

**An Exploration of the Impact of Childhood Life Limiting Illness
on Health Care Practitioners and Their Coping Strategies**

Victoria L. Ellison

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Abstract

Health care practitioners working with children with life-limiting conditions inevitably experience multiple traumatic and difficult situations throughout their careers. Their ability to cope with these experiences is vital to maintaining resilience when practicing in the field. Using a Narrative Inquiry approach, one-on-one interviews were conducted with 6 health care practitioners working with children with life-limiting illness within the IWK Children's Hospital in Halifax, NS. Their experiences on the job and reactions to difficult experiences were explored and coping strategies examined. Similar to the current literature, the findings of this study suggest that health care practitioners experience several different reactions to grief, and cope in a number of different ways. This research contributes to a growing body of literature on the experiences of health care practitioners working with children with life-limiting illness and providing exploration into their ability and processes to cope and maintain resilience in the field.

Keywords: End of life Care, Health Care Practitioner, Life-Limiting Illness, Palliative Care, Professional Coping

Chapter One: Introduction

Research on the experiences of practitioners in the field of pediatric end of life care in Canada is limited, there are a few authors contributing in this area including (Davies et al., 2017; Muskat et al., 2020; Plante & Cyr, 2011; Widger, et al., 2007; Widger et al., 2016). This study looks at a mix of health care practitioners experiences focusing on social work, nursing and other allied health professionals. Incorporating other professions is purposeful as palliative care is an interdisciplinary field, and this will provide a broader range of perspectives on the issue. This study does not focus specifically on pediatric palliative care, instead it focuses on the experiences of health care providers who provide end of life care as an aspect of their role. This is important to consider as palliative care is typically provided by a team or department focusing on comfort care at the end of life. While aspects of pediatric palliative care are relevant to this field, relatively little research has been done on the experiences of health care workers in acute care settings working with children at end of life in Canada (Muskat et al., 2020).

Research in the field of palliative care has been exploding in recent years. There is a smaller portion of that research focused on pediatrics relative to the number of deaths. Within this field there is relatively little research on the experiences of health care providers, this research study strives to contribute to the current growing body of literature in the field. Through an in-depth exploration of practitioner's experiences working with children who have life limiting illnesses and an investigation into the skills they use to cope with these experiences, this study seeks to generate new ideas of supporting practitioners in the field. This information is important to investigate because previous research highlights the vulnerability of health care practitioners working in the field of pediatric palliative care to experiences of secondary trauma, burnout and compassion fatigue (Rourke, 2007). As a student who has completed a placement in

Pediatric Intensive Care, Cardiology and the Emergency Department within the IWK, I worked alongside many professionals who provided care for children with life limiting illnesses. My experiences brought to light the recognition that many practitioners whose main area of practice is not palliative care still work and care for children with life limiting illnesses. While palliative care is generally provided by a particular team or department many health care professionals not among these teams provide ongoing care throughout the illness continuing into end of life care. This study includes participants working both in palliative care teams as well as those providing this care as a part of their overall role in ongoing care. Additionally, research suggests many practitioners working in this field receive little to no training specific to pediatric palliative care (Clarke & Quin, 2007; Docherty, Miles, & Brandon, 2007). This demonstrates the importance of providing increased support for practitioners working in this area.

What is Pediatric Palliative Care?

Pediatric palliative care has been defined by the World Health Organization (1998) as the act of controlling physical pain as well as emotional, psychological, social and spiritual symptoms. The goal of palliative care is to provide patients and families with the best quality of life. Although palliative care is often associated with end of life care once curative treatments are no longer responsive, it can be a beneficial service throughout the illness trajectory (World Health Organization, 1998). Palliative care emphasizes an interdisciplinary collaborative approach highlighting the value of holistic treatment often missing in other areas of health care (Canadian Hospice Palliative Care Association, 2006).

There are some notable differences in pediatric palliative care in comparison to palliative care provided to adults. Life limiting illnesses in children are often rare and little is known about them, making the trajectory and prognosis difficult to predict (Canadian Hospice Palliative Care

Association, 2006). As a result, palliative care services are often provided to children and their families for longer lengths of time and earlier in their illness. This means health care practitioners often have long term involvement with children and families throughout their illness. Long term relationships can help foster rapport and trust, however this deeper investment in families can also make it more difficult on the practitioner when a child gets worse or dies.

Children and adolescents also have differing needs and concerns dependent on their developmental stage (Canadian Hospice Palliative Care Association, 2006). A child's developmental stage affects their communication styles and ability to comprehend their illness. Thus, issues regarding the illness may need to be communicated and framed in developmentally appropriate ways. Additionally, family members often have a more active role in patient care of their children often advocating and communicating with health care practitioners on behalf of them (Canadian Hospice Palliative Care Association, 2006). This highlights the importance of a family approach to pediatric palliative care, valuing a family's cultural and spiritual values, beliefs and practices and allowing for shared decision making with the family (Canadian Hospice Palliative Care Association, 2006). These concerns also demonstrate the need for pediatric specific training for palliative care practitioners. Trainings identified by health care practitioners as important to include are communication skills, exploring the dimensions of pediatric palliative care and recognizing the phases of palliative care (Clarke & Quin, 2007).

Socio-Political Context of Pediatric Palliative Care in Nova Scotia

The IWK is one of the major children's hospital in Atlantic Canada, providing specialized services for all of Nova Scotia, New Brunswick, and Prince Edward Island. The IWK is the main hospital that provides palliative services to children in the Maritime provinces. As the hospital is located in Halifax, Nova Scotia, patients outside the city and province may receive

care through their local hospital in collaboration with IWK teams, however for some specialized services there is limited access and families may need to travel long distances for services.

Palliative care patients must be referred. Research in Canada indicates rates of referral to pediatric palliative care are incredibly low averaging between 5-12% (Widger et al., 2007; Widger et al., 2016). Additionally, the referrals that are made are often not made until very late in the progression of care which results in families not having the chance to utilize the resources that are available to them and may be potentially helpful for them in this process (Widger et al., 2007). This may also suggest that health care teams that have been involved in the long-term care of the child with a life limiting condition have been providing a type of palliative care as well.

As Rallison and Moules (2004) identify pediatric palliative care is a relatively new concept it is not surprising that it is only recently gaining attention in the area of research and policy development. The Canadian Hospice Palliative Care Association (2006) outlines several guidelines and norms for health care practitioners to use in pediatric palliative care in Canada to frame their practice. These guidelines include providing a continuity of care throughout the illness, dying and bereavement, providing supportive and open communication patterns, as well as being sensitive to the child and family's cultural and religious values (Canadian Hospice Palliative Care Association, 2006). Papadatou (1997) indicates when training pediatric palliative care practitioners, it is important to emphasize they are not the experts, the families are and they guide the journey. Providing this type of care can be rewarding creating special bonds with families, however it can also be challenging when families and health care teams do not agree on a treatment course.

Location as a Researcher

I am a Master's of Social Work Student, and have been a Mental Health and Addictions worker for the past 2 years. Over my education I have placed myself in health care environments including a placement at the IWK Pediatric Intensive Care Unit. This is one of the only children's hospital in the Maritime Provinces, providing abundant specialized care and palliative services. My interest in pediatric palliative care and life-limiting illnesses began several years ago. I lost both my parents to different medical conditions at a young age. Their deaths sparked my interest in the healthcare field, and my experience with grief as a young person inspired me to volunteer helping people who were going through medical crises, beginning with volunteering in the emergency department of a local hospital. In my path to find meaning in their deaths, I began volunteering with the Ronald McDonald House in Halifax. It was during my time with this organization that my passion for supporting families and children going through medical crisis began to develop.

Having watched my father enter into palliative care, experience the difficulties of navigating the system, and gain an understanding as a caregiver of the impact upon him accessing services has made me interested in this topic. I began volunteering with the Nova Scotia Health Authority and Canadian Cancer Centre providing support to individuals who had completed their cancer treatments. This experience further opened my eyes to the challenges experienced by individuals in these medically traumatic environments. I saw myself pursuing work in this field, however, began to wonder for myself how practitioners cope with such repetitive traumatic experiences in their line of work.

Purpose of the Research

Pediatric palliative care has only recently begun to draw more attention in the field of research. Despite recent interest in the field, few studies focus on the experiences of practitioners working in the setting or how they cope with stressors they encounter (Graves & Aranda, 2005, as cited in Rourke, 2007, p. 1220). Research shows practitioners who work with traumatized populations are vulnerable to the effects of secondary trauma (Bride, 2007). Bride (2007) indicates most social workers in direct practice encounter traumatized populations in their work. Indirect exposure to trauma at work increases the risk of social workers experiencing secondary traumatic stress symptoms (Bride, 2007). It is reasonable to assume that practitioners working with children who have life limiting illnesses are vulnerable to experiences of secondary trauma in their work. Rourke (2007) suggests families going through experiences of pediatric illness often have experiences of post-traumatic stress, making the job of health care practitioners in the field at times resemble trauma work. This goal of this study is to investigate the experiences of practitioners working with children who have life limiting illnesses and identify how they cope with these experiences. Exploring this topic is important to the growing body of knowledge and research in the field of pediatric palliative care because:

1. Research highlights the vulnerability of health care practitioners working in the field of pediatric palliative care to experiences of secondary trauma, burnout and compassion fatigue (Rourke, 2007).
2. Many practitioners working in this field receive little to no training specific to pediatric palliative care (Clarke & Quin, 2007; Docherty et al., 2007).

3. An investigation into an area with little current research from a narrative inquiry approach can provide detailed accounts of the experiences of health care practitioners and their recommendations for practice.

Chapter Two: Literature Review

Pediatric palliative care is a newly developing field that is still gaining acceptance in health care practice (Rallison & Moules, 2004). With advancing medical technology, the death of a child has become increasingly uncommon. When a child does die the overwhelming loss affects more than just families, it is often felt throughout communities and schools. Health care practitioners also experience grief and loss with the death of a child after being involved in the child or family's care over the course of the illness (Rallison & Moules, 2004). Rallison and Moules (2004) indicate the rarity of a child's death has contributed to the taboo nature of the topic and an overall silencing of it in society. This can affect the ability of everyone involved to cope and heal following the death of a child.

Literature on the field of pediatric palliative care and the experiences of the health care practitioner have been largely untouched until recent years. Many of the studies on the experiences of health care practitioners have utilized quantitative approaches with questionnaires to document rates of burnout, grief and job satisfaction levels (Koh et al., 2015; Plante & Cyr, 2011). Some more recent studies used qualitative methods to explore the experiences of health care practitioners (Erikson & Davies, 2017; Taylor & Aldridge, 2017; Treggalles & Lowrie, 2018). The findings of the literature will be reviewed in depth below.

Challenges for Health Care Practitioners

The current literature on the experiences of health care practitioners in the area of pediatric palliative care focuses mainly on nursing. McCloskey and Taggart (2010) conducted a study on the experiences of nursing staff providing care to children receiving palliative care in the UK. In their finding's nurses reported significant stress related to ethical dilemmas and the relationships developed with children and their families. They described the bond as much closer

than that of other nursing relationships. McCloskey and Taggart (2010) also identified a theme of carrying anxiety in participants narratives, acknowledging they often take on a family's distress and it affects their personal lives outside of work. Instances of stress were reported as more frequent when stressors outside of work were more significant for participants (McCloskey & Taggart, 2010).

Other challenges that contribute to the stress health care practitioners encounter in the field of pediatric palliative care include ethical challenges. These can arise when parents and health care teams disagree on treatment decisions (Klassen, Gulati & Dix, 2012; McCloskey & Taggart, 2010). When children are patients consent must be obtained from their parents or legal guardians to complete treatment. This can pose difficulties for practitioners if parents refuse treatments that health care teams believe are necessary. Health care practitioners can also experience stressors in relation to conflicting relationships with parents of children. Nurses working in pediatric palliative care reported parents with poor coping skills or struggle with mental health (dis)Abilities take out their anger and aggression on the health care practitioner at times (McCloskey & Taggart, 2010).

Team conflict was also identified in the literature as a primary challenge for health care practitioners caring for children with life-limiting illnesses (Bartholdson, Lützeén, Blomgren, & Pergert, 2015; Taylor & Aldridge, 2017). Differences in opinion on treatment plans can be a major source of disagreement and conflict for health care practitioners. When there is a lack of clarity in professional roles competition can develop between health care practitioners which can hinder patient care (Klarare, Hagelin, Fürst & Fossum, 2013). Developing good professional boundaries and clear paths for communication can limit competition between health care practitioners and improve patient care. Tensions and conflict generated from differences in

treatment plans often rise when “timing the breaking point” (Bartholdson et al., 2015, p. 128). The breaking point is when treatments switch from curative to end-of-life. This can be a sensitive time, and health care practitioners have differing beliefs on when this transition should begin. This conflict is amplified by the hierarchical structure in healthcare, where the opinions of some health care practitioners, particularly physicians, are given more weight than the perspectives of other allied health professions (Bartholdson et al., 2015).

Practitioners also note feeling stress when they do not feel the job they have done is to their standards (McCloskey & Taggart, 2010). This can happen when practitioners feel overloaded in their caseload, have insufficient time to provide services and do not have the resources available to provide necessary support (Clarke & Quin, 2007; McCloskey & Taggart, 2010). Papadatou (1997) suggests health care practitioners experience the loss of a child as a triple failure: first by not being skilled enough to save the life; second, for failing to protect a child from harm; and third for betraying the trust of parents. This highlights the significant possibility for stress and caregiver burnout in the area of pediatric palliative care and thus the need for practitioners to have sufficient positive coping skills and supports.

Rewards and Highlights

Compassion satisfaction is defined as a sense of personal and professional fulfillment that accompanies the difficult work that is provided in crisis situations (Rourke, 2007). A study with child protection workers demonstrated compassion satisfaction served as a protective factor from experiencing compassion fatigue (Conrad & Kellar-Guenther, 2006, as cited in Rourke, 2007, p. 643). Compassion fatigue is identified as an experience of emotional exhaustion that follows providing care in repetitively traumatic and high crisis environments. Unlike burnout the experience of compassion fatigue is more immediate, and trauma related (Figley, 1995, as cited

in Rourke, 2007, p. 632). While health care practitioners themselves may not be experiencing a crisis in their work environment, they often work in environments of high emotional intensity accompanying families who are experiencing medical crisis. Compassion satisfaction could be beneficial and provide a buffer against experiencing compassion fatigue when practicing in pediatric end of life care as well.

