families in the inpatient pediatric acute care setting?* The question grew out of my experiences working as a staff nurse with children with PLSIs. For a while I wondered if perhaps the topic was one that I needed to investigate to satisfy my own curiosity and not a topic that was of much interest to others. I could never have predicted the response that I have received when I have spoken about this topic. To date, I have delivered presentations on three continents and following every presentation I have been faced with a line-up of a dozen or more audience members (nurses, physicians, social workers, chaplains, educators, administrators, and volunteers) who all wanted to tell me their stories of pain, trauma, and heartbreak. I would never have anticipated that this topic would resonate across not only professions, but also languages and cultures.

It was through the process of coming to a better understanding of the topic that I also came to further appreciate that life is messy and there is something lost when we try to solve the problems in life by flattening them out and trying to make them orderly (Jardine, 2006). The purpose was not to box the experiences for nurses working with children with PLSIs and present

a few problem-solving strategies, but rather to offer ways to shift current approaches to the topic and to open the conversation and consider the possibilities of shifting current health care approaches for nurses caring for children with PLSIs. The complexity of the topic is such that having clear answers showing the way forward with well-defined strategies with delineated steps is not reasonable. Rather posing the research question allowed for the exposing of the complexity of the topic and the need to address the issue of nurses' distress and suffering from multiple levels. Therefore, the implications presented are not firm with fleshed out new policies, innovative models of practice, and clear plans for organizational change. The implications for this study are presented as ideas for where positive change needs to stem from and where further investigation can begin.

The findings of any research study are inextricably linked to the question posed and the methodology chosen to answer that question. Hermeneutics is one way to answer a given question. The notion of truth in hermeneutics is cultivated and gained through interpretation. Truth is not a static, unchangeable reality. Rather the truth, as it is understood in hermeneutic philosophy, is always shifting, always changing. Reality and truth are constantly evolving in the in-between of what is and what may be (Caputo, 1987/2000). In this space, interpretive inquiry allows for the unconcealing of something about the world and for continual openness where new understanding is always possible. Therefore, hermeneutics accepts not only the possibility, but also the reality that there are multiple truths in the world and multiple interpretations of those truths. As a result, any interpretation of the world can be explained differently. In fact, we are always in the process of interpretation and understanding: "interpretation is always on the way" (Gadamer, 1981, p. 105). In short, hermeneutics is the answer to a question that can always be answered differently (Moules, 2002). The moment that we begin to believe that we are right, or

believe that we have found the truth, is the very moment that we betray the philosophy of hermeneutics (Moules et al., 2015). As a result, what I offer as implications to these findings is a truth and a possibility of how improving the lives of children with PLSIs and those who love and care for them may be possible. Hermeneutics has much to offer researchers to explore relevant and timely topics and to perhaps point the way forward to further understanding and further dialogue. What hermeneutics does not offer is a definitive truth and solutions to a research question where decisive action can be immediately undertaken. Rather it is through new understanding that possible ways of moving forward are revealed.

So What?

A key component to any research study is answering the question, “So what?” Uncovering truths about life certainly has value, but offering ways of moving forward and making life more liveable is what gives the topic its true purpose. In keeping with the nature of interpretive work where there is always another possibility, I offer these implications as one way the experiences of pediatric acute care nurses can be taken up. The challenges nurses face could be seen as a deep-rooted problem to wearily overcome, or worse, simply something to endure. However, I would offer that these implications are meant to present a perspective that, when looked at from a particular angle, looks more like a place for positive change, hope, and innovation, rather than a problem with which to resignedly live with.

Implications: Casting a Stone

I alone cannot change the world,

but I can cast a stone across the waters to create many ripples

(Mother Teresa, n.d.)

The topic of nurses' experiences in caring for children with PLSIs is one that I am very passionate about. A well-known nursing leader once told me, after I had explained the importance of my research, that “without a doubt, you have found the hill you are willing to die on.” That statement certainly rang true for me and it is my commitment to the topic that has kept me moving forward with this research. Nevertheless, despite my commitment to the topic, I am but one nurse and “I alone cannot change the world, but I can cast a stone across the waters to create many ripples” (Mother Teresa, n.d.). So it is through this work and the dissemination of this work that I cast the stone and hope that the ripples inspire others to join me in changing the world to make it better for nurses, patients, and families.

A Call to Action: Participation is Needed by All Nurse Leaders

When I first heard the term “nurse leader” being used in graduate studies, I immediately assumed that this did not include me as I was “only a bedside nurse” and never held a position in administration or advanced practice. However, leaders are those who have influence and I would argue that some bedside nurses, for better or for worse, hold more influence in the context of acute care than those who hold official leadership positions. What is more, some of the issues that presented themselves through this research ask for the attention of nurses themselves—those in the minefield—rather than simply assuming that sweeping changes can be made by those in administration. Bedside nurses need to do their part too.

The Cost of Doing Nothing

Change is undoubtedly needed in order to decrease the distress experienced by nurses working with children with PLSIs in acute care, but not necessarily revolutionary change. Small shifts in thinking and acting within the culture of pediatric health care are needed and could significantly improve the lives of everyone involved.

It is no secret that there is a growing need for nurses to fill positions in the health care system. Furthermore, the issues of nurse turnover and attrition are an increasing concern as nurses are leaving the profession in droves (Cavaliere et al., 2010; Corley et al., 2005; Czaja et al., 2012; Kelly, 1998; Maytum et al., 2004). The number of nurses resigning from practice is “an indication that the healthcare environment has become toxic” (Austin, 2012, p. 28) and the departure of so many nurses should be cause for alarm as it is an indication of deep-rooted problems in the current health care system (Austin, 2012). Reports on the rate of turnover, according to administrators I spoke with during my research, range from 50% to 75% within the first two years of practice in acute care. What is more, one administrator revealed that 70% of the nursing staff currently working on the inpatient unit have less than one year of nursing experience. With the cost of replacing a nurse between \$92,000 and \$145,000 (Cavaliere et al., 2010; Hatcher et al., 2006), the system can ill afford this trend. Moreover, it is becoming all the more difficult to recruit nurses in the first place. Therefore, the practice of simply replacing nurses who have left is unsustainable. The need for initiatives to mitigate this trend are becoming all the more important.

Investing in Nurses

Investing in nurses to mitigate some of these long-term and costly consequences of distress in practice is needed now more than ever. Investment for nurses is needed in terms of adequate staffing, debriefings following incidents and patient deaths, supporting nurses by showing appreciation, education both at the baccalaureate level as well as continuing education, and mentorship of new graduates. It is possible that investing health care dollars in order to mitigate nurses’ distress would not necessarily be increasing the size of the health care budget, but rather re-allocating funds. The current need is for creative and upstream thinking as money is

being poured into fixing problems after they have occurred rather than developing ways of effectively preventing the problems from occurring in the first place.