Several studies have identified how recognizing rewards and having a sense of job satisfaction can increase resilience to burnout and motivation to pursue work in the field of pediatric palliative care (Hulbert & Morrison, 2006; Klassen et al., 2012; Reid 2013; Penz & Duggleby, 2012; Taylor & Aldridge, 2017). Penz and Duggleby (2012) found nurses working in end of life care in the community also spoke to the privilege and honour of being a part of the work they are doing and developing connections with families amidst these difficult times. Amidst the challenges of nurses working in community palliative care they also experience a deep sense of reward knowing they can provide support through difficult transitions and contributing to a “good death” (Penz & Duggleby, 2012, p. 366).

Borbasi, Wotton and Redden (2005) explored what acute care and community nurses believed contributed to a ‘good’ death. Key aspects in the descriptions of a ‘good’ death included keeping the family informed and including the individual and family in decision making (Borbasi et al., 2005). Nurses also noted it was important to have adequate staffing and thought it was important to cater to the wants and needs of the patient in order to contribute to a ‘good’ death (Borbasi et al., 2005). Garros (2003) conducted a literature review generating guidelines for pediatric intensive care units to contribute to a dignified and humane death. Guidelines included managing pain and symptoms, preparing the family for the death, allowing

opportunities to say goodbye and recall important moments, and involving the family and child in decision making processes as much as their development allows (Garros, 2003).

Nurses in palliative care settings have identified that feeling valued and respected were rewarding aspects of their careers (Penz & Duggleby, 2012). Reid (2013) also found nurses working in community palliative care were deeply impacted by their work experiences describing it as an “emotional rollercoaster” (p. 543). Despite the emotional toll they endure in their work they also described feeling privileged to do their work, explaining the rewarding feeling they experienced providing care during such a private time.

Klassen et al. (2012) indicate health care practitioners identified long term relationships with parents of children with cancer as rewarding as it is appreciated and valued by families. Practitioners also identified that playing a role in alleviating the distress of families is rewarding. For instance, making their stay in the hospital more comfortable, providing families opportunities to make memories, and celebrating milestones helped to alleviate family distress (Klassen et al., 2012). Receiving positive feedback and appreciation from parents was also seen as rewarding by health care practitioners (Klassen et al., 2012). This feedback helps to validate that health care practitioners are doing a good job and reminds them of the positive work they do. Finding the positives and remaining optimistic about the work being done in pediatric palliative care has also shown to contribute to lower levels of perceived stress and higher levels of self-efficacy and satisfaction with available supports (Hulbert & Morrison, 2006).

Reactions to Grief

Papadatou (2000) indicates health care practitioners react to grief in a number of different ways. Health care professionals often face death, grief and challenging situations on a daily basis

as a result of the career they have chosen. Health care practitioners experiences of grief and death are not explained as well by most grief models, which Papadatou (2000) highlights steps of going through grief, due to the differing nature of their encounters with grief regularly.

Papadatou (2000) proposes six categories of loss experienced by health care practitioners when a patient dies. The proposed categories suggest practitioners can experience loss due to a close connection with the patient, personally identifying with the loss a family experiences, loss resulting from unmet expectations and goals in a professional role, loss of beliefs and assumptions around life, triggering of unresolved past or anticipated losses, and confronting one's own mortality. Health care professionals may experience one or multiple forms of these losses following a patient's death (Papadatou, 2000). These experiences can also be felt in anticipation of the loss of a patient.

Papadatou (2000) explains health care practitioners can experience the loss of a patient in a number of different ways, some experiencing significant impacts. The nature of the relationship needed to support families through such vulnerable times can require investment beyond a typical health care practitioner relationship, which can also result in greater experiences of loss. Papadatou (2000) indicates that health care practitioners have a wide range of different reactions when they lose a patient. Emotional reactions include crying, feeling anger, and sadness. Other reactions may be more behavioural, such as withdrawing from others. While some report not being affected by the loss in any major way, remembering only small details that are sad to them.

Many health care practitioners report openly expressing emotional reactions of grief in the presence of families and other health care practitioners (Erikson & Davies, 2017; Papadatou, 2000). While some health care practitioners are comfortable sharing reactions to grief others

describe having to put their emotions to the side until they are finished working with families (Erikson & Davies, 2017; McConnell, Scott & Porter, 2016). Erikson and Davies (2017) emphasized the importance nurses placed on establishing boundaries regarding what is professionally appropriate to emotionally display when working in palliative care settings. Boundaries established both physically and emotionally can also be a coping skill used to avoid becoming too personally connected to patients and families and becoming more vulnerable to impacts of loss (Erikson & Davies, 2017).

Coping and Support

The ability for health care practitioners to cope with their experiences in the field of death and dying is crucial and yet it is not a significant area of research (Keene, Hutton, Hall & Rushton, 2010). Clarke and Quin (2007) found participants reported taking breaks and having colleagues to talk to are helpful ways to deal with their experiences, however more is needed from an organizational level to support staff. Rothaug (2012) conducted a study in the UK exploring the dilemmas and coping strategies of pediatric palliative care practitioners. Coping strategies used by participants within this study included accepting the inevitability of death, engaging in self-care activities, and having a large social support network (Rothaug, 2012). Participating in self-care and leisure activities was noted as important for participants in distancing themselves from work experiences. The importance of having a large and diverse social network was also noted highlighting the need for several outlets to cope with the challenging experiences that can occur in the field of pediatric palliative care (Rothaug, 2012).

The grief experienced in palliative care settings is inevitable and having sufficient coping strategies to manage these experiences is critical for health care practitioners to process these experiences. Occupational therapists working in palliative care settings in Australia explained the

experience of grief in their practice as necessary and described the value these experiences added to their lives (Treggalles & Lowrie, 2018). Occupational therapists described managing their experiences of grief by recognizing triggers, allowing themselves to have connections and feelings, and separating personal and professional lives being careful of what experiences are brought home. Erikson and Davies (2017) similarly report the importance of establishing strong personal and professional boundaries in nurses working in pediatric palliative care to prevent emotional exhaustion. At times nurses initially lacked strong boundaries, reporting more memorable deaths in the beginning of their careers and the need to re-negotiate their boundaries. Physicians in pediatric palliative care indicate difficulties in setting and maintaining boundaries because of the emotional investment in their patients (Swetz, Harrington, Matsuyama, Shanafelt, & Lyckholm, 2009). Learning and setting professional limits is an important aspect of setting boundaries that can protect the wellbeing of health care practitioners.

Health care practitioners also use distancing as a coping skill to manage difficult experiences in the workplace, protecting themselves from becoming too involved in any particular case (McConnell et al., 2016). Palliative care professionals identify having to balance personal and professional boundaries, creating enough distance to avoid over involvement, but not to impact the ability to create a connection to care for the patient (Chan et al., 2015). Cook et al., (2012) found many nurses working with dying children in cardiology units described needing to disconnect work and home lives. Nurses explained needing to move forward, choosing not to discuss work when they returned home.

Most health care practitioners working with children with life limiting illness report acceptance following the death of a child (Plante & Cyr, 2011). Despite emotional reactions of

sadness, anger, relief and anxiety, health care practitioners had acceptance for their emotional responses to the circumstances (Chan et al., 2015). Unexpected deaths have been noted as more memorable, making health care practitioners more vulnerable to emotional reactions (Plante & Cyr, 2011). Despite vulnerability often being seen as a sign of weakness, vulnerability is necessary to make genuine connections with families in this field of work.

Plante and Cyr (2011) indicate providing increased support following patient deaths including psychological support, debriefings and providing additional education can help health care practitioners become more comfortable with caring for those who are dying, and ultimately feel lower levels of grief intensity. Debriefing sessions with open inviting questioning formats have been seen to be highly beneficial, informative and meaningful for health care practitioners following child deaths (Keene et al., 2010). These provide space for practitioners to express their experiences and gain a sense of closure through their shared experiences with others. Additionally, feeling supported can enhance the work environment increasing resilience to suffering and foster learning from experience.

Training

Studies have shown up to 75% of health care practitioners working with children with life limiting illnesses have requested additional training in palliative care (Plante & Cyr, 2011). Training is important to improve the confidence, comfort and skills of practitioners, particularly those who have less experience in the field (McConnell et al., 2016). End of life training curriculums provided to pediatric palliative care practitioners have also demonstrated effectiveness in improving confidence and comfort levels in providing care at end of life (Peng et al., 2017). More informal trainings in interprofessional settings that are driven by needs

identified within the group have also been identified as helpful by health care practitioners (Rushton et al., 2006).

Clarke and Quin (2007) conducted a study on the experiences of nursing staff, social workers and doctors in palliative care teams in Ireland. They found participants indicated a lack of training and debriefing support in their roles. They highlighted the need of additional education for staff working in the area and spoke to the lack of resources available to work with. Without enough training health care practitioners risk feeling a lack of confidence in their abilities, and a higher potential to shy away from difficult conversations with families. Parents of children with life threatening illnesses have reported experiences of poor communication, insensitivity, judgement and feeling dismissed by health care practitioners all which have the potential to cause further distress in their experiences and can contribute to complicating their grief (Contro et al., 2002, as cited in Browning, 2002 p. 23). Training programs aimed at improving practitioners skills have often shown success at improving practitioners behaviours and skills in difficult conversations (Browning, 2002). Health care practitioners also indicate most of their learning in the field of pediatric palliative care happens when they are on the job (Docherty et al., 2007). Organizational training could help to provide practitioners with confidence in their skills to practice in the area of pediatric palliative care. This can lead to reducing burnout and compassion fatigue experienced by practitioners and an increased ability to cope with experiences (Rourke, 2007). The following chapter outlines the research design and methodology used in this study.

Chapter Three: Methodology

This chapter will outline the methodology of this research. First the purpose of the study is outlined, stating the research question and objectives. The research design is explored highlighting the rationale for using a qualitative, narrative inquiry approach. Participant sampling methods, data collection and data analysis processes are described, outlining the rationale for the chosen methods. Concerns regarding privacy and confidentiality are also described within this section, along with ethical issues and potential benefits of this study that were considered.

Research Question and Objectives

In accordance with the identified gaps in the area, the overall objective of this study is to identify the ways practitioners working with children who have life limiting illnesses cope with their experiences. Additionally, this project seeks to gain insight into health care practitioners narratives of their experiences working with children who have life limiting illnesses. The objectives of this research are to:

1. Explore what draws practitioners to the field and what they find rewarding about their practice.
2. Gain a better understanding of the educational and emotional support health care practitioners perceive receiving from their organization.
3. Identify any recommendations practitioners would add to current organizational support strategies.

Research Design

This study utilized a qualitative exploratory research approach. To gather a rich understanding of the experiences and coping strategies used by participants a qualitative

methodology seemed the most appropriate. Faulkner and Faulkner (2014) indicate qualitative methodologies are often used when there is little known about the topic under investigation. With little known about practitioner's experiences or coping strategies in this area a qualitative methodology with an exploratory design was suitable to use. Qualitative research seeks to increase understanding about the characteristics of a phenomena through the ideas of individuals involved (Faulkner & Faulkner, 2014). Exploratory research designs are exclusive to qualitative research and is often utilized when little is known about the topic by the researcher (Faulkner & Faulkner, 2014). An exploratory approach allows the researcher to investigate the experiences of individuals in a particular area and gain insight into their common experiences.

The design of this study is aligned with a social constructionist paradigm. A constructionist paradigm challenges the notion of knowledge being objective or as unbiased observation and recognizes the influence of historical, cultural and social processes in the shaping of what is accepted as truth (Burr, 1995). From a constructionist viewpoint the understanding of the world is specific to the historical and cultural context in which it is happening. Knowledge and understanding are seen as products of social processes and interactions (Burr, 1995). Social constructionism accepts an objective reality and focuses on how knowledge is constructed (Andrews, 2012). In social constructionism the emphasis is placed on daily social interactions and the ways language is used to construct reality (Andrews, 2012). This study followed a narrative inquiry design which is rooted in social constructionism which maintains our ideas emerge within socio-cultural and historical contexts which contribute to our understanding of ourselves, society and what constitutes reality.

The focus of narrative inquiry is on the exploration of individuals accounts of stories and the social, cultural and institutional narratives that shape the lives and stories of participants

(Clandinin & Rosiek, 2006, as cited in Clandinin, 2006, p. 45). Narrative inquiry draws from narrative theory elements of the importance of story and its use in giving meaning to experience (Clandinin, 2006). Narrative therapy originates from the ideas of Michael White who created the approach while practicing at the Dulwich Centre in Australia (Denborough, 2012). White's work was heavily influenced by feminist concerns, rooted in the political and social context of the experiences of individuals (Denborough, 2012). Narrative theory has epistemological influences from some of the core elements of postmodernism, including the assumption there are no essential truths, reality is socially constructed, and realities are organized through narratives (Healy, 2005). Narrative theory acknowledges that multiple truths exist however not all are afforded equal power and privilege. Practices of deconstructing and unpacking socially constructed "truths" within stories are necessary to expose the power and privilege inherent in them (White, 1997).

Clandinin and Connelly (2000) indicate there are three dimensions to narrative inquiry, including personal and social interaction, a temporal dimension and a situational dimension (as cited in Clandinin & Huber, n.d, p. 3). Attending to these dimensions of experience separates narrative inquiry from other methodologies (Clandinin & Huber, n.d.). Narrative research methodologies have been frequently utilized in both health care studies and social sciences (Squire et al., 2014; Wang & Geale, 2015). Thomas et al. (2009) identify narrative research as an important approach to understanding the experiences of patients and care providers in end of life situations. A narrative methodology in this study allowed for a focus on the meanings generated within the stories provided by participants. Riessman and Quincey (2005) indicate there are many examples of narrative research in the field of social work. Social work is centered around interaction and the experiences of people making narrative research an attractive methodology in

the field (Riessman & Quincey, 2005). Narrative approaches fit with a social work perspective as they are multilayered, focusing on intersecting aspects of an individual's situation and circumstances to understand the narratives they create about their lives.

Participants and Sampling

This study interviewed a total of six participants who identify as health care practitioners working with children with life threatening illnesses at the IWK Health Centre in the Halifax Regional Municipality. A small sample size was chosen due to the limited number of practitioners working in this field within the study area. Crouch and McKenzie (2006) argue small sample sizes with intense engagement are more important than large quantities of participants to produce meaningful results. Small sample, exploratory qualitative interview-based research is clinical in nature, including an account of narrative histories, cross-case comparisons, intuitive judgements and reference to existing theoretical knowledge (Crouch & McKenzie, 2006). The complexity of this approach “is not something that can be done with a large number of cases” (Crouch & McKenzie, 2006, p. 493).

Convenience sampling was used for initial participant recruitment in the study using existing connections in the field. Faulkner and Faulkner (2014) indicate convenience sampling relies on available subjects and is frequently used in social work research. A secondary method of snowball sampling was used for participant recruitment as well. Snowball sampling allows participants to refer other colleagues who may be interested in participating in the study (Faulkner & Faulkner, 2014). Participants were encouraged to forward the introductory email to other colleagues who they thought may be interested in the study, and the names of potential participants were provided at the end of interviews as well. The initial contact with potential

participants was through a recruitment email inviting them to participate in the study.

Participants who expressed interest were sent a follow up email with the informed consent letter.

Individuals who identify as health care practitioners who have provided care to children with life limiting illnesses in the Halifax Regional Municipality met the criteria for inclusion in this study.

A variety of different professions were purposefully recruited for this study as many of the existing studies on health care practitioners experiences of pediatric palliative care focus on one professional demographic, and often nursing despite the interprofessional nature of end of life care (Erikson & Davies, 2017; Maunder, 2006; Treggalles & Lowrie, 2018).

Data Collection

This study utilized a semi-structured interview, with open ended questions to gain further understanding of health care practitioners experiences working with children who have life limiting illnesses and how they cope with their experiences. Using a semi structured interview approach allows for the proposition of additional questions to elicit more information or clarify responses (Faulkner & Faulkner, 2014). Participants from this study were recruited from the IWK as it is the only hospital in the HRM that provides specialty services for children including pediatric palliative care. Participants were interviewed in person within an office space at their worksite or a meeting room at Dalhousie University. Participants were asked to complete an approximately 90 minute in-depth interview with the researcher which explored their experiences working with children with life limiting illnesses and investigating ways they cope with these experiences. Interviews were audio recorded and later transcribed. An interview guide was used to direct the questions participants were asked. Asking the same general questions to participants allowed for comparisons between participant responses.

Data Analysis

Data collected in this study was analyzed through a narrative process. A narrative analysis concentrates on both individual and symbolic understandings of participants, focusing on both the similarities and differences in their responses (Earthy & Cronin, 2008). The emphasis on experience in this study makes narrative analysis an appropriate fit. Braun and Clarke (2006) identify thematic analysis as a widely used flexible approach in qualitative research. Thematic analysis organizes and describes a data set in rich detail through identifying, organizing and reporting patterns within data (Braun & Clarke, 2006). Thematic analysis fits well with a categorical approach to narrative analysis which compares all references of a particular phenomenon across participant responses (Earthy & Cronin, 2008).

Categorical analysis is often used to analyze data concerned with experiences shared by a group of people (Earthy & Cronin, 2008). Thematic analysis as a constructionist method examines the ways in which participants socio-cultural context and conditions are rooted in their responses (Braun & Clarke, 2006). Moving beyond a descriptive analysis of the data this study utilizes a discursive analysis of the patterns and meanings identified in the data. Further utilizing a critical realism perspective will allow for the acknowledgement of how participants make meaning of their experiences, as well as moving beyond the surface of the narrative to uncover the broader social context impacting those meanings (Braun & Clarke, 2006).

The six phase analytic process proposed by Braun & Clarke (2006) provided a framework for the analysis of the data. Initially data was transcribed and reviewed several times; followed by systematically coding data; generating themes from all coded data; reviewing and revising themes; before the final themes in the report were produced.

Once themes were produced, they were contextualized within the broader social constructs of the settings, environments and experiences individually and collectively through a discursive analysis. Cheek (2004) indicates discursive analysis rooted within postmodernism seeks to draw information past the content of the narrative and connect with the context and how the text is situated. The expressions of health care practitioners when they were speaking was noted and used for context when relevant. Through the use of both thematic and discursive analytic approaches it was possible to generate more descriptive narratives of practitioner's experiences and the impact and meanings they held.

Discursive analysis operates on the basis that there are multiple realities and stories, however some are given more attention and light (Cheek, 2004). The lens I bring to the research inevitably comes from my perspective. While I have attempted to stay true to the narratives and meanings of participants, the portrayal of the analysis is interpreted through my worldview.

Privacy and Confidentiality

After prospective participants were identified and a meeting arranged, an email containing the informed consent form was sent to participants. Participants were asked to review the informed consent prior to the arranged meeting and were given time at the beginning of the meeting to ask questions and express concerns. The consent form explained the purpose of the study and provided an outline of the research and examples of interview questions. Participants were informed of the possible benefits and risks to them, and how their information would be protected. Participants were made aware of what they would be asked to do and how they could withdraw their participation from the study if desired without consequence.

Identities of participants were known to the lead researcher conducting interviews and therefore anonymity could not be ensured; however, steps were taken to ensure this information

remained confidential. Interviews were audio taped for transcribing purposes using the voice memo application on the researcher's iPhone, protected by a password known only to the lead researcher. Audio-files were transferred from the cellular voice recorder, to the lead researcher's password protected computer. Once interviews were transcribed audio-files were deleted. Participants were asked to choose a pseudo name to be used on transcriptions. Many participants opted not to choose a name and therefore pseudo names were assigned alphabetically. Electronic data was stored on the lead researcher's password protected computer, known only to the lead researcher. Hard data was secured in a locked file cabinet with a combination known only to the lead researcher, and consent forms containing identifying information stored in a separate locked cabinet. Data will be retained for 5 years, after which will be shredded. Data in the final report has utilized pseudo names, and left out professional titles, and departments of work, due to the identifying nature of these details. Any direct quotes used in the final report do not include any information that identifies participants.

Ethical Issues

This research project was considered minimal risk, however inherently in any research there are risks. I recognize that the topic I am investigating is sensitive in nature and some questions may bring up difficult memories for participants. Participants were informed they were able to decline to answer any questions, and their vulnerability and risk level was relatively low as interviewed health care practitioners had experience working in this environment daily.

Asking participants details about the organizational and management support they receive in their practice could lead to potential risks in their place of employment. To mitigate this risk measures were taken to ensure the confidentiality of participant responses. Participants were

invited to contact the researcher following the interview if they wanted to change or add anything, they forgot following the interview, however no participants contacted post interview.

Although participants did not receive financial compensation for their participation, there are several potential benefits that could arise from this study. This study allows participants to contribute to the current growing body of literature in pediatric palliative care. Additionally, it allows practitioners an opportunity to explore their own experiences and coping strategies as well as learn from the practices of others. The discussion of coping strategies and suggestions for improvement of organizations supports could initiate conversations about training, education and supervisory support that is provided to health care practitioners working in this area.

Chapter Four: Findings

This chapter presents the findings from the semi-structured interviews conducted with participants. The guided interview questions focused on four main areas of practitioner's experiences working with children with life limiting conditions, their perceptions of rewards in their field, the difficulties in their field, their coping strategies for managing these experiences and recommendations for change to current support systems available to practitioners.

Due to the limited number of professionals who work in this field, and confidentiality concerns, demographic information collected about participants was kept to a minimum. All participants work with children with life limiting illnesses within the pediatric hospital IWK in Halifax, NS. Participants occupations included social workers, nurses, doctors and physiotherapists. Two participants had formal training in the field of palliative care prior to or upon entering their roles, while others had some self-sought education and knowledge in the area through attending conferences and doing independent reading.

Table 1: *Super-Ordinate Themes and Corresponding Sub-Ordinate Themes*

Super-Ordinate Themes	Sub-Ordinate Themes
Rewards in The Field	<ul style="list-style-type: none"> · Privilege · Connections · Making a Difference
Difficulties in The Field	<ul style="list-style-type: none"> · Team Conflict · Inability to help · Difficult Progressions · Intersecting Issues · Separating the Personal and the Professional
Coping Strategies	<ul style="list-style-type: none"> · Supportive Connections · Making a Break – Self Care · Accepting Limitations · Setting Boundaries · Rituals
Recommendations for Change	<ul style="list-style-type: none"> · Shifting the Culture in the Workplace · Practical Support Interventions

Rewards in the Field

Participants mentioned several rewards to working with children with life-limiting illnesses and their families. Participant’s narratives elaborated stories of privilege, connections and making a difference. Despite recognizing challenges in working with children with life-limiting conditions, it was evident in the reports of all participants in this study that there were several rewards in the work they did which seem to reinforce their decision to pursue careers in this field of practice.

Privilege

Several of the participants in this study spoke to the concept of privilege in the work they were doing, indicating that it is an honour to have families allow them to be present in such vulnerable moments. Participants suggest some of their work experiences have been difficult to witness, however it is a privilege to be a part of them. Angela describes both feelings of fear and privilege being able to be present for difficult times and conversations with families:

...you hear a lot of intimate details. I have been there at the time of diagnosis, but I have also been there when the person takes their last breath. ... you just can't be afraid of those conversations. And the thought of having those conversations in the beginning was very, very scary. Still something I don't love, but I feel very privileged to have them, and really, really pleased when someone feels comfortable enough with me to talk about things.

Angela acknowledges that while experience makes these conversations less intimidating for her they are still not easy conversations to have. Angela notes that despite the discomfort she may feel in some difficult situations, it is a good feeling when a child is able to trust and open up.

Participants also spoke to the privilege and honour they feel being able to share in difficult times with families and provide support to help them through the process. Deborah shares about how being involved in vulnerable moments can be both emotionally challenging and a privilege:

I think as difficult as it is sometimes it's just rewarding to have the honour to be present in really difficult and trying times for families, and for staff. You see families go through a lot. You're present for a lot of raw, vulnerable moments of humanness and that's an honour... as humans ourselves, ...we're not spared from that feeling. From feelings of grief or vulnerability... sometimes we have a tendency to ... want to walk away from

this... But to be able to stay there and be present and walk with a family ... just being able to be present with them and hold their emotions and just be available to them... I really think at the end of the day ... that's what I take from it... Is that this is an honour, this is a privilege.

Deborah's account suggests that the most difficult moments can also be some of the most rewarding for her. Deborah describes a rewarding feeling being able to bear witness to the difficult moments and stand by families for support. Deborah acknowledges that staff can also experience grief and distress during difficult child illnesses and deaths. Deborah signifies the importance of supporting other staff and colleagues through difficult experiences on the job and the enjoyment she gets in doing this:

I've been part of ...facilitating debriefings... and even just supporting staff if we're involved in a difficult case...just being there... listening... just being supportive...I love that part of my role and I think it's important that we support each other and our colleagues. And I think that's a big component of leadership and our ability to do that.

Connections

All participants in this study identified the connections they have with children and families as a reward that stood out to them. Participants shared about the importance of building rapport with families and the reward they experienced being able to facilitate a genuine connection. Angela talks about how good it feels to connect with children in her role and help to make their experiences more enjoyable:

...when kids get excited to see you...that feels really, really good, you know. I have kids that they can't wait to be a smart ass with me...cause they enjoy the banter... I mean that's fun...or you know they come in, and they are looking for you because they want to

tell you a new joke or they want to be sarcastic with you or whatever. You know, that's good, that's good.

Angela's description highlights notions of joy in being able to bring fun and normalcy to children's experiences when they are in the hospital. Establishing relationships where kids feel comfortable enough to joke and share were parts of the job Angela seemed to enjoy most.

Angela continues on to explain the importance of having this type of connection with children when they have to be in hospital environments which are largely unenjoyable:

Sometimes when kids come in [hospital] I don't talk about [their illness] at all, I talk about what's important to them like... they have a crush, or they're on the outs with their best friend, or you know... their moms too picky, or too strict. Normalizing it...I think it builds on ... the uniqueness of this ... position...the long-term relationship, you know.

Many participants spoke about how rewarding it was being involved with families over time and being able to have an ongoing connection. Carmen spoke to how rewarding it is having long term connections with the families and the reward she feels seeing success throughout their journey:

I love working with the families and... watching them succeed and do well. Both families and younger kids, because you get to watch them grow through all their little milestones.

Carmen highlights in this passage that there are enjoyable moments to share in with families and children throughout their experiences. The long-term connections and seeing improvements are reflected in the most rewarding things for Carmen in the job. Participants accounts on connection often focused on the positive memories and moments with children and families throughout their relationship with them. Brenda talks about how having a connection is rewarding because of the impact it can have on families going through difficult circumstances:

Doing a small thing sometimes has a big impact and so you sometimes feel like that that is a rewarding part of your work, that you are able to make some difference to make that process somehow easier for them. To have a connection with that family when it's helpful. You know it can be, it can be that.

Brenda stresses how making things easier in the smallest of ways for families can be rewarding. Facilitating a genuine connection helps to establish the rapport necessary to support families in times of crisis.

Making a Difference

Participants emphasized seeing a positive physical change in the projection of a child's illness as a rewarding experience as well. Reducing symptoms and discomfort for children was one of the ways participants noted they were able to make a difference that would improve the quality of life for children and families:

...Kids can often get better in a function or symptom... for most of them [we] cannot fix whatever condition... there's no cure per se. But that does not mean they cannot live a good life, and live happy. And that's our reward. It's to make sure that they're living well... it's really not about dying... it's everything that comes before. It's about the living.
(Elaine)

Participants saw improving quality of life as a significant reward in their work. Faye describes the reward she gets from being able to teach someone a skill and give them the ability to control their symptoms better:

Sometimes being able to help someone ... is about trying to teach them the skill. It's not necessarily what I do to, to them, or to help them... When you can teach someone a skill that's even, well it's just as rewarding but maybe even more so in a different way because

now you're giving them the tools to manage their health and it's not a one session dependent triumph.

Some participants in this study described making a difference as supporting in small ways through gestures such as getting food and coffee, pillows, providing care for siblings and other acts that can alleviate the stress on families. Angela explains how being identified as a support for families during challenging times is both a benefit in the care of the child and a reward in her work:

When someone asks me to sit in with them for a procedure, I'm so glad [they] think of me as a support, like someone that's helpful ... You know we go through scary things at times and [kids] can identify, I want you, cause you help me...I mean I always feel really good when I know that...When you see someone's life improve because of something you've put in place or something you've done or said. You know that feels really, really good.

Carmen also described being able to do whatever they can to improve the situation for the family in their worst moments as a rewarding experience:

That's what we strive to do with every family that we see...help them in the best way that we can. Have the best experience for them...I think most families really appreciate, you know invite us into... their family...grieving process.... It's rewarding because you're helping them do the worst thing in their life.

Having the ability to be present for families and do their job was noted as a reward by each participant. During the more difficult aspects of their roles participants still found rewards in supporting families in whatever way they could. Establishing close relationships and making a difference in the lives of families underlined the rewards described in all participant responses.

Rewards and difficulties reported by participants were often intertwined. Some situations described as challenging for participants were also rewarding when participants were able to be present and helpful.

Difficulties in the Field

Many difficulties related to working with children with life-limiting illnesses were brought forward by participants in this study. These difficulties were broken down into five subthemes: Team Conflict, Inability to Help, Difficult Progressions, Intersecting Issues and Separating the Personal from the Professional. Each participant noted detailed accounts of the challenges presented in their work.