The stress and burden placed on nurses through chronic inadequate staffing levels was described by participants as well as it has been well documented in the research literature (e.g., Corley et al., 2005; Schluter, Winch, Holzhauser, & Henderson, 2008). The excessively heavy workload not only has a negative impact on organizational ethical climate (Wall et al., 2015), but it is also linked to issues of nursing staff retention (Corley et al., 2005; Hart, 2005; Wall et al., 2015). Therefore, investing in ways to not only train and recruit nurses, but also to retain them in the workplace are likely health care dollars well-invested.

In addition to the need for adequate staffing, ongoing support for nurses is also essential to decreasing distress experienced by nurses in the workplace. Participants indicated that they would like to have debriefing sessions offered, which is consistent with the findings of other studies (Pauly et al., 2012; Wall et al., 2015). It is recognized that debriefing is beneficial to nurses and other members of the health care team (Pauly et al., 2012); however, logistical issues such as scheduling debriefings at a time that it is possible for employees to attend are significant in a health care system that runs 24 hours a day, seven days a week (Wall et al., 2015). If there is a delay in holding a debriefing session, or those most affected are not able to attend, there are often lingering concerns, questions, and frustrations (Wall et al., 2015). Finding ways to offer debriefing sessions that include a larger number of staff are probably worthwhile pursuits. For example, offering more than one debriefing session, taking advantage of technology such as Skype to include those who are wanting to participate but cannot attend in person, or communicating the key outcomes through email could increase the number of staff who can take advantage of the positive benefits from a debriefing session. Debriefing sessions are one way of

offering support to staff, but this intervention, which is offered following a distressing event(s), should not be the only intervention offered to support nurses.

The health care system has increasingly been looking to the corporate world to guide ways of delivering health care with increased efficiency and economy. While there are some troubling issues that come to light when taking up models that do not have patients at heart, the ways the corporate world encourage employees and support them is a strategy that the health care system would be wise to consider. For example, corporations are successful in encouraging employees, increasing teamwork, and fostering productivity through events such as staff parties or supplying staff with occasional meals or treats to acknowledge a job well done. While it may seem frivolous to spend tax payer's dollars providing nursing staff with tea on Mother's Day, alcohol-free drinks on New Year's Eve, or pizza dinners during stressful periods in acute care (e.g., RSV season, increased number of patient deaths), the cost of those minor investments are negligible compared to the cost of replacing nurses or the indirect costs of nurse suffering. Perhaps an allotment of funds to be spent at the discretion of unit leaders toward "the little things" for nurses will not eliminate the suffering for nurses. Nevertheless, it could prove beneficial in allowing nurses to feel appreciated, supported, and encouraged to continue their vital, albeit difficult, work. This strategy has the potential to mitigate some of the suffering of nurses and perhaps help to curb the cynicism and distress that is overwhelming nurses.

Simply offering more education for student nurses in an already over-packed curriculum, or creating mandatory continuing education programs for nurses in practice, is an overly simple solution to a highly complex problem. Education is clearly an important part of developing and sustaining nursing practice, but education alone does not necessarily translate into positive change in practice. Therefore, education is needed in conjunction with other approaches to

alleviate nurses' suffering in order to affect change. Improving the ways in which nursing students are educated about the challenges and realities of practice, supporting new nursing graduates through a mentorship program, and offering continuing education programs for those nurses in practice could help to curb the negative outcomes of workplace distress.

It is well known that nurses who are new to practice experience a shock (Boychuk Duchscher, 2008). In fact "the real world experience of the new graduate is extremely traumatic" (Kelly, 1998, p. 1135) as they are "intensely aware of the discrepancy between what they experience in hospital practice and what they are taught in schools of nursing" (Kelly, 1998, p. 1135). Critics of current approaches to nursing education report that difficult and important topics such as ethics are being squeezed into an already full curriculum and not a central focus of necessary knowledge for nurses entering practice (Varcoe, Pauly, Webster, et al., 2012). One suggestion to address this issue and help to diminish the theory-practice gap for the education of nurses is to move away from the abstract and formal approach to topics such as ethics by working through formal case studies in the classroom setting (Edlund-Sjoberg & Thorell-Ekstrand, 2001). Rather than this formal and abstract approach, it is thought that for students to have the opportunity to work through difficult situations based in practice is a far more effective learning strategy for students who were able to work through the challenges of real work scenarios versus theoretical learning (Woods, 2005). "There are clearly identifiable cognitive problems for students when simulating reality (i.e. in game playing, case studies or even general debates) instead of applied theorizing in the clinical setting" (Woods, 2005, p. 15). Furthermore, the opportunity for nursing students to engage in learning and problem solving with students from other disciplines could strengthen inter-disciplinary work. This strategy has the added

benefit of allowing students to gain an appreciation of the roles, responsibilities, and perspectives of those working in other disciplines in the health care system.

The transition from a baccalaureate program into the practice setting can be further eased with the presence of a mentor for all new graduate nurses in order to support them as they enter the profession (Wall et al., 2015). As is often the case, new graduate nurses are, as

[o]ne senior nurse remarked on the support offered to new nurses entering the unit...

‘they’re being expected to just jump in and take on these very complex situations, not only from a nursing standpoint but from the psychological and spiritual side of it as well, and they’re not given the tools that they need,’ such as mentorship. (Wall et al., 2015, p. 7)

A mentorship program, where a new graduate nurse is paired with a more senior nurse, has the potential to assist new nurses as they enter the profession with its demands. Furthermore, “experienced nurses need to realize the importance of providing a supportive environment for new graduates” (Kelly, 1998, p. 1144).

Continuing education for nurses in practice is another method to further support nurses who face distress in their practice. Programs to educate nurses about what is known about topics such as moral distress and compassion fatigue could help nurses to better understand how these evolve, present, and perpetuate themselves in the practice setting. Programs to educate nurses further about continued wellness could prove to be helpful as well. Not only to discuss self-care strategies, but also reflective practice and nurse-to-nurse support.

Policy and Philosophical Changes Across the Board

Based on the findings as presented by participants, the two changes to practice philosophy and policy involve the re-envisioning of FCC for acute care pediatric practice and having genuine conversations about heroic measures carried out in pediatric acute care.

FCC: A Practice Philosophy in Need of Re-envisioning

FCC is a contentious issue in pediatric health care. While it is beyond the scope of this study to examine how FCC is taken up in the broader arena of pediatric health care, it is in the context of acute care pediatrics, on the hospital units, where FCC in its current form is in need of re-envisioning. When the challenges of FCC in the context of pediatric acute care began to reveal themselves through the words of participants, I felt a sense of dread as I did not want to address this. Furthermore, a critique of FCC did not seem to quite fit within the findings of my research. However, to overlook it completely would be doing a disservice to the research, but more importantly, it would take away from what participants wanted to put forward as a fundamental problem with the way in which care is delivered to patients and their families in the acute care setting. The current interpretation and execution of FCC is problematic and causing much distress for all involved. The critique here is to further develop the case for needing a new approach to FCC and a solution that is embedded within a re-envisioning of FCC.

The Pendulum has Swung Too Far: Parents Bear Too Much Responsibility and are Given Too Much Power

We've always been Family Centred Care, but I think now it's almost been run-over. I mean you've been taken over by "The Family." The family gets to decide everything, you know?

(Trina)

Families and FCC

We ask a lot of these parents. (Sarah)

When families first walk onto the unit, they are frightened. They have a sick baby and they do not know what is wrong or what will happen. Their world is crumbling and life is not working out the way they had expected. They are suddenly torn from their lives and are forced to enter a brand new reality, which is terrifying.

It's hard because you [the family] only have such a short time frame to make that decision. You birthed a baby, the baby comes out gasping at 22-weeks and she [the mother] was shopping an hour ago in Superstore. So it's a complete shock and so it's a, "Save it! Save it! Do everything! It's my baby!" (Lily)

When I think of what it must be like for families in these difficult situations with sick children my heart aches. Despite my years of practice, I really have no idea what it is like for these families and I can hardly breathe thinking of the panic, sorrow, and despair they must feel in those moments. As a mother of three young children, I can attest to the fact that even with healthy children, the early years are difficult and stressful. I cannot imagine the challenges and struggles faced by parents when the child they have been expecting is unwell and is living with a PLSI and is expected to die. I am aware that in this context I am speaking with my prejudices of being a mother as well as a pediatric nurse: "it is necessary to fundamentally rehabilitate the concept of prejudice and acknowledge the fact that there are legitimate prejudices" (Gadamer, 1960/2006, p. 278). Adding to the distress is that "*unreasonable demands are being made of the family*" (Sarah) whose child is living with a PLSI. Not only has the family's world been turned upside down, but they are also now being asked to make very difficult decisions for which they are unprepared.

With a lot of these children, you know especially the ones that are born early and the neonatologist resuscitates no matter what state that child is in and they do all live-saving measures to get that child to exist and not die and then we hand it over to parents and say, “Now what would you like to do?” (Sarah)

My topic did not necessitate seeking out the voices of parents or family members of children with a PLSI. However, to cast some light onto the struggles of families in this context, it is useful to call forward the voice of a parent of a child with a PLSI. To exemplify the stress and responsibility the health care team places on families, I have included a quote from a study by Kim Widger (2013) to illustrate the perspective of the family, in this case, a bereaved mother:

They’re saying what do you want to do? Like I deal with [my child’s death] everyday. Why don’t you tell me what I’m allowed, give me some options. I don’t think it should be up to me as a distraught, bereaved parent, to be trying to figure out what is okay and what’s not; or what’s available and what’s not.

From what I know to be true about how health care teams conduct themselves in these situations, the team often lets go of their responsibilities following resuscitation and then they back away without necessarily coming alongside the family and supporting them through their journey. The pendulum has swung from a situation where physicians and nurses were the experts in care and patients and families were passive recipients of care. This has left a space for power that needs to be filled. Health care teams are no longer in ownership of this power as they have abdicated the responsibility for decisions other than resuscitation and prolonging life at all costs. Families, by default, are taking not only the abandoned responsibility, but also the power.

They [the parents] don’t always have the medical knowledge to make a true risk versus benefit analysis. So A, they don’t always have the medical knowledge to make that and no

matter how hard the doctors try because a lot of that is experiential knowledge, right?

It's not theoretical knowledge. The other thing is that they're emotionally invested and we all know being in a highly emotional state is not the best state to make decisions in. So we have now asked families to direct care for this child.... But in a crisis, you cannot let the one who is hurting and in pain and confused and scared be the leader. That makes no sense at all. (Sarah)

This reality is reflected in the work of MacKean (2005) who interviewed parents who recognized what the health care team could offer, but was very clear where the responsibility ended as parents

...felt that the health-care system did a reasonable job of diagnosing their child's problem, but then handed the job of finding appropriate services to meet their child's needs over to parents.... I feel like you guys have given me this devastating news that my child has a lifelong disability, and sent me afloat in an ocean and said, okay here it is, now go and do something about it.... (parent). (MacKean et al., 2005, p. 79)

The pendulum has now swung so far that the culture of FCC has adopted the belief that nurses and physicians no longer make the decisions, but rather than working together to make decisions, those decisions are left to the families. Not only are families left feeling ill-equipped to manage the decision making and abandoned by a system that helped to create a difficult situation, but then health care teams become frustrated when parents act like consumers of health care:

Recently, the concept of parental involvement in the care of hospitalised children has also come to include parental involvement in decision-making as well as participation in the care provided. This concept has been linked to an increase in consumerism in healthcare. (Paliadelis, Cruickshank, Wainohu, Winskill, & Stevens, 2005, p. 32)

Family/Parent Driven Care

Well, we quite often call it Family Driven Care, right? It's not "centred" care, it's Family Driven Care and that's, it can even be more specific to Parent Driven Care because it's not driven by the child. I don't know what else to say, because I'm lost in what Family Centred Care means now. I only really see it now as Parent Driven Care.

(Meg)

Before conducting the interview with Meg, I had heard the expression of "Family Driven Care" used to describe what it is like working with particularly "difficult parents." Nevertheless, based on what the participants said, and what I know from my own practice, this is a reasonably accurate way of describing the current state of affairs in pediatric acute care. Care that is driven is "powered, operated, or controlled" (The Free Dictionary, 2015) by, in this case, parents. While it is the parents who seem to be blamed when nurses use this sort of language, it is really the health care system and how it has taken up FCC that should bear much of the responsibility and should take the initiative to address the problem. What is particularly sad about this is that the system creates a situation where parents seem to have little choice but to fulfill the role of driving the care of their child. It is through the unfathomable responsibilities that parents are given to make decisions for which they are not prepared. What is more, the system allows them to be this way and does not offer them boundaries in order to keep them safe, nor do they have clear boundaries in terms of roles and responsibilities. The anger from nurses is often directed towards parents as they are the ones who are directly fueling the frustration of the nurses who are torn between fulfilling their responsibilities to the institution and providing appropriate FCC. However, it really is not the fault of the parents as they have been thrust into a terrible situation and given inappropriate support.

In this next example, Sarah described a mom I have also worked with who had PTSD from a traumatic birth that left her child severely brain damaged. Because of the institutional rules and a lack of mental health resources, the health care team was unable to care for the mother's mental health issues on site, nor could help be imposed from the outside. Therefore, we had the challenge of caring for a very sick child, while at the same time trying to manage a seriously mentally ill mother. I cared for the child one evening and early on in the shift, the mother started screaming for me to come as the child was in cardiac arrest. I ran into the room to find the child stable and comfortable, but needing some oral suctioning. The mom kept screaming at me, claiming that I was allowing her child to die, threatening me with lawsuits, and even threatening to harm my family and me. This sort of behaviour became commonplace over the months and years the patient lived on the unit. Nurses were terribly abused for years as the system had created a situation where we were powerless to help the mom and powerless to protect ourselves from horrendous abuse. As a way to manage the situation, the health care team began to submit to her illness and respond to her perceived needs of her child regardless of whether or not it could be considered appropriate. This is obviously an extreme example, but it highlights how our system is deeply troubled.