Team Conflict

While having supportive colleagues seemed to make difficult situations a bit better for health care practitioners many noted that team conflict contributed to making those situations even more challenging. Participants talked about the benefit of collaborating with other teams and being able to discuss ideas, however also the difficulties of having multiple teams involved in the same work and the frustrations that can go along with that when their role is not understood. Angela explains when collaborating with palliative care at the end of life it can be challenging to incorporate a new team when a patient is already followed long-term in a clinic:

The people that work up there don't know how closely we work with the kids down here. And that's the major source of frustration in my life right now around people who are end of life and dying... [palliative work] can be done by multiple professionals, outside of the team. Years ago, it was that we were more collaborative, in that they allowed us to be the primary physical people.

Elaine further talks about how conflict and disagreements between teams can make for some of the most significant difficulties in the job making challenging experiences more difficult than they already are:

...what seems to make things worse um, usually it's when there's a conflict that you get caught in. Not necessarily with the family or patient. That's really rare. Um, to me it's more when there's a conflict within the team... And there's tension and you feel it, or some of those complex ethical situations where um you feel somebody really disagrees... and it's okay to disagree... we cannot always agree, but it becomes personal. And that to me is, is the worst...they're really rare, but you never kind of forget them...

It is clear that working with children who are experiencing painful symptoms and nearing end of life can contribute to a high stress working environment. Participants acknowledge that at times tensions can get high and it is particularly challenging when teams and colleagues do not see eye to eye. Participants indicate that at times work roles can overlap and navigating collaboration in these experiences can be difficult.

Inability to Help

Narratives around the difficulties of not being able to improve symptoms or difficult situations for children and families appeared throughout all participants responses. Health care practitioners discussed difficulties of both not being able to be as involved with some families as they would like due to policy restrictions or by the family's choice to remain less involved. Remaining present through difficult illness progressions without symptom control was also highlighted as particularly challenging for health care practitioners to experience. Elaine spoke to the challenges of witnessing terrible diagnoses and progressions where they are not able to control symptoms:

...its, the sometimes the terrible ways how people end up there that's personally, that's what I've found difficult you know...It's really rare when we're in a situation where we cannot get better symptom control... And we cannot take away all symptoms, but usually, we can make things better, so, so that piece, at least for me is not the most challenging...it's the difficult situation when people are really stuck between a rock and a hard place, and you cannot take it away from them...

Not being able to help was also noted as challenging when patients lack the motivation to participate in the care for their health or when families pull back from care. Faye talked about an experience where she became frustrated in an exchange with a patient who was not participating in her treatment, and later was disappointed in how that frustration influenced her reaction:

I had an interaction with a patient who was just not um participating in the exchange... this patient was just exceptionally, non-interactive...it was, it was a very difficult session to get anywhere. So I kind of said "Look, you're capable of communicating here and chatting with me. If you don't want to chat with me, that's totally fine, but I need to move on because there's other kids that I need to see and need to see me. So, you know what do you want to do?"... She kind of came around a bit...but I didn't feel like I got any benefit to her...I know...they were both upset about me being so forward about you know the communicating and participating in the session. And then I find out the grandmother then shares that they've had, there's tons of family stresses going on, ...I say condolences... I was frustrated with myself. I'm a bit of a perfectionist so that that was, upsetting to me that I just didn't do it well, right.

This narrative highlights the pressures health care practitioners put on themselves to get things "right" and improve situations. Carmen also highlights the difficulty of not being able to help in

cases where families were not interested in having team involvement and were less engaged in care on the child's behalf:

You know just the process of it. Honestly, it's a privilege to be a part of that process with a family. I feel very privileged that they want me to be a part of that. I mean I totally respect if they don't want us to be. I mean it's even harder if they don't...you know, even though you do go to the funeral and stuff, it just felt like, you just felt like you weren't able to do your job fully. Because they wouldn't let you in to help.

These narrative's indicate that despite how difficult cases can be when working with children with life limiting illnesses, participants found not being able to help families more difficult than anything. When families are distant and unresponsive to help and support, practitioners note their desire to be able to do more.

Difficult Progressions

Many participants noted first experiences with a child's death on the job as painful, riddled with fears about what to say or how to help. The narratives around first experiences as well as sudden deaths reflected concerns surrounding the uncertainty of the situation and the unfamiliarity with death. Angela explains her first death on the job and how the experience impacted her:

The first death I ever had... it was around the clock kind of thing. I came in that morning and I had a message on my phone that said... we're up on the floor, come up when you can... so I went up to the floor, the family had gathered, went up to the room, it was all dark, they do that chain breathing, which is awful.... it was a long night, and in the wee hours of the morning she...passed, and a few at a time family went in to say goodbye to her.... Cause I had such few personal experiences with death. And I've never seen

anybody die...it was so eye-opening in so many ways ... I remember I don't know it was probably 2 o'clock, 3 o'clock in the morning I got home, and my mom had stayed up for me. And when I came in the door, and I saw her I just lost it. And cried and sobbed like you wouldn't believe. I didn't even know it was there, but I couldn't even speak. And I just, and she just held me and stuff, and I've not cried like that since.

Brenda explains the raw grief she experienced early on in her career, following hearing that a child's prognosis would be terminal:

I was within the first year or two of doing this job, and it was umm a patient that I had...met from diagnosis and followed through ... It was never a good outlook for her...and I did get to know her family fairly well...and the day that she was having the surgery ... we got the news that they had not been able to complete [it] ... [which] essentially meant that she was now not curable... And I remember walking into the room like you know there were tons of people there...And walking into the room to try to say something to be helpful to that family and umm, and I really had no idea what I was going to say. You know, what I could offer like I just really didn't know what to say... I didn't know what to do, and I was in tears, and you know it was just it was a bit of a mess ... and I felt like I didn't offer anything. I stayed I don't know how long I was in the room, maybe 20 minutes, half an hour and then I sort of left the family on their own, and I felt like you know, I didn't do anything good there, you know. And it was very emotional, like I felt, just that sort of raw grief was so powerful.

Situations, where children faced difficult progressions without any good options, were also noted as extremely difficult for health care practitioners. Participants indicate having discussions about difficult topics like giving additional diagnoses, changing circumstances, and families

experiencing multiple child deaths. Narratives of having difficulty keeping emotions under control in situations of delivering unfortunate news were present in many participants responses.

Carmen describes her experience keeping her emotions under control:

One of our...kids who was you know, sicker and in a lot got diagnosed with diabetes as well, and I ended up being the one to have to break the news to her, and I cried when telling her, and normally I'm in better control. I don't usually lose it but, I think I was just feeling sad for her that you know, she now has to deal with this on top of it. But in the end, she's like well why are you crying? And I was like, well I don't like to tell you bad news. That now there's one more thing that you have to do, on top of what you're already doing. Anyway, it was fine. She actually did really well, I was surprised. (Carmen)

Deborah also describes her emotional struggles knowing and witnessing life limiting illnesses progress over time:

...it's definitely hard emotionally sometimes... the challenging parts are, I think you know you just meet so many good people and good families and...you ask yourself. You can't ask yourself, but you do cause it's natural to ask yourself the why. Like why is this happening to them? Like why, why do some people have to watch their child go through these things? Whether it's just treatments, procedures or just you know what I mean, having a life-limiting condition or a condition that's going to progress and get worse over time. Knowing that their child is not going to live a full life. Everyone deserves that, everyone deserves to see their child grow up and have pleasure and joy in their life and some families that's more difficult than others and that's hard... (Deborah)

Deborah continues on to discuss the toll it takes facilitating some hard conversations:

[There is] a child that has a life-limiting condition that will eventually die from this... [the family] were in the hospital...in and out... and we had a lot of really hard conversations with them as things were changing, and they also had a previous child that died from this same illness... you know you're having some really tough conversations about how, how are they doing, you know as a couple, as parents, that are still grieving the loss of their other child and grieving the loss of this child's future and all the what-ifs that were not [going to] see. So of course, you can tear up, and you walk away, and you're like you know, you just, your heart is heavy for them. Um, but did it affect my ability to do my job, no, I don't I don't think so. I think I was still able to be present. Do I hurt for them? Yes. (Deborah)

Like other participants Elaine describes how hard it can be emotionally to do this work:

There's a lot of complicated ethical situations that we're facing that um, its often there's no good and bad, there's just bad and bad. And it's you know it's hard to witness that. I mean we're not necessarily personally involved. We are as professionals you know it's not somebody in our family. But to see just really bad stuff happening to good people. Cause really everybody we meet... is a good person, and then we see some terrible stuff happening and to witness that and seeing you know them being kind of phased. Like they have to choose between terrible or terrible. There's just no good choices, and it's really hard to witness that without being able to change it. (Elaine)

Experiences that reminded professionals of their children stood out as exceptionally challenging situations as well. Faye describes how similarities between a child who passed away in her clinic and her daughter made one experience, in particular, stand out to her. Faye drew on the parallels

between their experiences of both having their hair cut, but for one it was tied to an ending, and for the other tied to a beginning:

... the similarities ...part of the plan was that uh, her mom was going to save her hair. So, she was cutting her hair; I think she cut her hair after she passed. And uh, at the same time my own child was getting her hair cut for the first time. And I found that really.... upsetting. Yeah, so and this mother who's lost her child, same gender as mine. Imagine all of that. It was really...

Intersecting Issues

A few of the participants indicated that intersecting issues often compiled on top of the health care concerns and were some of the things that made experiences even more difficult for them. Issues of child protection and parental mental health were identified as contributing to how difficult the setting can be to work within. Brenda indicated that knowing a child will have a problematic progression with their illness is not the hardest part of the job for her. She emphasizes the compounding nature issues of child protection and parental mental illness have on experiences making them more challenging:

You know, I think child protection stuff can be really challenging...working with parents who may have an undiagnosed mental health issue and trying to work supportively and therapeutically...who has a mental health issue and doesn't identify that. That can be really tough...

Carmen also speaks to how concerns about child protection and mental health have impacted situations resulting in additional challenges and heightened stress. She highlights some of the difficulties of those experiences but also draws on narratives of reward in seeing circumstances improve from these actions:

There was [a] family ... a single mom who was mentally ill...a very difficult case...Ended up having to apprehend the kids, so that's a stressful situation. It doesn't come up very often. I think I've only had a couple of cases ... it's tough going through that, but when it all comes together it's the best interest of the child, and it's what you need to do, but it's just sometimes difficult getting there. Cause you have a lot of anger from families...

Separating the Personal and the Professional

As a child's illness progresses and they get closer to death, participants explained that period can become increasingly difficult as well. The unpredictable nature of how long a child will survive with an illness can add to the difficulty's practitioners face. Practitioners describe experiencing anticipatory grief as children approach the end of life, and difficulty in setting boundaries during these times. Angela's narrative indicates that she is willing to go above and beyond, extending her hours of work to be available to families during times of need:

I've been here 48 hours straight. No sleep... I'll come in on weekends, I've come in through the night at 2am. I've come in in the morning and been here the following morning straight. And then gone right, the longest time was (a client), and he was one full day and he didn't die until the wee hours of the next night and I was up all that time.

Brenda also explains that when a child is about to die those thoughts and questions about what is happening come home with her as well:

Yeah, I mean it's hard to, you know, you can't just park it at the door and there are times that you go home and your expecting that something may happen overnight or over a weekend when your home and your kind of waiting for that, and umm. But I think it you know you can contain it in some way.

Carmen delves further into the anticipation that can be felt leading up to the death of a patient and how she too is more readily available during these times:

It's hard when you know they're probably [going to] die within the next week...then they're kind of... sort of like, hyper because you know you could be called at any minute ... sometimes it would be hard to sleep because you thought, oh is he [going to] go through the night? Or isn't he? So, I usually phone in and just check in and see... And I might just come back for an hour, a couple hours, sometimes were there all night.

In these accounts it is apparent that both practitioners describe having flexible boundaries when a child is about to die and cannot help thinking about their work while they are at home at times. They explain that it is not as simple as leaving work behind when they return home. Some practitioners have expectations in their roles to be available in emergency and end of life situations, meaning they can be on call and not able to fully disconnect from work. Beyond that practitioners described taking the emotion of these difficult situations home and feeling the need to return to work or call to check in on their patients.

Participants talked about trying to contain how work experiences affected them when they are at home because they don't want it to affect their families, and they are not able to share details freely with families. Deborah speaks to the issue of sharing about work experience at home and the boundaries she has to set to maintain confidentiality of families:

I probably open up about things more at work with my colleagues in terms of because they know the patients and the families. And the staff right, I can't get into that detail with my husband. It's not fair to him and he wouldn't have the understanding and then there's confidentiality and stuff too right. And I certainly don't bring all those details to my children, like that's not fair to them.

Deborah's statement highlights the challenges of her talking about work at home, not only with confidentiality, but also how it could impact her family sharing information. Elaine explains that since having children her ways of coping have had to change so she is not imposing her mood and experiences onto her child:

Um it used to be I would get home and my husband would know right away just looking at my face, "Oh dear, something happened today." He wouldn't, he doesn't need to know why. But he would know, um, but then I could be sad all evening and sit down on the couch and watch crappy tv and have a glass of wine. It was fine to do that. I can't anymore. And so, so now I've, I've learned I need to put a strict face or a happy face, cause my son wants to be happy.

Participant's acknowledge that they are not able to leave many of these difficult experiences at work when they return home. Many participants in an effort to protect their families from these experiences and maintain confidentiality find ways to contain these feelings to keep them from affecting their personal lives. These difficult experiences effected participants at home in a number of ways. Deborah describes how a tragic experience at work can limit her ability to participate in her normal routine:

Like some days you want to go home, and you want to hug your kids really tight and play a game with them or something. And some days ... Like your ability to like, there's nothing left in you to give at that moment. Or to make supper, or its coming home and being like I can't cook tonight, like were ordering pizza... So I think in that way it does affect you and your ability to do other parts of your life.

Deborah also discussed how stress and difficulties in personal life can impact one's ability to cope as well at work with challenging cases:

...if you have things going on in your personal life. You know we can't...park things at the door. You can try, but human nature is, you have your own...family, you have your own experiences and I think anytime there's any added stress, whether it's just busyness, or whether its emotional...not sleeping or, anything right. I think that that can make things harder to deal with sometimes, it naturally makes us more emotional and affects our coping.