When I see a child who, I know you know I'm thinking about a particular family, but mom's emotional state would often dictate what kind of diagnostic or testing or bloodwork or lab work we would do, she would perceive a problem with her child and we would do thousands of dollars' worth of tests rather than say: A, your perspective might be off or B, you know even if she does have a cold, that's what it is. Like, do we need to do cap gases on her and lytes and this and that? You know, that made me angry, sometimes and it's not fair to the parent because though it made a lot of people angry,

you cannot hand the reigns to someone and say, “You’re the boss” and then halfway through say, “Now you’re not the boss or you’re the boss today and you’re not the boss tomorrow” and why were they the boss in the first place? I think that needs to be explored. I think that a pendulum has swung far one direction and that we’re needing to come back to the middle. (Sarah)

The concept of a pendulum speaks to the balance in managing difficult topics. Either extreme of the pendulum swing is not good but being repelled by one side it is easy for the pendulum to swing all the way the other way, causing harm in other ways. Pendulum swings “make for cynicism and exhaustion” (Jardine et al., 2003, p. 194). If the two extreme points upon which a pendulum swings can be thought of in terms of FCC with paternalized medicine on one side and parent driven care on the other, the pendulum has now swung too far in the other direction.

At equilibrium, the pendulum just hangs straight down, motionless. But when the pendulum is pulled to the side and released, the bob is constrained to move along a circular path. If the bob has some speed, it will overshoot the downward position and continue upward again, thereby causing the motion to repeat. Gravity is only able to “restore” the pendulum to its equilibrium position by forcing the pendulum along the circle. (Baker, 2011, p. 9)

Who is the Employer?

The effect of parents being left with too much responsibility and power is that it can breed confusion over patient/family rights and roles. This is evidenced in the phenomenon of parents, under the right circumstances, come to see themselves as the employer of the nurses. It is not uncommon for families to keep a list of nurses who they have “fired” and will not allow these nurses to care for their child.

It was the families who would hover and control everything and make our lives a living hell....[parents] would make lists of who can and cannot look after the baby and talk about us in front of other nurses and try to undermine us. (Jeanie)

In the case of one family in particular, at one point the list of “fired” nurses was so long that the administration had to become involved as only six nurses out of 70 were deemed competent enough to care for the child and it became impossible for those six nurses to cover the 24 hours per day over the weeks, months, and years that the child was admitted to the unit. What is more, the stress and burnout this caused the six nurses has had long-lasting effects. Nurses ended up feeling torn between the expectations of their employer (the health care region) and the families who want to dictate how and what care they want for their child.

When they fire people from the care? That’s, that’s not right. Someone needs to step in and say, “No, you get who you get and you don’t get upset!” (laughs). (Trina)

Some parents want to be in charge of the nurses who are employees of the health region and they want to run the health care side as well and inform the health care providers what to do. This is not a partnership, nor is it even a safe way to care for complex children when those with the knowledge, expertise, and experience are not being given the chance to practice their profession.

I see sometimes families coming in and with their tails blazing in the morning and saying, “Can you page the surgeon and tell him that we want our feeds to go up by 10cc an hour?” I’m kind of like, you get to make that decision? (laughs) Things like that where they say, “Tell the surgeon this is what we want.” And they do get it in the end of the day. It might not always work, but sometimes it does. Some parents have the “customer is always right” attitude. (Rachel)

With the pendulum swing, the physicians and the nurses are no longer in charge of the care and no longer have the professional responsibility based on knowledge to do what is right for the child. The families have now taken up that role, which was abdicated by the health care team. It is apparent that the ability for the health care team to walk alongside families and keeping the child's best interest at the focal point has not been achieved. It begs the question: how do we find a middle ground? Can we restore "the pendulum to its equilibrium position" (Baker, 2011, p. 9) where the opinions of everyone are heard equally and the power and responsibility is evenly balanced amongst the stakeholders? This challenge and the consequences for the health care team are not for nurses to suffer alone. While nurses seem to bear the brunt of it, it is clear that other health care professionals, such as physicians, are also challenged working in an environment ruled by parent driven care:

And somebody needs to say, enough is enough. And there are doctors who say, enough is enough [to the families] and then they get fired [by the parents]. Like I know some docs who refuse to pick up on [the complex care team] because they don't want to deal with that. Because they don't want to get yelled at either. (Trina)

Re-envisioning FCC

It is beyond the scope of this study to present a new model of practice philosophy. As a result, I do not have a new model to present. I do, however, have some suggestions to guide the re-envisioning process of FCC: the need for health care providers to return to their leadership position at the helm of the health care team, taking up the practice of primary nursing, and the role for APNs in supporting both nurses and families in the delivery of care to children with PLSIs in acute care. These strategies have the potential to refocus FCC in order for health care

professionals to partner with families in moving forward with decision making and delivery of care.

Health care providers need to return to their place at the helm of the health care team and help families to direct care for their children that is appropriate and ethical. Models of care that reflect this need to be implemented where maintaining the important role of families is upheld, but at the same time, families are not between the health care team and the child. Rather the family comes alongside the health care team to find ways to best care for the child. The family plays an important partnership role within the entire system, rather than a buffer between the child and the health care team. The work of Wright and Leahey (2000) illustrate how this can be conceptualized: the child is the individual who is the focus of care delivered in the hospital setting and the child's family is part of this context, but they do not dominate it.

The care approach known as primary nursing (Manthey, 1980) could prove to be a better way of caring for children with PLSIs (particularly those who are admitted to acute care for an extended period of time), while fostering a supportive and professional relationship with the child's family throughout the admission. This has long been proven to be an effective way of working with hospitalized patients and families even though there are logistical issues to having one nurse caring for a particular patient over the long-term. However, a primary nurse does not have to be assigned to the patient on every single shift, rather the expectation would be for the nurse to have regular contact with the patient and family and be prepared to attend and contribute in decision making meetings focused on the child's care. The primary nurse role would not necessarily be assigned to a single nurse for the entire duration of the child's admission, which can last for months or years. However, a consistent nurse for even weeks at a time would help to

keep the patients' and families' needs in the foreground and perhaps facilitate beneficial conversations between bedside nurses and families.

Further to the proposition of introducing the model of practice utilizing primary nurses, another role that could prove beneficial is for the initiation of an APN role focused on supporting the ideals of FCC for both families, but also bedside nurses. It is indisputable that parents whose child is admitted to acute care find themselves in a highly stressful situation. It is scary and unpredictable. Nurses caring for children and supporting families can sometimes find themselves in a position of conflict with families. A way to help both nurses and families navigate this important, although sometimes challenging, relationship could involve the role of an APN who understands both the perspective of the nurses as well as the need to work closely and collaboratively with the family.

Furthermore, this APN role could include the responsibility of maintaining connections with children and families who have been discharged (for patients and families who wish to participate). Children with PLSIs and their families come to the unit and are sometimes admitted for months and years. Nurses develop relationships and become invested in the children as well as the family. Once they have been discharged, it would be meaningful for nurses to know what has happened to the child. For instance, the APN could provide nursing staff with updates on children through a password protected online site. Furthermore, the ability to follow patients after discharge might also be able to provide nurses with a different perspective on children with PLSIs and the lives they lead outside the walls of the hospital.

Engage in Real Conversations about Heroic Measures

There are genuine and valid concerns about the cost and direction of health care across the province as well as the country. It is time for difficult, but necessary, conversations about

resource allocation. In chapter five, Isla talked about the challenges nurses, along with patients and families, face with the culture of cure and its heroic measures. Re-envisioning a hero that could be mindful and not simply chase the next intervention, but thoughtfully wade through the options with families is needed. One of the concerns that breeds from the culture of cure is not only the terrible distress of watching children suffer, but also the insurmountable costs associated with caring for children with PLSIs in this way.

The Cost of Cure

Participants live with cost cutting, nursing layoffs, and cut backs. Collapsed within this is harmful and costly output of resources. This section serves to illustrate where change is possible to benefit patients, families, nurses, health care providers, and the health care system as a whole. It also illustrates how nurses could contribute to decisions.

I really struggle with some of the costs to health care in that we have a finite amount of resources and I think sometimes those resources are poorly allocated and I know that's not a popular thought. (Sarah)

The state of our health care system and the increasing costs are an issue. The expensive and futile tests and treatments that we see on the unit are often hidden costs to the system:

Awe-inspiring medical technology has combined with egalitarian rhetoric to create the impression that contemporary medicine is highly effective. Undoubtedly, during the last generation, a limited number of specific procedures have become extremely useful. ... most of today's skyrocketing medical expenditures are destined for the kind of diagnosis and treatment whose effectiveness at best is doubtful. (Illich, 1976, p. 13)

I have to admit, I struggle on the financial side. I really struggle sometimes with the cost.... I think we, we are not 100% aware of how our decisions affect the whole system

and so just on a bigger—you know, no one wants to say in pediatrics “We’ve only got five bucks and we can only afford 50 cents for your child.” No one wants to have that conversation, but the bigger picture, I struggle with some of the cost. (Sarah)

There are many costs associated with continuing with life-prolonging treatments for children with PLSIs. The most immediately obvious cost is the monetary value of continuing to embark on the quest of curing at all costs. The monetary costs of children to live in acute care facilities are staggering. When caring for one child in an acute care bed for a 24-hour period costs thousands of dollars, the cost of a child to live there for even a year is overwhelming. The number of children living in hospitals for years, often from birth to death, is steadily increasing (Hewitt-Taylor, 2005) and this has already become unaffordable to our health care system. With concerns around sustainability of our health care system, consideration to the allocation of medical interventions should be addressed in all areas of the health care system.

The money! Oh man! ... [the health region] doesn’t want to hire more staff, but that’s not really what you need to do. You need to kick out all the people who have been there for three years that could be at home and make room for, you know, sick people who are going to get better and go up. Like, seriously. The cost. The cost. I don’t know if the government has any idea. I have seriously thought about writing a letter, but what’s one letter going to do? (laughs) It might not even get to the right person, but...seriously? You want to fix your budget, go to [the unit]! (Trina)

However, the costs of cure are certainly not limited to financial. The costs are widespread and affect our hearts, minds, and spirits: “cost is not about money, but the toll such lifesaving procedures take on the lives of all who are involved” (Mekechuk, 2006, p. 3). Those affected by the use of life-sustaining measures include family, friends, and health care professionals.

Making a Place at the Table for Bedside Nurses

Throughout the interviews, nurses expressed their desire and fundamental need to be at the decision-making table. These findings were presented in chapter eight. However, it is not simply an issue of getting nurses to the table, but also an issue of having nurses attend and actively participate at the meetings. Nurses' voices are desperately needed now more than ever with the culture of cure and the ethical issues that need to be addressed in the care of children with PLSIs. However, nurses need to come forward and not be a critic on the sidelines.

Nurses Need to Dare Greatly

It is not the critic who counts; not the man who points out how the strong man stumbles, or where the doer of deeds could have done them better. The credit belongs to the man who is actually in the arena, whose face is marred by dust and sweat and blood; who strives valiantly; who errs, who comes short again and again, because there is no effort without error and shortcoming; but who does actually strive to do the deeds; who knows great enthusiasms, the great devotions; who spends himself in a worthy cause; who at the best knows in the end the triumph of high achievement, and who at the worst, if he fails, at least fails while daring greatly. (Theodore Roosevelt as cited by Brown, 2012, p. 1)

Through conducting this research, I came across many examples of how bedside nurses feel excluded from the decision-making process and uninvited to the table where those decisions are being made. Having been a bedside nurse for many years, this truth resonated for me. However, as I worked through my research and spoke with APNs and administrators through the course of my research, I came to realize that this is a two-sided issue. Administrators told me that they face many challenges in trying to engage nursing staff. From the perspective of APNs and administrators, it is very difficult to get nurses to come to the table when they are invited. For

instance, I was invited to present my research and announce recruitment at a staff meeting shortly after I received approval from CHREB. The staff meeting was regarding proposed changes to nurses' schedules—changing from an eight-hour rotation to a 12-hour rotation. Of the 70 nursing staff who would be affected by the change, only two nurses attended the meeting. Furthermore, APNs from other units reported inviting bedside nurses to the decision-making table and when asked for their opinion, the nurses often would simply shrug and say, “I don’t know this patient. Do whatever.” So while bedside nurses are not always invited, when they are, they have not been known to attend or make an effort to actively join the conversation going on around the table.

Bedside Nurses want to be Invited to the Table

The specialized nursing positions (e.g., Nurse Practitioner) offer nurses protection as well as respect—the power of the position. I was not listened to at decision-making meetings until I was in a Clinical Nurse Specialist (CNS) role and a PhD student. When I started my practicum with a CNS, I was suddenly included in meetings. I was shocked at the decisions that were made without any voice from the staff nurses. There were times when bedside nurses were acknowledged, for example, in a comment such as “the nurses are having a hard time with this patient and family.” This reality was acknowledged, but without the impact that such a statement carried with it as no one around those tables could know just how excruciating the experience was for those nurses that they spoke of. Nurses were being ripped apart from the difficult situations they were faced with on a daily basis. Because I knew this reality, I felt distressed knowing what the nurses were suffering in their practice that was not being addressed. In that moment, I felt that the collective pain we were experiencing as nurses caring for a very sick child with a PLSI in a disturbing situation that had been terribly mismanaged from the start, was

ignored. The grim reality and nurse suffering was simply dismissed in that moment. I realized that physicians and administrators are largely unaware of the significant weight of the burden and the depth of the pain of the direct contact with families in a deeply troubling situation. I realized the depth of the problem. The extent of the pain and that no one outside of this group of nurses understood, could appreciate what was at stake, or could offer any ways of mitigating the distress.