Elaine also explains how home life and work life can interact making it more difficult to deal with experiences in either environment:

... when you're very busy, your sleep deprived and there's a combination of things stressful both at work and home and you know it's the perfect storm...the first few times you get caught by surprise, and then after a while it's like okay I know this is happening. And I need to put something on hold and take care of it. Before it gets, you know... and I think it brings me to the self-care piece that you don't necessarily recognize early in your career, but then you get older and it's like no okay, I need a break. I need a break before somebody tells me you need a break [laughter]. So, you kind of learn the pattern.

Elaine speaks to the importance of recognizing how experiences are impacting her and making sure she is doing self-care to maintain her ability to cope with and manage her reactions to these experiences. All practitioners spoke to how their experiences at work transferred to their home experiences in different ways. When children were nearing death, participants disclosed narratives that reflected feelings of anticipatory grief and the need to be readily available at all times. This at times results in long working hours and difficulty disconnecting from their work at the end of the day.

Coping Strategies

All participants indicated that there are things that they do daily to help them manage the experiences that they witness in their line of work. Coping strategies at home versus in the workplace did not differ greatly other than the depth of processing participants felt able to do. When processing experiences in the workplace participants found the spaces, they were working in too busy and loud to do in depth processing. Coping strategies for the workplaces tended to emphasize skills that helped them manage with emotions in the moment.

Supportive Connections

Each participant spoke to the importance of having close relationships with colleagues in which they were able to confide in during difficult circumstances on the job. Often times these relationships were seen as some of the most important in terms of coping with difficult experiences on the job. Although all participants acknowledged the importance of supportive family and friendships outside of work, they also identified barriers to being able to share freely with those outside of the work environment. Every participant identified patient confidentiality as a barrier to being able to share with friends and family about difficult work experiences. Participants also spoke to the notion of not wanting to burden others with the heaviness of their experiences. Many participants spoke about wanting to protect their children from hearing about the difficulty of their experiences.

Angela describes how she seeks support in relation to difficult cases at work, and the importance of utilizing professional support herself:

I get lots of support that way from my colleagues, but I mean I have gone to counselling on and off through the years, not so much because I'm in crisis but to offload... I've had crisis workers that have come to talk to me after certain cases because they have been so tragic.

And I'll be like I'll talk it through and it just doesn't. Like I don't feel I have any post traumatic... but my take on it is... if I have to go through this kind of grief every time I lose somebody, I don't think I'm [going to] be able to do this job for 28 years.

Angela's description of her experiences in her role shine light on how overwhelming experiences of grief can be. Angela explains the significance of reflection and professional support to process and seek different perspectives to cope with some of the challenging things she has witnessed:

I can't stress the importance of therapeutic relationships with us. And developing those to just say, you know I just I want to I need to recharge somehow, or I'm not doing enough of this or, you know and just getting perspective and things. I've done that off and on I've gone to social workers, different psychologists, whenever I've needed to.

Many participants found connection and sharing of experiences with co-workers to be one of their main ways to cope with difficult experiences. Brenda explains her colleagues are often in tune with the difficulties that are happening within the workplace.

I think I would say...colleagues are the primary support... And usually they're aware... particularly my sort of closest colleague, works on the same floor she's aware of what's going on, on the floor...you can't help but know when things are going poorly, that things are tough, so she's a good support... (Brenda)

Carmen explains how teams can work together to support each other through shared losses and difficulties.

Everybody's kind of supportive of each other, and aware that... it's hard, to go up there and you know, you're helping staff up on the ward as well, go through it with them. And we have...the pain and palliative care team... they are very attuned to what you are going through as well... we have lots of chats and stuff like that. (Carmen)

Deborah highlights the importance of having colleagues to be able to validate an experience and collaborate with.

I think having good supportive colleagues... the support and awareness of colleagues, and people you can go to if you're having a hard time or you just want to talk about things. Like I don't know if I handled this right, or this is how the conversation went. That is so important. Because we can't ask families that, like "How did I do?" And um, so it's really good to have good connection with your teammates and your colleagues and to have people that you can go to when it's tough. (Deborah)

Despite the difficulty participants indicated about sharing their experiences with friends and family, many noted the importance of spending time with their families and being connected with them in maintaining self-care. Deborah speaks below to the importance of having support both at work and home:

I think having a supportive family... My husband is wonderful, he knows when I've had a hard day, and I don't obviously, due to confidentiality I can't tell him details but he gets it. Not every day is like that right, there's a lot of good day's but I think that's important to have a supportive work environment but also home environment. Cause they transfer, you take your feelings with you right.

Deborah describes how spending time with family can help to shift her perspective and supports her ability to cope with challenging experiences at work:

I love, coming home to your family... I think the normalness of siblings fighting over who's sock it is or who knocked over his lego tower or whatever. As annoying as it is sometimes, sometimes it's like that's the things your grateful for. You're like I'm so

lucky that this is the biggest deal in the house right now... it does put things in perspective...

Several other participants described how travel and weekend getaways with friends help them to disconnect from work and get the support they need:

I have great co-workers... And I like to travel, and we do, we go [on vacations] and summer retreats we do together...and we laugh. I like being around people who can be silly...I gravitate toward people who are like that and so we have the best times, and I'm telling you a great trip, will last me a year. (Angela)

Carmen reflects Angela's sentiments highlighting the importance of making time for friends and getaways to maintain her wellbeing.

I have a group of [coworkers] I worked with...there's probably 10 of us, and we've been together for over 30 years and we do like girl's weekends... like a spa weekend... and we're at least together once a month... We'll go out for dinners...it's kind of like our therapy group we call it...They're like a really supportive group... (Carmen)

The support of family, friends and co-workers is described as helpful in many ways for participants. These types of support can allow health care practitioners to debrief, feel understood, validated and re-connected. Even in situations where participants identified not being able to talk in detail about experiences with loved ones, they identified the understanding from their family that they have had a tough day can often provide that desired level of support.

Making a Break – Self-Care

Participants had several different ways of implementing self-care into their lives. The one thing that continued to present in narratives was finding ways to get a break from their experiences. The importance of breaks both while at work, and once home to maintain self-care

were highlighted by many participants. Deborah describes how simply shifting activities at work or taking a coffee break can help her maintain her self-care through difficult cases:

...knowing okay, it's been really rough, I'm [going to] take a couple of hours and put myself in my office and do some emails and other work that is not [going to] take my emotion ... And sometimes that's the break, the little bit of a break that you need...

sometimes at work if were really busy or its tough like we'll sneak over walk across the street, get a coffee and come back. Like 10-15 minute chat with a couple of colleagues, and that's I feel like that's part of our self-care too.

Elaine also explains that a small break can be enough to carry through a difficult day:

...To me what's helpful sometimes is to just to pause. It's like okay I will cross the street, go, like walk to Starbuck's across the street get myself a coffee and come back... I just need to get out of this situation for a few minutes so I can go back again. Sometimes you feel like you're kind of swimming and like you just need to get your head above the water and that's kind of the... yeah that's very helpful.

Several participants indicated they get the break they need to process events and disconnect from work through physical activity:

...some meditation, some yoga, you know or working out at the gym I find are kind of my go to things for kind of coping... and you know walking the dog, taking her out and that sort of this it's a good stress reliever as well. (Carmen)

Deborah describes exercise breaks as therapeutic and explains for her exercise and the outdoors helps her to process her experiences:

... getting out, moving my body, being in the fresh air is really healthy for me. And that's when I do a lot of processing, a lot of thinking through things...I play out conversations, I

think about how I'm feeling, how I'm going to get through the day...It's really therapeutic for me. (Deborah)

Elaine alternatively describes running as a way to break completely between work and home environments, however also identifies it as a therapeutic experience:

I mean the break for me is I run or I bike to work. So, when I put my running shoes on and I run home, just the physical aspect of it, it's a break. By the time I get home, I'm in home mode. There's a clear break...It's... a cut. And...its very therapeutic. (Elaine)

Carmen explains the impact getting a break from work and implementing self-care into her daily routine has on her:

[It] kind of gets you recharged... you just kind of get a bit of a break. You know, you're not thinking about your responsibilities here, what's going on, you get to just, everything gets kind of shut off.

Accepting Limitations

Health care practitioners in this study indicated that although they want to do as much as they can for clients, it is sometimes imperative that they recognize there is nothing they are able to do. Participants acknowledged that it can be important to recognize when there is nothing you can do to fix the situation, and the role is to walk alongside families through those difficult experiences:

I experienced... a loss of my own and it made that grief less scary to me.... that sort of really facing what does that feel like, it makes it less scary to see that in other people... you know people can live through this...you know what it feels like to some extent. You know that people can get through this and...that it, there really isn't something for you to do... there's nothing I'm going to say that's going to take away that pain. There's nothing

magical I can do. I can be present, I can be as kind as I can be and that means something, that means something... But there's no magic for it. It sort of takes the pressure off a little bit to really understand that in an internal way, that kindness means something, but it's not [going to] fix it. (Brenda)

Deborah spoke to how difficult it can be as a health care practitioner when there is nothing you are able to do to fix the situation. Deborah continues to explain that being aware of her role, and accepting the limitations of what she is able to do has helped her to manage expectations in these situations:

Knowing that their child is not going to live a full life... that's hard and you can't ask yourself the why's but sometimes you struggle with why...and you wish I think as human beings you wish that you could fix that for people, and you can't fix things. You can make things better and you can be there to support them and guide them but you can't just fix it and I think that's, I think when you go into a health care profession that's what you want to do, you want to you want to make it better, you want to fix it...I think knowing where your place is, knowing that you're not going to be the person that's going to do it all... knowing that you can't fix it and you can't take their pain away and you can't take their struggles away. But you can listen, and you can support them.

Elaine also explains that while not being able to control symptoms for patients is difficult to witness, being able to accept and come to terms with death in her practice can help to cope through these difficult experiences:

I mean it's, of course it's hard to see kid's dying, but it is part of medicine. It is part of life and you; it doesn't necessarily make it less sad. But you learn to live with it, you

learn to cope with it, cause its part of any professional health care position pretty much, at some point you're going to lose some of your patients.

Participants speak to the intensity of some of the experiences they are witnessing and acknowledge that these experiences are inevitably going to affect them. Being aware of their limitations going into the situation can help them manage expectations and put their role in perspective. Health care practitioners in this study report recognizing that witnessing death and difficult cases is unavoidable in their roles, however remembering that supporting does not always mean fixing can help practitioners cope with some of these situations.

Setting Boundaries

Half of the participants acknowledged expectations of their roles usually go above and beyond their daily duties, including sacrificing lunch hours to see more patients, being on call during crisis times, coming in on off hours, and calling to see how families are doing when they are not there. Impacts from difficult experiences on the job are not isolated at work, all participants noted during difficult cases the impact of those cases can carry into the home environment. Five participants identified the importance of having sufficient boundaries to ensure that they are able to disconnect when they are away from work, and that they do not cross the line of remaining professional when working with clients. Brenda explains how setting boundaries of not checking her email at home, and leaving her work in her office allow her to disconnect from work a bit better:

Some days I just... go home and I say, a child died today...and...then you can kind of move on. I mean it's, it's not... I don't think impacts...my family life, and I don't know why...I feel like I have some good boundaries for myself. Like I don't look at my email at home, I don't carry my pager usually when I'm off duty... I don't bring any kind of

work things home usually. I try to contain my work in my work time. And, but that doesn't mean you don't think about patients when someone is doing poorly...

Brenda's form of establishing boundaries appears to help her physically and mentally disconnect when she is away from work. Many participants also talked about setting boundaries for themselves in the form of compartmentalizing their feelings and experiences to help them manage their reactions:

...I have a wonderful ability to be able to distance myself...Those are sad events. It just shapes your way of how to look about death, it's something we're all [going to] go through. And it's not anything fun, or, no matter how many you go through, it doesn't get any easier. I just, I compartmentalize... I'm pretty good at not bringing it home. I'm good at knowing like, I need some space right now, for a little bit. (Angela)

Similarly, Brenda describes needing to control her emotions:

I usually feel like I'm controlling my emotions, I'm not in an emotional mess with people but umm, but to say that you don't have an emotional reaction each time... I think you probably do have an emotional reaction each time. You know, it's just how do you, you know sort of contain that a little bit so you can still do something useful for the family. (Brenda)

Deborah reinforces Angela and Brenda's need to keep their emotions in check.

I think... the ability to park your emotions and leave yourself at the door and be with a family is not I don't think is realistic...we are human we have hearts we care and were going to take that with us... I try to tell myself this is not my story, it is their story and I am a part of this journey as a health care professional...I [have] become emotional, yes, but not overly emotional...it's appropriate to be emotional you can cry, but we can't be

more of a mess than the family themselves. They can't be turning and comforting you...

I've always kept myself in check and then you know you leave work and you cry on the

way home. Or you know you have your moment when you get home... (Deborah)

Compartmentalizing and managing emotions was described as important in the moment when working with families in crisis, as well as for preventing work life from overtaking their personal life. Participants indicated that the intensity of the experience of these difficult cases does not get easier over time, and that the ability to compartmentalize these experiences has been vital for many in practicing in this field.

All health care practitioners within this study indicated that the feelings of loss following the death of a child or a traumatic experience at work are often carried with them. These experiences shape the way in which they live their lives going forward. Boundary setting was also discussed in the form of avoiding painful memories when possible. Participants indicate that there are often triggers associated with these experiences, and things such as songs or places that they will avoid preventing the pain of some of these memories. Faye shares how difficult experiences such as a child's death become a part of who she is:

I don't know. I go home I do my thing that day, but it's. It's every experience like that just becomes part of your fabric. And you, I sometimes...things will come up that will remind me of that person at work or even outside work. More so at work. But sometimes outside of work...

These triggers for some can make the memories of these experiences too much to endure outside of work, and therefore some practitioners avoid their known triggers. Angela explains how she will avoid certain songs as a way to protect herself because of the memories that they will trigger for her:

I have so many songs I refuse to listen to because it triggers oh a memory of this person, or they had this one played at her funeral. Or and I'm like turn that off, nope we can't listen to that anymore.

Participant responses indicated that setting boundaries is key to them maintaining their practice as well as a home life. Participants have many different ways that they set boundaries for themselves to ensure they are able to disconnect when they leave work.

Rituals

Half of the participants acknowledged the importance of having rituals to help staff process grief following the death of a patient. Participants indicated attending funerals and services can provide not only an opportunity to continue to provide support for families, but also provides an opportunity for staff to gain closure. Angela explains the importance of attending services following the death of a patient:

I've even travelled as far away as Cape Breton for a funeral...because its important, your there not just for yourself, of course, you go to say your own... But more importantly you are there for the family, and siblings sometimes. Your work's not quite done, and we do do follow up, around grief and check in.