Nursing leaders often advocate for nurses to “be at the table”:

Be at the table. clinical experience isn’t enough. Always say “yes” when asked to be at the table. If you believe you’re ready but haven’t been asked, then ask to be involved in a board or committee of interest. Nurse Leaders in the Boardroom... is working to bring more nurses into leadership positions at the local, state, and national levels. (Hassmiller, 2010)

However, often the tables that nurse leaders have in mind are the big boardroom tables where big decisions for entire health care institutions or even entire health regions are made. I would not dismiss the importance of having nurses at the helm in the big boardrooms as nurses bring an important and unique perspective to decisions that affect patients, families, and health care workers. Nevertheless, the table that Isla referred to is not the one in the boardroom. Isla wanted the inclusion of bedside nurses in decisions—nurses without an MN, PhD, or MBA. The decision-making tables that the participants referred to in the interviews are the small tables around the hospital where decisions are made that directly affect patients on the unit. Often, bedside nurses are not particularly interested in the decisions that are made in the big boardrooms in terms of budgets, policies, and overarching programs. Participants are interested

in making a difference to the patient in front of them; the patient and family who are in need of the best care nurses can offer and advocate on a one-to-one basis.

It is in the power of the particular—in the recognition of one voice, one experience, one diminishment of suffering, one experience of healing—that our professions have always found their real power and their real, living knowledge. It is in the moment of being present at the death of one child; or watching one patient walk for the first time on artificial limbs; or the privilege of being present while *this* family hears bad news or good news. It is in the richness of the power of these individual, particular moments of grace, kinship, and human relationship where the professions have always found their own graceful and powerful place—in the context of one human life, here and now... (Moules et al., 2013, p. 2)

Nurses are faced with the obligation to assist the patient and family they are caring for and nurses pay attention to the particular needs of the patient and family in front of them (Gadamer, 1960/2006). The majority of nurses are involved with direct care and make a difference for patients and families at the bedside. The assumption that the only difference to be made is in the boardroom is a limited horizon. What nurses learn through directly caring for patients and families should inform the policies that govern the institution:

The individual case on which judgment works is never simply a case; it is not exhausted by being a particular example of a universal law or concept. Rather, it is always an “individual case,” and it is significant that we call it a special case, because the rule does not comprehend it. Every judgment about something intended in its concrete universality. (Gadamer, 1960/2006, p. 35)

What is more, bedside nurses with a BN do not always possess the language and skills to advocate in team meetings. With the exception of the province of Québec, all Canadian provinces require a bachelor's degree in nursing (BN or BScN) as a basic entry into practice (Canadian Nurses Association, 2015a): "CNA believes that the knowledge, skills and personal attributes that today's health system demands of its RNs can be gained only through broad-based bachelor's nursing programs" (Canadian Nurses Association, 2015a). However, having a baccalaureate degree in nursing does not prepare nurses to have direct conversations with health care decision makers or even prepare nurses to have honest and open conversations in the setting on a multidisciplinary team meeting. Nurses do not speak the same language and perhaps for the sole reason that bedside nurses' priorities are different from other members of the team and the administration. "To serve as successful and knowledgeable board or committee members, nurses must be familiar with governance, strategy, fundraising, financial systems, health law, and policy" (Hassmiller, 2010). If decision-makers heard directly from bedside nurses invited to the table, they would gain a better understanding of what it is like on the front-lines. What is more, bedside nurses would be increasingly aware of the challenges faced at the administrative level and be further engaged in finding and supporting solutions. It is possible that through further interdisciplinary collaboration amongst the various members of the health care team, better decisions could be made if both sides listened respectfully with an openness and not simply listen for what they already believe to be true and what they want to hear (Gadamer, 1960/2006). This has the potential to allow for improvements in how care for children with PLSIs and their families is delivered in pediatric acute care since the interest of individual patients and families are what nurses are good at advocating for because there is an obligation when faced with the particular.

A Role for an APN

It may be a logistical impossibility to include bedside nurses in all decision-making meetings. With the absence of primary nurses and the increasing acuity and heavy patient assignments, that may not be feasible. However, perhaps a more viable option is to create an APN role where his/her responsibilities are to attend decision-making meetings to represent the concerns and recommendations of bedside nurses (as opposed to furthering the medical management position). Additionally, the role would include the requirement that the APN return to the bedside nurses with a recounting of which decisions were made and why. Another option would be for the APN to cover for the bedside nurse or primary nurse at times so that nurses would truly have the opportunity to participate in these meetings. This may be a cost effective initiative as it could mitigate the cost of bedside nurses leaving if they feel heard and supported. The communicating back to bedside nurses would have the potential to improve patient care and further the culture of inclusivity of all stakeholders.

Strengthening Nursing Communities

Supporting the Positive

Nurses are already engaging in strategies to support one another. Building on what nurses are already doing to help each other is a good strategy. The chapter on nursing wisdom offered a glimpse in to how nurses are accomplishing this. Further fostering and encouraging this would further help nurses. Considering the use of social media sites, such as Facebook, to offer a place for nurses to seek out support from one another is another strategy. The support nurses require from each other does not often entail a great deal of time, but rather a few moments for nurses to remind themselves that they are in it together and are not alone in the work that they do. While social media has the potential to offer nurses a great deal of support, it is problematic in terms of

confidentiality and privacy. Establishing a means for nurses to communicate with each other through social media and not violate patient, as well as colleague, privacy is an important issue to consider and address.

Developing Awareness to Curb the Negative

Interestingly enough, there is also a need to be aware of the negative aspects that come with the community support nurses are able to offer each other. There are negative occurrences that go on between nurses and that needs to be addressed in order for the profession to move forward. We need to be aware of the powerful culture of cynicism and bitterness that invades many areas of nursing, not just pediatric acute care. There is a need to ask ourselves what ghosts are slipping into our words and actions? While we may be outwardly allowing a nurse to talk about a difficult experience and debrief, but are we then quietly judging that nurses who exposes her vulnerability?

Research: Next Steps

Learning about the world seems to have a way of illustrating how much more one has yet to learn. The completion of a PhD dissertation is a particularly poignant example of this fact. The research completed for this dissertation is in no way the end of the conversation on the topic, but rather a continuation of a conversation that was already underway. The need for further research to learn ways to better support nurses and to care for children with PLSIs are important areas that require the attention of researchers as well as the support of granting agencies and funders who would do well to recognize the cost effectiveness of investing in this topic.

The need for further research on ways to appropriately support nurses in the work that they do is needed—not only in pediatric acute care, but across health care institutions and even across health care disciplines. There is a thirst for knowledge by those working on the front-lines

of the health care system as well as those responsible for providing support for nurses. Those tasked with these responsibilities are often left wondering how best to support nurses considering the complexity of the issues, the variability in individual nurses' needs, and even the limitations of nurses' knowledge regarding their own needs. While strategies such as debriefing sessions are often used as a primary response, they are not always effective. There is a need to explore other options to support nurses. Furthermore, efforts to better support nurses should not be limited to after-the-fact challenges, but to ongoing support with particular focus on improving and expanding staff wellness programs and support. Research into ways of supporting nurses before there is a problem is desperately needed for the wellbeing of nurses, but also for the sustainability of the health care system. It is well recognized that not any one approach will be suitable for all nurses, but a diverse program of support that meets the needs of the nursing population is what is sought. The cost of investing in wellness programs for nurses would likely be offset by the savings of retaining nurses rather than replacing nurses who have abandoned their positions. Addressing the issue of nurse suffering is timely and cost effective as the issue bleeds our health care system of more than just money.

Research of this nature does not need to be started from scratch as interventions to support nurses are already being undertaken in health care facilities across the country and around the world. Efforts to mitigate nurses' distress are being done at the local level through small programs targeting small numbers of nurses. I would encourage the leaders involved with those programs to take the responsibility of disseminating the successes and failures of these programs as a way to share knowledge to help to build successful and larger programs to benefit nurses as well as the patients and families they care for.

Children with PLSIs are a growing population, yet there is a paucity of research being undertaken for this particular group of children. Certainly there are many challenges in developing and implementing research studies on a population that is so diverse. Studying such a heterogeneous population is fraught with challenges. Nevertheless, the need to better understand disease progression and treatments/cures is essential. However, there is also a need to better understand the needs of children with PLSIs and their families in order to make their lives more liveable and to help nurses to further understand the experiences of children with PLSIs and their families in order to improve partnerships.

Looking toward the Future

Tell me, what else should I have done? Doesn't everything die at last, and too soon?

Tell me, what is it you plan to do

with your one wild and precious life?

(Oliver, 1992, p. 94)

As I was in the midst of analysis, I was invited to present my preliminary findings at the hospital where I had worked and done my research. The proposition was daunting and, as is often the case, the hometown crowd is the hardest. Following my presentation, one member of the audience asked me if I thought it were possible for nurses today to have lengthy nursing careers given the findings of my research. The question made me pause. Through this research I had uncovered some difficult and painful truths, yet, I was more certain than ever that the work that nurses do in the area of pediatric acute care with children with PLSIs is important, valuable, and worthwhile. To the audience, I replied that I did believe nurses could engage in lengthy and meaningful careers and I lived with the hope for a bright future for nursing. There does need to be hope in nursing from bedside nurses, advanced practice nurses, educators, and administrators.

Regardless of where a nurse is situated in the profession, hope is necessary. Hope is required if for no other reason than to combat the cynicism that is alive and well in the culture of nursing and threatens to take us over. Furthermore, I would ask nurses to pause and clarify for themselves, what it is that attracted them to the profession of nursing in the first place and the difference they want to make with their careers. Perhaps the question is even more fundamental: “Tell me, what is it you plan to do / with your one wild and precious life?” (Oliver, 1992, p. 94). I do not pose that question lightly. My supervisor, Dr. Shelley Raffin Bouchal, once told me never to ask a question of participants that I was not also prepared to answer. This is a question that I can answer as it returns to the aim of my life’s work: making the lives of children with PLSIs and those who love them worth living...and I want to be part of the effort.

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APPENDIX A: SEARCH TERMS AND DATABASES

PEDIATRIC PATIENTS

Concept	Synonym
Pediatric patients	Pediatric
Children with progressive life threatening illnesses	Palliative End of life Neurodegenerative illness Terminal care Congenital abnormality Medical anomalies Anatomical anomalies

PEDIATRIC NURSES: NEGATIVE EXPERIENCES

Concept	Synonym
Pediatric nurses	“pediatric nurs*” (nurse, nursing)
Acute care	“acute care” Hospital Inpatient “hospital setting”
Compassion fatigue	“compassion fatigue” “vicarious traumatization”/ “vicarious traumatisation” “secondary traumatization”/ “secondary traumatisation” “psychological burnout” burnout “professional burnout”
Grief	grief* (griefs) mourning* (mournings) loss suffering bereavement “cumulative grief” “compound grief” “professional bereavement”
Moral distress	“moral distress” “mental suffering” “emotional stress” “psychological stress”
Burnout	(synonyms appear with the concept of compassion fatigue)

PEDIATRIC NURSES: POSITIVE EXPERIENCES

Concept	Synonym
Pediatric nurses	“pediatric nurs*” (nurse, nursing)
Meaning	“meaning”
Personal growth	“personal growth”

Databases:

CINAHL

Medline (EBSCO and Ovid)