Brenda explains how society has created rituals around death, however when practitioners experience a death in their professional lives, there is not always an opportunity to attend the funeral. Brenda describes how her involvement in planning and attending remembrance ceremonies at the hospital helps her gain closure and process these experiences:

... one of the things that [bereavement advisory committee at the IWK] does is...organize an annual service for remembrance for all of the children who have passed away in the previous year. And I go to that service. And I feel like that's helpful for me.

Because...societies have rituals around death for a reason...often the deaths that we

encounter in our professional lives we don't have any ritual around those right? And I find it's hard you know, it's not really a day I look forward to in the sense that... it's a hard day. But I feel like it's has a purpose...you know you sort of think about the children that have died in the last year and you see some of those families... some families come back year after year, so you get to see them recovering from that loss and doing better and you know. And still remembering their child, but also moving ahead with their lives, and that's helpful.

The attendance at funerals was noted to be an important aspect of their role by two participants, another participant explained that this is not always operationally feasible, and services for in house are also a great opportunity to connect with others around the loss and process. Carmen explains the impact this service has for her as well as families she has worked with:

We often used to do a service here for the kids as well, cause not all the staff would be able to get to it, and you know it's an important part of closure...it's partly for us, and it's a little bit selfish [laughter]...but it's something we can also give back to the family as well...They want to be able to talk about their child and celebrate... we have a time of sharing ... all the little relationships and ...that their child has had an influence on people. You know, that's amazing. So, they get to know a little bit more about their kid too...and it's always been really helpful.

It is clear from participant responses that bonds are formed with children and their families, and there is a need to be provided time and space to cope and accept this loss. Providing services and rituals is one way that staff members are able to honour and share experiences and stories with other staff and family members.

Recommendations for Change

All participants felt that more could be done to support and promote the well-being of practitioners in this field. Four participants acknowledged that there are some formal supports in place for them to access, such as Employee Assistance Programs, and debriefing sessions following difficult cases; however, they all indicated that these efforts alone are not enough. Participants suggestions were separated into two sub-themes of Shifting the Culture within the organization and practical support interventions to better support health care practitioners working with children with life-limiting illnesses.

Shifting the Culture in the Workplace

Participants in this study spoke to the concern's they have with the current culture of their workplace and how that impacts the level of support they perceive within their organization. The belief that self-care and staff well-being is undervalued, based on their job expectations and lack of support available for health care practitioners was reflected in the responses of half of the participants. One participant reported feeling misunderstood by management, and that their needs were assumed rather than asked, suggesting a shift in management culture could improve the understanding and representation of the roles and needs throughout the organization. Angela brought up concerns surrounding managements understanding of her role and the desire to have more representation from different professions on the management level to provide diverse perspectives and a greater understanding of the roles of allied health members:

They don't get it. There's a disconnect. But we're an institution run by nurses. And that's the only perspective they have naturally. And it should; there should be a mixture. I think that's how you have a better management.

Angela explains how team leaders for the different health professions have had their positions cut back, and are not provided time to attend decision making meetings anymore, limiting the variety of perspectives in decision-making processes:

So they're not even going to the meetings anymore. Because they're not going to have the times to do those things. So that perspective's going to be missing at all those decision making meetings. So, they will be well attended by nurses. I have nothing against nurses, it's just there is more than just nursing in a hospital setting... I think there should be a manager of social work, I think there should be a manager who is the psychologist, a manager as an OT, a manager that is a physio, a dietitian, representation of the services because everything that we come across is so unique to the things we do with our families and the people that um, are making decisions are getting information from the wrong people.

Angela's concerns draw attention to the challenge of having limited perspectives in upper management positions and the importance of diversity in decision-making processes. Carmen reported similar sentiments of feeling her position has been misunderstood by management and talked about the challenges that can be associated with these concerns:

I would say management have been pretty supportive. Not always...sometimes you just have to, they make assumptions... sometimes it's just kind of clarifying with them. I mean there was a time when they were like, uh, well staff can't, uh, you know I'm not giving you time back for going to the funeral. It's like, well bereavement care is part of my job.

Carmen's report demonstrates the difficulties that can be associated with having limited perspectives in upper management. Carmen acknowledges that communication is key to building

an understanding with management; however, validates the experience of having to justify the importance of bereavement aspects within her role. Participants also discussed concerns regarding the perception of accessing services if they needed due to work stressors. Elaine emphasizes the importance of having a shift in the approach to how mental health is perceived, noting the available resources may be underutilized because practitioners are concerned with the stigma associated with accessing them:

The thing I would like to change the most is not the system; there are lots of really good things out there. It's the stigma around it that's still very much there... still just saying that you're having a bad day is a big deal. And having to deal with any mental health issues is still...still there's stigma, its taboo to talk about it...like you cannot sail through a career without any bumps on the road, there will be some...I've seen colleagues, not necessarily in my close team, really not doing well but would not ask for help because they were afraid of the repercussion, which I don't think there would be any but you know it's easier to have a broken leg then to say "I'm going through depression." It's still very much like that.

Elaine's description of how stigma associated with mental health holds individuals back from accessing services highlights the concern of practitioners carrying the weight of these experiences without feeling safe to access support. One participant also felt the expectations for their role following the death of a patient were unclear, leaving them to question their involvement during bereavement. Faye explains that in her role, there is a lack of direction in what her responsibility is once a child has passed on. This lack of direction leads to confusion, increased time to plan, as well as more mistakes:

...In the earlier years... there was a culture kind of, it was an unspoken directive...that you're not to be in contact with families...our nurses would typically stay in touch with the families and do this bereavement care and social worker and what not but for me, that's not my role... we would get updates [on how the family is doing] I find that helpful in the process, but ...at death it's done and your, there's a disconnect with the family. And you're the culture was you're not to contact the family...And I think some families were offended...And you know what there was actually no direction. There was a culture of there was almost this like..." I don't think I'm supposed to contact this family?"

Faye's concerns indicate that when there is no direction to guide a practitioner's actions, it becomes even more challenging to navigate end of life situations with families. This can lead to increased distress and a lack of closure when working closely with families. Confusion in role responsibility appeared to leave Faye questioning whether she has made the right choice not having contact with families and concerned about the harm this may have caused with families who had close relationships within the hospital.

Practical Support Interventions

Participants noted several practical supports that would improve the promotion of well-being from their organization as well as their ability to sustain self-care in an emotionally challenging environment. All participants indicated there was room to improve the promotion of self-care within the workplace. Deborah recognizes that there is a heavy burden for staff to shoulder, and encourages more supports to be put in place:

As supportive as one manager is, they are also confined to the guidelines, the protocols, the constraints of the organization. So is there more that [can be done] yes I think so, to support ... staff. Do I know what that looks like? I don't know... is there enough support

for staff, are they expected to muddle through a lot? I think they are, I think the weight on staff is quite heavy.

Deborah stresses how much staff are expected to manage in their roles emotionally, and although unsure of what a better system would look like, she recognizes that more should be done to support staff through these experiences. Participants also suggested making spaces more functional for their roles and implementing facilities and services to improve self-care among employees. Angela speaks to issues of not being provided with the tools needed to be successful in her work, such as a proper workspace, resources to tap into, and feeling isolated in her workspace:

...For the longest I had a photocopier right outside my door, and I had to fight that. Can you imagine? Somebody who does therapeutic relationships and conversations and they thought ok... Cause sometimes when (co-worker) is on the phone... you could totally hear her conversation.

Angela's commentary highlights some critical issues regarding sound, and lack of confidential space, which can prevent her from doing her job to her full abilities at times. Not having an appropriate office space means spending time searching for another available room to utilize, or limiting conversations within the space to minimize what others are hearing. Angela also notes concerns of being isolated within her current workspace and the challenges associated with this:

[management] don't get why we need to be together. They don't get the sharing of information... And or if there's a concern that comes up or an end of life things and somebody's divulged something to you. You want to bounce it off somebody. Other than the team because they've told you you're not supposed to... I mean, management just

doesn't get that...I don't even meet families in my office anymore. Do you see how quietly I'm talking? It's because there's people walking back and forth there.

Angela's concerns indicate that having access to co-workers with similar professional backgrounds helps to work through ideas and determine strategies for interventions. Not having access to this can lead to feelings of being unsupported, isolated, and unable to access needed resources to perform job duties. Carmen notes other ways to improve the workplace to promote self-care and well-being, such as incorporating fitness facilities and programs to make it easier for staff to access these activities:

...it would be nice to be able to have a gym or area of activity here... they have physio that are here now. Like in the building, so you can book appointments, and I'm like god like that just makes it easier... I wish they would have daycare here for family members, cause I think you know if you look after your staff they're more productive right? So, I mean I think it would be nice to have some more sort of facilities here.... Cause were good at [providing support] for families but were not, you know I'm just lucky we have a good team ... we do support each other. But...I know all the places aren't like that and you know I just think there should be more of that available for staff here... It'd be nice if they had a massage therapist on staff that you could just go here... I know space is a priority, but honestly, you get stuff like that to promote wellness amongst staff.

Carmen's suggestions point out the importance of investing in staff well-being. Participant's suggestions indicate that the more interest and importance invested in their well-being, the better capable they feel to do their job. Faye also discussed the challenges of health care practitioners always being expected to put patient needs above their own:

... I've worked in centers...in Sweden, they had staff rooms that had a cot, rocking chair, I think you could play music in there, ...staff could go, and at least have time there if they needed it and... If you want to get a nap on your lunch break, if you're really struggling and you're tired, you have to go lie down in your car. Right, there's nowhere for you to go to actually physically go take a load off...every ward had...big fruit baskets... it was just this nourishing, nurturing environment...and it was okay to first have the fruits before we went to see the patients. And we don't do that. We sacrifice ourselves...and that's okay; it's okay to do that, in fact, it's almost a bit of a you get more credit for doing that.

Faye indicates that in other work environments, she has experienced cultures that promote self-care in practical ways, which demonstrated to staff how important their well-being is, and allowed them to meet their needs as well. Faye's concerns indicate that not only is there an expectation for health care practitioners to push themselves to their limit with minimal supports, but it is also often praised. This notion points out issues surrounding burnout, as practitioners have also reported needing additional supports to manage the current expectations placed on them. Furthermore, this highlights a narrative around self-care and wellbeing as the responsibility of the practitioner to maintain rather than the employer. Other participants noted a lack of support clinically. Brenda explains what she would get out of having clinical supervision within her job:

Well you know one of the things that I think we don't really have here is clinical supervision right. You know I think if you had a relationship with someone in a sort of a clinical supervision role, I think there would be opportunity to um, you know think about that in terms of impact on your practice and your well-being and some of that in a more

um, formal way... we talk amongst ourselves...but, um, but I think there's a difference in you know that, that relationship that's sort of a bit um, developmental in the sense of helping you to develop your practice and your skills and um, yeah. You know what you'll take from each experience to sort of um, develop your skills and develop your practice and maintain your well-being.

Practitioners had several ideas of ways to improve the supports they are currently receiving.

Participants responses indicated that having their needs prioritized would help them to feel better supported and more productive in their roles.

Chapter 5: Data Analysis

In this chapter I will connect the themes from the study back to the current literature and provide an in-depth analysis of the findings. The analysis will further examine the experiences of health care practitioners working with children with life-limiting illnesses and what they find rewarding and challenging about their experiences. I will explore how the difficulties identified by participants within their practice impact their work experiences and personal lives. Suggestions for improvement to supports for staff brought forward by participants in this study will be analyzed and compared with the current literature. Based on participant concerns and suggestions recommendations for additional supportive interventions will be explored.

Health Care Practitioners Perceptions of Rewards and Challenges

Health care practitioners narratives spoke to fears, reward, difficulties, and privileges in their field of work. Participants narratives often indicated rewards and challenges of their work intertwined with one another. Participants acknowledged that despite the difficult nature of the work at times, this very aspect contributed to a feeling of privilege to be able to support families in difficult circumstances. The literature identifies that the health care practitioners ability to recognize rewards and positive aspects of in their work can contribute to feelings of value and respect and increase resilience in their respective fields (Penz & Duggleby, 2012; Taylor & Aldridge, 2017; Zander, Hutton & King, 2010). In a study based out of a Toronto children's hospital health care practitioners working in pediatric acute care providing end of life care have highlighted the personal fulfilment they experience in their work, describing their roles as rewarding and opportunities for personal growth (Muskat et al., 2020).

Furthermore, practitioners in palliative care who look for positives within their work to cope with their experiences have been reported to have lower rates of burnout than health care practitioners utilizing alternative coping mechanisms in pediatric intensive care units (Colville et al., 2015). Participants spoke about confidence levels changing throughout their experience in practice influencing their comfortability and acceptance with difficult experiences and conversations. Health care practitioners also noted the importance of boundaries and disconnecting in response to working in such difficult environments at times, which affects both their professional and personal lives.

Is it a Reward or a Challenge?

Participants in this study identified several different rewards they experience working with children with life-limiting illnesses. All participants within this study discussed feelings of privilege and honour in being able to work with families during such sensitive and vulnerable times. Papadatou (2000) also speaks to the profoundly privileged nature of the work of pediatric palliative care professionals who are let in at the most vulnerable of times and establish unique bonds with their clients. Klassen et al., (2012) found health care practitioners working in pediatric oncology described “being welcomed into people’s lives ... to participate with and help them through...” as a privilege (Klassen et al., 2012, p. 95). Participants in this study spoke to the importance of developing long term relationships with the families they are working with and connecting deeper than just their health care experiences. Best practice health care providers have also highlighted the importance of an authentic connection with clients and getting a deeper understanding of families to better understand them as people (Davies et al., 2017).

All participants within this study acknowledged the positions they are in allow them to have conversations about difficult topics with families which they often are not having with others. The ability to have this type of relationship and provide support during difficult times was identified as both a privilege and a challenge. The ability to work alongside families during these times and facilitate difficult conversations with them was recognized a rewarding process. Practitioners also described feeling a sense of reward, knowing that the work they were doing was making a difference for families. Making a difference is identified in the literature as a rewarding aspect of health care practitioners experience caring for children with life-limiting illnesses (Klassen et al., 2012; McConnell et al., 2016; Taylor & Aldridge, 2017). All participants indicated that being able to make any positive impact was a rewarding feeling. Positive impacts include actions improving the quality of life for families through symptom management, teaching skills, small acts of kindness, and allowing space to discuss difficult conversations. Despite the difficulty of the work, most reported finding the work rewarding. Feelings of fear and uncertainty entangled with participant's responses about being present for families through difficult situations and cases. These responses illuminate that practitioners are not immune to the fear present in these difficult circumstances, and despite the uncertainties that can arise through these challenges, participants leaned on their ability to support families through these times. The very situations that can generate unimaginable concerns and uncertainties are also the experiences practitioners describe as privileged interactions, that result in feelings of fulfilment.