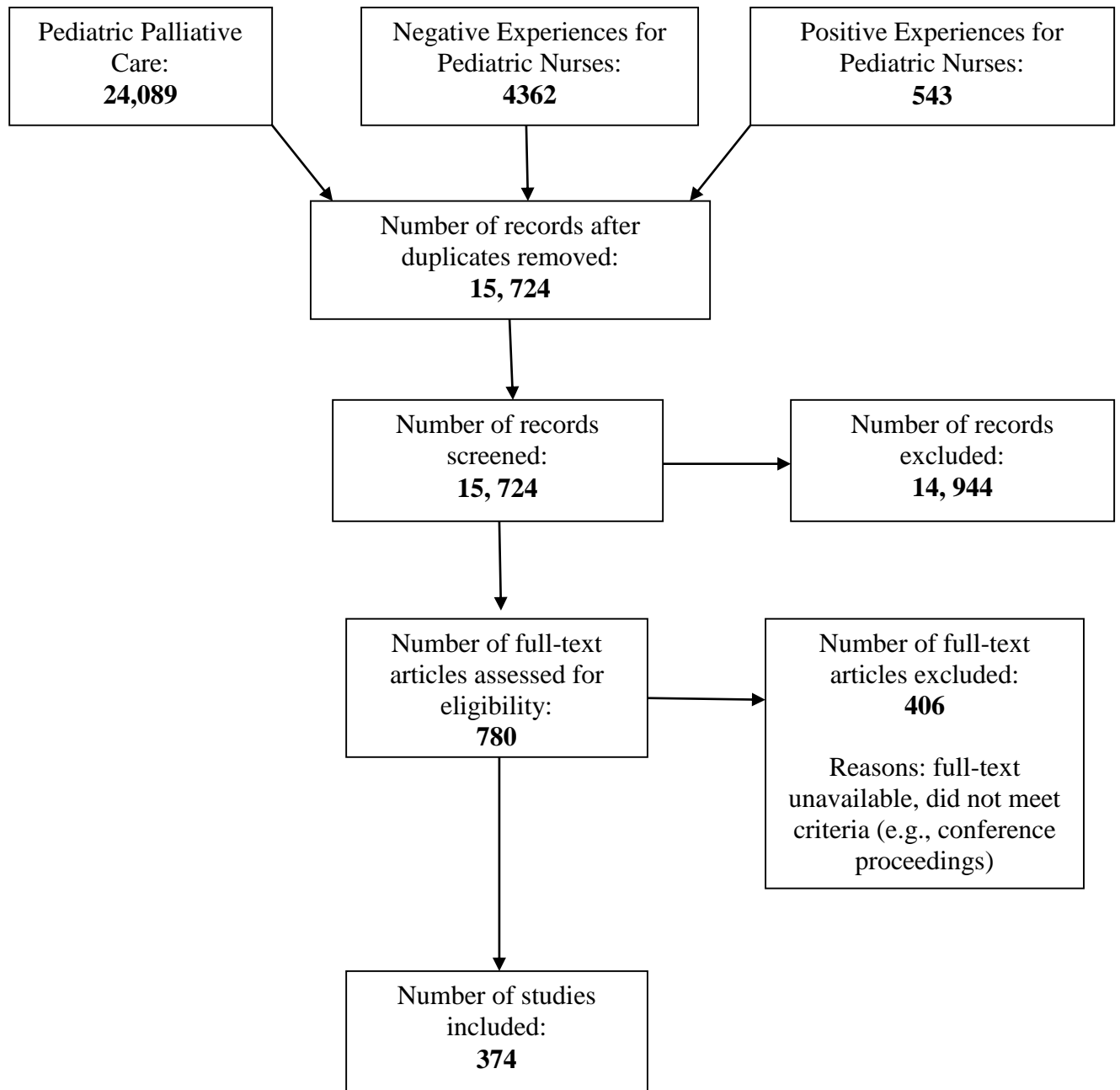
PubMed

EMBASE

EBM Reviews (includes Cochrane Review)

Academic Search Complete

APPENDIX B: LITERATURE SEARCH PRISMA FLOW DIAGRAM



APPENDIX C: RECRUITMENT POSTER

Are you a pediatric nurse
working in inpatient acute
care?

Would you like to participate
in research to better
understand the experiences
of nurses who work with
children with Progressive
Life Shortening Illnesses?



FOR INFORMATION CONTACT

Shelagh McConnell
(PhD Student)



Ethics ID: REB14-1204

NURSES' EXPERIENCES IN PEDIATRIC ACUTE CARE

YOU ARE INVITED TO PARTICIPATE IN THIS IMPORTANT RESEARCH!

We are recruiting nurses (RNs and LPNs) who have 2 or more years of experience working in pediatrics to be part of a study to better understand the experiences of nurses caring for children with Progressive Life Shortening Illnesses (PLSI) in the inpatient setting. You will have the opportunity to share your experiences of being a bedside nurse working with children with PLSI and their families.

APPENDIX D: GUIDING QUESTIONS

- What is it like to work with children with Progressive Life Shortening Illnesses and their families in the hospital setting?
- What have you found to be the most rewarding in your work?
- What have you found to be the most challenging?
- What is it like to be with patients and families in times of illness and loss?
- How has your experience caring for children with Progressive Life Shortening Illnesses and families affected you?
- Has there ever been a time when you felt distress with the level of invasive treatment and number of interventions children with Progressive Life Shortening Illnesses are given to extend their lives?
 - Did that experience change how you think about the culture of cure at all costs?
 - Did that experience change your beliefs in any way?
- Have you ever considered leaving pediatric acute care or even the profession of nursing all together?
 - If yes, what were the circumstances that surrounded that consideration?
- Can you tell me about a patient you have cared for with whom you shared a special bond?
What was that experience like?
- Has the way you think about life, illness, and death changed since beginning to work in this area?
- If you were to offer advice to nurses just starting their careers in this area of nursing, what would you want them to know?

- Is there anything that you would like to add?
- Is there anything that you'd like to ask me?

APPENDIX E: PARTICIPANT CONSENT FORM

Consent Form For Interview

TITLE: Walking Alongside Children with Progressive Life Shortening Illnesses:
Experiences of Pediatric Acute Care Nurses

INVESTIGATORS: Dr. Shelley Raffin Bouchal, RN, PhD
University of Calgary, Faculty of Nursing
Associate Professor, Associate Dean (Graduate Programs)

Shelagh McConnell, RN, BN (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 acute care nursing is an area that is both rewarding and stressful. Research indicates that nurses who work with children with Progressive Life Shortening Illnesses (PLSI) find meaning and purpose in their work. However, a growing body of research literature also points to the reality that nurses also struggle with moral distress, compassion fatigue, traumatisation, and grief. While it is possible to make generalizations about the nursing population, what is known about nurses is based on nurses working primarily in critical care and oncology. In fact, very little is known about nurses who work on inpatient pediatric units and how nurses manage the challenges while also enjoy the benefits of choosing to work with very sick children and families.

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 acute care nurse working with children with PLSI in the acute care setting. In a context where relationships form and are sustained over time by the very nature of the long-term contact nurses have with children with PLSI and their families, how do you as a nurse navigate, live alongside, and experience your own losses within this context? This research will serve to add to our understanding of these relational impacts on acute care pediatric 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 nurse working on an inpatient acute care unit at Alberta Children's Hospital. If you take part in the study Shelagh McConnell will interview you about your experience. The interview is expected to last approximately 1 to 1 and 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).

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 illness and/or 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, the researchers can refer you to a range of counselling services, including the Employee Assistance Program offered through Alberta Health Services.

All responses from the interview will remain confidential. A pseudonym (fake name) will be used in any written information, publication, or presentation of the study results. There is a small risk that something that you said in the study may be recognized by other nurses in the quoted material used for publication or teaching. The researcher will make every attempt to use these quotes in a way which does not identify you directly.

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 experiences of pediatric acute care nurses working with children with PLSI and this will translate into better ways of supporting nurses in their important work.

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 entirely 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. However, a coffee card for \$10 to the Good Earth Coffee Company will be given to you as a thank you for your participation.

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 not appear on the typed interview, 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 participant. 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 employment. If you have further questions concerning matters related to this research, please contact:

Dr. Shelly Raffin Bouchal

Or

Shelagh McConnell

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary.

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.

APPENDIX F: THE SUMMER DAY BY MARY OLIVER

The Summer Day by Mary Oliver

Who made the world?

Who made the swan, and the black bear?

Who made the grasshopper?

This grasshopper, I mean-

the one who has flung herself out of the grass,

the one who is eating sugar out of my hand,

who is moving her jaws back and forth instead of up and down-

who is gazing around with her enormous and complicated eyes.

Now she lifts her pale forearms and thoroughly washes her face.

Now she snaps her wings open, and floats away.

I don't know exactly what a prayer is. I do know how to pay attention, how to fall down

into the grass, how to kneel down in the grass,

how to be idle and blessed, how to stroll through the fields,

which is what I have been doing all day.

Tell me, what else should I have done? Doesn't everything die at last, and too soon?

Tell me, what is it you plan to do

with your one wild and precious life?