The sense of reward became a challenge for participants if they felt they were unable to perform their best or meet the needs of families due to circumstances of the situation. Close

connections developed between nurses and the children and families they encounter in their work have been identified in the research as both a stressor and reward (Zander et al., 2010).

Treggalles and Lowrie (2018) report that some health care practitioners in palliative care settings identified the connection they had with their patients balance some of the stress that is also associated with the role. Not being able to develop this type of rapport and relationship was ultimately a challenge and contributed to feeling a lack of professional fulfillment. Similarly, Taylor and Aldridge (2017) found in a qualitative study of practitioners working in pediatric palliative hospice settings that the commitment to delivering high standards of care was seen both as a challenge, a reward and a motivator for the work they did. Feelings of disappointment, distress and dissatisfaction in their work occurred when they were prevented from being able to perform to their standards of care. Some participants noted it was particularly challenging not being able to improve existential and psychological pain. The inability to resolve nonphysical suffering has been identified as one of the most difficult and distressing aspects for health care practitioners working in palliative care (Rattner, 2018).

The entanglement of rewards and difficulties reported by participants suggests there is not necessarily one particular thing that is rewarding or challenging about working with children with life-limiting illnesses. Papadatou (2000) indicates there is a different level of expectation on health care practitioners in end of life and palliative care to create deeper connections with patients. Communication between health care practitioners and families at the end of life requires health care practitioners to be fully present, engaging with the child and families suffering is not optional (Browning, 2002). The importance of health care practitioner's investment is exhibited in its impact on the families they are working with. Parents identify the importance of balancing

providing information and attending to questions of families and children with emotional support (Davies et al., 2010). This higher level of expectation of emotional investment on the part of the health care practitioner into the relationship results in a potential for a more significant impact of loss. Many practitioners' reports indicate there are positive and negative aspects associated with most parts of their jobs, depending on the situation or the health of the patient at the time these experiences can affect practitioners in more positive or negative ways. The privilege of being welcomed to provide support and care through difficult times can be rewarding but bearing witness to multiple tragedies can become emotionally burdensome. When health care practitioners find rewards in their work, it can contribute to the resiliency health care practitioners have working in such emotionally demanding and challenging environments.

Teams in Conflict

One of the challenges emphasized by almost all participants was difficulties related to team conflict. This reflects the current literature, which suggests poorly operating teams are a primary stressor for health care practitioners working with children with life-limiting illnesses (Papadatou, 2000; Taylor & Aldridge, 2017). Participants within the study noted challenges with team members not understanding one another's role, and overlap can lead to conflict and disagreement.

One participant noted disagreement is understandable, and it is possible to work through, however explained tensions and conflict rises when disagreements become personal. Raised voices and reactions out of anger hinder the ability of teams to collaborate effectively. This type of dysfunction in a team can also lead to a lack of understanding of allied professionals' roles, resulting in a lack of collaboration in services. This can result in teams and departments not

being appropriately consulted as well as duplications in services. Another participant spoke to a situation where her team was involved in a case, and other teams later stepped in to assist. The teams disagreed on the care plan, and frustrations developed because of strategies impacted by different levels of relationship and knowledge of the patient. Angela explains the patient was not doing well but was wanting to go home for his birthday:

He was like, “I want to go home for my birthday.” Which was about a month away. And the people on the floor thought he was delusional, and must not understand how sick he is if he is wishing for that... And, so much so, that without the team’s knowledge or consent, referred him to psychiatry to be assessed and didn’t consult with me... I was livid, because had they talked with me, I would have said, he doesn’t need a psychiatric evaluation, he’s perfectly sane and he does know how sick he is, and it’s not bad for him to have that goal...He’s still alive today, and he did go home for his birthday.

Angela’s knowledge of the patient led to a difference in opinion on how to support this patient. This example depicts the impact a lack of collaboration can have in a care plan. Successfully collaborative inter-professional teams provide benefits both to the care practitioner as well as the child and family (Neilson, Kai, McArthur, & Greenfield, 2013).

Some participants indicated concerns about bringing in the palliative care team when a patient in their clinic is not doing well. Some health care practitioners believed they were already doing this work in their roles, and therefore, a consult was not always necessary. Participants also indicated having concerns about alarming families by bringing in the palliative care team because of the connotations connected with palliative care. Additionally, concerns about building connections with families late in the patient care relationship were another challenge noted by

participants. Pediatric oncology providers have also reported reluctance to consult palliative care teams, believing they were already providing these services to patients (Dalberg et al., 2013).

Szymczak et al., (2018) indicate there is both an emotional and symbolic fear health care practitioners express concerning consulting palliative care teams for fear of the impact on the relationship, and what consulting this team may signify in terms of treatment options. Despite health care practitioners concerns regarding collaborating with palliative care teams near end of life, several studies speak to the importance of early integration of palliative care (Ranallo, 2017; Robert et al., 2012; Widger et al., 2016). This indicates the importance of fostering collaborative environments for health care practitioners, where settings for communication and understanding are facilitated.

Grief Reactions

Difficult experiences, including the death of a child, impacted participants in several ways. Muskat and colleagues (2020) found health care providers experienced emotional and physical toll including disruptions in sleep and eating, impacts on mood, self-doubts and ruminating thoughts providing end of life care to children. These experiences occur both within the workplace as well as at home. Health care practitioners within this study indicated that emotional investment in the care of patients and families is needed to connect and provide the necessary care when working with children with life-limiting conditions. Taylor and Aldridge (2017) also found health care practitioners working in pediatric palliative care reflected similar sentiments and indicated that the excess emotional investment required to provide necessary support made them more vulnerable to the risk of distress at work.

Health care practitioners in this study reported a multitude of different reactions to grief within the workplace and the home. Experiences of grief impacted participant leading up to the death and following. Practitioners explained some circumstances would make them more vulnerable to reactions of grief. Circumstances increasing vulnerability to grief included the length of connection with the patient or family, similarities in their lives to the patients, and when stressors are high at home. Another study similarly found Canadian pediatric oncologists reported finding deaths especially challenging when they were able to identify with the family, such as having children of the same age or identifying with the same religious or ethnic background (Granek, Bartels, Scheinemann, & Barrera 2015; Morgan, 2009; Papadatou, 2000). All participants emphasized the importance of connecting with the families. This aspect of their careers was also cited as a rewarding element to their positions. However, participants also indicated that the longer and deeper the connections made with their patients and families, the more difficult it was for them to manage their grief reactions.

Anticipating the End

Practitioners' descriptions of difficult experiences emphasized the difficulty of the unknown. Participants noted they would call in to check on patients when they were concerned death was imminent, come back into the hospital multiple times to check on families and stay for extended periods overnight and into the next day without sleep to provide additional support. Participants responses emphasize the extra mile they are willing to go to help to support families in any way they can when they are going through such difficult circumstances. Participants responses also indicate feelings of anticipatory grief are experienced and worrying about the

outcome of patients can cause difficulties disconnecting even for short periods to sleep. Health care practitioners

Zilberfein (1999) describes anticipatory grief as a process that can help individuals to prepare for a death and allow them to feel they have more control in a situation. Health care practitioners report feeling a loss of control and feeling powerless and helpless in palliative care environments as families undergo difficult experiences (Chan et al., 2015). It makes sense with this description for health care practitioners to display behaviours and reactions congruent with anticipatory grief, in an attempt to gain control in an uncertain situation where they are looked to as a source of support.

As health care practitioners working with life-limiting illness often develop long term bonds and closer relationships with patients, they must reflect on how the death of patients personally impacts them. It is common for health care practitioners to go through their own grieving process, which can include anticipatory grief (Zilberfein, 1999). Finding ways of working through feelings of grief is imperative for health care practitioners in being able to support families in this field.

Initial Experiences

While most participants in this study had an interest in end of life care or similar fields in health care such as disability before beginning in their field, for most their first experiences working with death occurred in these roles. Health care practitioners in this study emphasized the impact of the first death in their practice as a more memorable and challenging experience. Many participants indicated never having personal experiences with death before their first loss on the job. This lack of experience creates uncertainties around what to expect, and what will be most

helpful for families. Participants described feelings of being unprepared for end of life conversations in the beginning phases of their roles, and a lack of experience with grief in general. Angela spoke to her uncertainty when she began in her field, stating:

In those days the life expectancy was early thirties, and so you know that's always an average. So, then I knew that that meant young deaths and I thought, am I going to be up for this?

Angela goes on to recount in great detail each aspect of the first death she experienced on the job, noting when she first heard the news, who was in the room, music that was playing, what was done to comfort the family, and her experience with grief following:

...I had just moved back to Nova Scotia, so I wasn't in my own place yet, and my husband was away. So, I was still with my parents, and I remember, I don't know it was probably 2 o'clock, 3 o'clock in the morning I got home and my mom had stayed up for me. And when I came in the door and I saw her I just lost it. And cried and sobbed like you wouldn't believe. I didn't even know it was there, but I couldn't even speak. And I just, and she just held me and stuff, and I've not cried like that since.

Angela's vivid description of her first patient loss demonstrates the lasting impact. Angela indicates that although she has not had as intense of a reaction since her first patient loss, each experience of death is just as intense for her. Erikson and Davies (2017) similarly found with nurses working in pediatric palliative care that first deaths were particularly memorable experiences, often related to becoming too personally invested and attached with families. This is a delicate balance as health care practitioners in the field of palliative care are often expected to

foster greater connections with their patients, connecting on a deeper level with greater length in relationships than other medicinal disciplines (Papadatou, 2000).

Participants suggest that end of life conversations are always difficult to have; however, indicated feeling more prepared for these conversations with experience in their roles.

Participants suggested initial conversations, were full of fear and uncertainties of what to say or do, or where the bounds of their roles end. Research suggests that up to 59% of Health Care Practitioners describe feeling uncomfortable providing emotional support to the family of a dying child (Plante & Cyr, 2011). Expertise and experience in the role were also cited in the research literature as buffers to the difficulty experienced by health care practitioners around symptom management and having conversations at end of life (McConnell et al., 2016). This demonstrates the importance of proper training, supervision and mentorship throughout practice in this field.

Participants in this study indicate that most of the training they have is self-sought and often obtained through conferences and readings. Half of the participants were supported organizationally to attend training and conferences to further their knowledge in their discipline, while others reported not being financially supported by their organization to attend these types of training. The desire for additional training was noted by half of the participants, often indicating they relied on the knowledge and advice of more experienced colleagues and mentors in the field. Some participants felt unsure at the beginning of their careers of how to handle conversations around death. Participants described their first memories of these experiences as feeling unhelpful and fearful of what to say. Others explained concerns about not having clear guidelines around contact post patient death with families, and how to navigate these

relationships. Improving education is cited in the literature as one of the best ways to improve confidence and reduce death anxiety of health care practitioners working in pediatric end of life environments (McConnell et al., Peng et al., 2017). Increased training in palliative care for pediatric clinicians has been demonstrated in the literature to improve the confidence of working with children in palliative care as well as supporting colleagues and clinicians through these experiences (Peng et al., 2017).

Coping Strategies

The ability to cope and manage difficult experiences within this field of practice is imperative in maintaining the longevity of a career in an environment with abundant loss and grief. Existing literature demonstrates health care practitioners experience grief working with children with life-limiting conditions, as well as following patient deaths (Keene et al., 2010; Plante & Cyr, 2011). Papadatou (2000) suggests grief reactions are experienced in several ways by health care practitioners including needing to cry, thinking of the deceased, temporarily withdrawing from activities and others, anger and despair. These reactions can vary in how long they last and finding ways to cope with the experiences can help practitioners grieve and process loss. Rates of burnout can be predicted by the coping strategies a health care practitioner uses (Rodríguez-Rey et al., 2019). Active coping strategies used to learn from experiences have better outcomes than rumination and avoidance strategies (Rodríguez-Rey et al., 2019). The findings of this study were consistent with the literature that there are a variety of ways health care practitioners cope with difficult experiences (McConnell et al., 2016; Papadatou, 2000; Taylor & Aldridge, 2017). The coping strategies utilized by participants in this study will be compared and contrasted with the literature below.

Seeking Support

Every participant in this study thought the support of others whom they can talk to or share their experiences with was a primary strategy for coping with difficult experiences. Most participants indicated feeling most comfortable seeking the support of their close colleagues within their team, or their professional scope. These were seen as safe places to connect, share experiences and gain mutual support. Participants implied it was not just communication that was supportive in their connections with colleagues; these relationships also provide sources of enjoyment, where they can laugh and use humour to support one another. Humour is another way health care practitioners indicate they cope with their experiences, engaging in laughter and joking around with co-workers (Pearson, 2013; Plante & Cyr 2011).

Papadatou (2000) proposes that health care practitioners commonly turn to one another for support because of their shared experiences. Creating meaning out of grief experiences is a social process and storying these experiences with others can help to bring understanding to their involvement. Carmen speaks to the importance of having colleagues to share experiences with:

...being able to talk with our colleagues about it. You know, kind of what we're going through and you know, just you know, being supportive of each other is really helpful.

You know just the process of it...

Carmen's statement highlights the process of sharing experiences and the ability to support one another through the grieving process. Elaine further speaks to the inevitability of difficult experiences in the field of palliative care and the comfort of sharing in those experiences with close colleagues:

Like almost everybody at some point, especially working pediatric palliative care, like you cannot sail through a career without any bumps on the road, there will be some. And I think within our small group were very good at supporting each other, and we'll talk about stuff that we would never talk about with anybody else.

This type of support was mentioned by many participants, demonstrating a family-like quality to the relationships co-workers had with supporting one another. Participants all spoke to close connections within their teams, and reliance on supporting one another. One participant fondly laughed when asked about what the most rewarding aspect of her job was, indicating:

My team will laugh because they could all answer what I'm going to say. (Faye)

This response highlights this closeness teams felt with one another, having jokes, comfort and understanding of one another's experiences. One participant noted it could be challenging to recognize feelings of burnout as they are happening, stating she has a few close colleagues who also recognize these signs and provide friendly reminders:

I have a few close colleagues that would say, "I think you need to go out. I think you need to go for a run." You know it's a very polite way to say you know you're getting cabin fever you need to get out of here. (Elaine)

Two participants also highlighted the importance of professional supports such as therapy and Employee Assistance Programs for supportive counselling. The significance and desire for professional support for health care practitioners management of grief has been emphasized in the literature (Plante & Cyr, 2011). While professional supports have been emphasized in the literature as necessary for managing grief experiences, there is still a culture of stigma surrounding accessing these types of supports for health care practitioners (Knaak, Mantler &

Szeto, 2017). One participant highlighted the stigma that can be associated with accessing resources, and disclosing mental health concerns her field, holding professionals back from accessing available supports:

We're probably better than what it was, but we have a long way to ... there are some good resources out there, but people don't necessarily access them when they need them.

(Elaine)

This type of stigma can reduce health care practitioners outlets for coping with experiences of grief. Stigmatization around accessing support can result in relying on self-treatment, experiencing a lack of supportive peer connections and concern of judgement if found out by co-workers, as well as increased risk of suicide (Knaak et al., 2017). The detrimental effects that can be experienced as a result of stigmatization reflect a need to provide de-stigmatization initiatives through organizations to promote access to available resources.

Struggling in Silence

While all participants felt it was essential to seek support when they were going through difficult experiences, some participants felt restricted by the stigma associated with acknowledging you are not okay in a health care profession. One participant noted that colleagues of hers had not sought support that they have needed for mental health for fear of how it would affect them professionally. A few participants indicated they do not let their emotions out, or display grief reactions at work, implying it is an inappropriate setting, and there is a lack of privacy for them to have these experiences. These types of responses demonstrate a narrative of disenfranchised grief, which is under-recognized, and often hidden to maintain professional composure (McConnell et al., 2016).

High levels of emotional labour have been reported to be associated with conversations about end of life with children and their families (Szymczak et al., 2018). Emotional labour is a process in which employees are expected to manage their emotions and reactions within the workplace to maintain a level of professionalism (Wharton, 2009). These expectations around emotional expression can be woven into formal job requirements as well as informal expectation (Wharton, 2009). Papadatou (2000) indicates that rules around grief provide practitioners with space to grieve, but temper reactions to not disrupt the ability to work. With the long term relationships practitioners often build with families, it is reasonable to assume there is an emotional impact on the health care practitioner when patients go through difficult circumstances. The job then becomes to provide support and care to the family as well as managing any personal grief reactions. Emotional labour can lead to feelings of burnout and withdrawal behaviours in the workplace (Grandey, 2000). These types of reactions can negatively impact patient care and the resiliency of health care practitioners in the field.

Participants often explained they would compartmentalize and ensure their grief did not overpower that of the families or impede their ability to work. They reported they would express their emotions on their commute home, in the comfort of their home, or the privacy of their office. The literature also supports health care practitioners reporting their inability to openly express grief related to a patient loss (McConnell et al., 2016).

Health care practitioners face an added level of difficulty when unable to express their emotions related to grief at work and take them home to process. It is clear how professional can spill over into personal life when health care practitioners are not adequately supported within the workplace to manage their grief. Health care practitioners experiencing these reactions at

home report concerns of affecting how their children perceive their reactions, often minimizing their reactions within the home as well. Participants also indicated the inability to share details of events with their family members and friends due to concerns about confidentiality. Taylor and Aldridge (2017) also found that their participants reported patient confidentiality as a primary barrier to sharing work experiences with individuals outside of the workplace. Participants noted this inhibits them from expressing how they are feeling in-depth within the home. Additionally, they felt it an unfair burden to place upon their friends and family members. This was a common theme demonstrated in the literature, further silencing the experiences of grief that are experienced by health care practitioners (McConnell et al., 2016; Taylor & Aldridge, 2017).

Some participants reported they had expressed their sadness, frustration and anger related to grief from a work experience in an unrelated setting or event. Elaine explained that she has had displaced reactions to entirely different situations, for example:

So, it may be, you know, I, there's something going on at work that's just difficult to see and to witness. But I'll keep things together as long as I'm with them. And then I'll get I don't know; I'll get a call from the garage because my car needs repair. Or, like something completely unrelated... And I, I completely lose it, and it has nothing to do with them, but it's the thing that makes me tip, and then I apologize profusely because I feel horrible because of course it's not the fault of the...garage.

Elaine's account highlights how suppressing feelings of grief can result in them manifesting in different situations and different ways. Papadatou (2000) indicates when health care practitioners suppress reactions to their experiences of grief, they can come out when they are least expected.

This can lead to increased stress for professionals and potential inability to concentrate on performing their job.

Shifting thought processes.

Participants indicated feelings of grief are often carried with them, shifting their perceptions around life and death. Angela indicates that her life perceptions of death have been influenced by her practice working with children with life-limiting illnesses:

I mean the way I go into this, even in the way I live my own life and what I teach my own boys is that nobody is guaranteed length of life, it's all very day to day, so you better not waste any time, and try not to make any stupid mistakes. Because your only guaranteed right now, this moment. And um you know, if I can normalize it for parents for them to see it that way then it's like they don't have to worry about the impending decline.

Angela's response highlights how perceptions of death when working with life-limiting circumstances in children can shift to reflect the daily experiences of the job rather than that of mainstream society. Common narratives and beliefs around death often include dying at an old age, and elderly die before the young, however seeing young people dying contradicts these dominantly held beliefs (Chan et al., 2015). Health care practitioners working in these fields can experience conflict with their beliefs and shifts in perspective to fit the settings of their experiences (Chan et al., 2015).

Participants also talked about the difficulty of witnessing good families undergoing tragic situations, with little they can do to change or alleviate the struggles of the families. Health care practitioners have reported witnessing things that challenge their belief systems and ultimately

have difficulty accepting that bad things happen to good people (Chan et al., 2015). Furthermore, Papadatou (2000) explains that challenges to belief systems in these ways can lead to feelings of meaninglessness, hopelessness and grief reactions. Deborah describes the difficulty she has emotionally working with families undergoing difficult experiences, acknowledging she will express emotions with family members as long as they do not overpower the reactions displayed by the family or impede her ability to do her job:

You can't ask yourself but you do cause its natural to ask yourself the why. Like why is this happening to them, like why? Why do some people have to watch their child go through these things? Whether it's just treatments, procedures or just you know what I mean, having a life-limiting condition or a condition that's going to progress and get worse over time. Knowing that their child is not going to live a full life.... and you wish I think as human beings you wish that you could fix that for people, and you can't fix things.

These desire to fix situations and feeling at a loss when unable to can also contribute to feelings of grief with health care practitioners. Health care practitioners can face several levels of grief concerning the loss of a patient, including the loss of one's unmet goals and expectations in their ability to provide care for the patient (Papadatou, 2000). This can manifest in feelings of failure, in saving a life, gaining symptom control, or improving the situation. Participants narratives within this study highlighted the need to accept limitations and let go of control. Chan et al. (2015) also found that managing expectations in the workplace in a field of death and dying is a common way of coping with emotional reactions of grief at work. Acknowledging one's

limitations in these situations is imperative for practitioners to remain resilient in a field consistently facing difficult situations.

Having the ability to find the positives and practice gratitude is another coping skill that appears in the recent literature of the field (Chan et al., 2015). Faye explains how choosing a mindset of gratitude helps her to cope with experiences of loss:

Be[ing] grateful and appreciative... family, of health of all the positives in my life and the challenges that I don't have to carry that others do. I mean, we all have our challenges, don't get me wrong. But I'm like, "Okay, I'm happy with mine." (laughter)
I'll just take my lot.

Faye's statement acknowledges that the challenges she encounters in her professional work inspire her to live a life with more appreciation. Faye says this with some laughter at the end, seeming to give less recognition to her own struggles than the experiences of the families and children with whom she works. Chan et al. (2015) also found health care practitioners reported living a more meaningful life and practicing gratitude as beneficial ways of coping through challenges encountered in palliative care settings.

Self-Care

Exercising was noted by most participants as a vital element of their self-care. They noted it was an excellent way to release energy and disconnect from work experiences. This is consistent with the literature that maintaining physical well-being is an important protective factor against burnout (Koh et al., 2015). While it is commonly understood exercising is beneficial for health and self-care the literature also indicates that using exercise to cope with work experiences can lead to higher levels of burnout (Colville et al., 2015). This is based on the

theory that exercise is used as a means of distraction, and as such individuals do not have to confront or address the impact of an experience. Therefore, the intent of the activity can have an impact on whether or not exercise is beneficial for coping with grief experiences. Participants widely found physical activity to be beneficial in creating space from work, many describing it as having meditative effects where they can think more clearly. Balancing concern with maintaining a level of detachment from the experience was also described as a way health care practitioners protected themselves from intense emotional arousal that could interfere negatively with work performance in pediatric intensive care units (Rodríguez-Rey et al., 2019).

All participants also specified the importance of taking breaks to combat feelings of burnout and manage painful experiences both within the workplace and their personal lives. Breaks were often described as brief moments to step away from experiences to re-group and speak with a colleague or get a coffee. Having the ability to switch tasks to clerical duties was also seen as a break, as it gave the practitioner space from the emotional labour required in clinical work. Taking lunch was noted as another way to maintain self-care in this line of work. Faye highlighted the difficulties that can be associated with consistently taking lunch breaks, noting taking a lunch break will usually “jam up” her day:

Trying to make my lunch work can... jam me up... sometimes I'm rushed trying to make time for myself, and you're trying to give what you can and do the best job that you can and provide the service. But then it's kind of like okay, I'm [going to] wind this down because... I need this time. Sometimes days you sacrifice it.

Faye's account highlights the health care practitioners dedication to providing excellent services but also brings to light some of the sacrifices that are implicitly expected of practitioners to meet

the needs of patients and families. In order to meet the demands of the job, it can be challenging to take time to break for lunch. The importance of taking breaks is reflected in the literature as well for its benefits in helping health care practitioners cope with difficult experiences (Clarke & Quin, 2007; Erikson & Davies, 2017; Plante & Cyr, 2011).

Three participants noted the importance of taking extended breaks to travel. Through these experiences, they were able to disconnect, spend time with family, and create memories to reminisce on. Two practitioners within the study travelled with work colleagues for vacations annually, creating deeper bonds outside of the workplace. These types of traditions not only seem to facilitate strong rapport within team members; it was described as allowing practitioners space to disconnect from the stressors of their careers.

Funerals and Rituals

One factor half of the participants noted was foremost in coping with experiences of grief was gaining closure. Many participants described gaining closure through a symbolic ritual or ceremony. Some participants would attend funerals when possible. This was not always an option depending on geographic distance and workplace needs. Participants also noted there are ceremonies held in the hospital annually to celebrate the lives lost throughout the year. These rituals allow space for health care practitioners and families to share in their experiences of grief and build an understanding and acceptance.

The recent relevant literature reflects the importance of attending funerals for health care practitioners and families (McConnell et al., 2016; Papadatou, 2000; Plante & Cyr, 2011; Prochnau, Liu & Boman, 2003). Plante & Cyr (2011) found 19% of health care practitioners they interviewed reported attending funerals following the death of a child for closure. Practitioners

within their study more commonly indicated contact with families following a child's death through meetings. Prochnau, et al. (2003) also found in a study of occupational therapists working in palliative care settings, a common coping strategy to gain closure from experiences was to attend the funeral or light a candle in memory of the patient. Papadatou (2000) suggests that attending the funeral can be seen as a symbolic way for the health care practitioner to close their relationship with the child and family. Participants within this study reflected the notion that attending the funeral was not just for themselves. Participants spoke to the importance of providing support for families, and their responsibilities for bereavement care. The significance of rituals in gaining closure is apparent, and practitioners find individual ways to demonstrate this. Within the IWK, many practitioners reported feeling supported in their attendance to these ceremonies, and this adds to creating a sense of closure and ongoing support for families.

Personal and Professional Boundaries

Health care practitioners identified the difficulties of leaving work at work. Although they emphasized the importance of creating boundaries between personal and professional lives, they acknowledged these aspects of their lives are not siloed and spill into one another.

Boundaries were set in a number of different ways, ranging from not answering calls and emails at home to distancing themselves from the narratives of their clients. Some participants spoke to the notion of reminding themselves that this is not their story to help from getting lost in it.

Boundaries were also used following the death of a patient to avoid triggers of their memory, such as a song that was played at the funeral. Chan et al. (2015) indicate that one of the ways practitioners cope with their experiences in the field of death and dying is to separate their personal and professional lives to limit interference. Other participants spoke to enjoying

adventurous vacations or interacting with people outside of their work circle to connect on different topics and help to keep them grounded in their personal lives.

Recommendations

The findings of this study offer a basis to provide suggestions and recommendations on interventions and training that can help to provide support to health care practitioners working with children with life-limiting illnesses. Health care practitioners offered many suggestions to organizationally support employees intellectually, physically and emotionally in their positions.

Shifting Workplace Culture

Two participants within this study spoke to necessary shifts in organizational culture to support the changes needed in their perspectives. One participant felt the biggest necessary change is to the way that mental health is perceived on both an individual as well as an organizational level. Combating the stigma surrounding mental health for health care practitioners would reasonably help to reduce barriers to accessing care. When practitioners witness stigmatizing behaviors towards patients with mental health challenges, those perceptions are internalized, reducing the acceptability for themselves to disclose mental health concerns (Knaak et al., 2017). Individuals with mental health challenges are often reluctant to self-disclose about their concerns in the workplace for a variety of reasons such as social isolation, impact on reputation and credibility, skepticism and judgement (Moll, 2014; Stromwall, Holley, & Bashor, 2011).

Specific trainings for mental health coping and stigma reduction have been shown to reduce perceptions of stigma among employees in the workplace (Dobson, Szeto, & Knaak, 2019). Concerns about one off trainings have been noted as not enough for long term effects of

stigma reduction (Knaak et al., 2017). Providing strong leadership support along with ongoing training including listening to and learning from individuals with lived experiences have been emphasized as alternative strategies to long-term stigma reduction (Knaak et al., 2017).

Another participant discussed concerns about the heroic narrative often used to describe self-sacrificing behaviours in health care practitioners. Individuals who forfeited lunches, stayed long hours and put their needs on hold were often described as praised for their work. These beliefs can promote concerning behaviours in employees if maintained long term. Coupling high expectations on health care practitioners with the limited number of practitioners working in the field of childhood critical and life limiting illness can result in increased overtime hours resulting in increased risk of burnout. Working overtime and extended hours in environments of palliative care has been demonstrated to contribute to added risk for burnout and psychological morbidity (Koh et al., 2015). Working over 60 hours per week can make health care practitioners over eight times more likely to develop emotional exhaustion (Koh et al., 2015). Participants in this study indicated they had worked for days with little to no breaks in between if death was anticipated. While maintaining flexibility in support is essential in end of life care, practitioners must balance this with their care needs to mitigate concerns of burnout. Shifting the organizational culture to promote self-care needs and the emotional well-being of health care practitioners can help to challenge this narrative that promotes self-sacrifice to the detriment of the provider.

Practical Interventions

Education and training related to the field was primarily described as self-sought and self-organized. Responses about beginning experiences in practice highlighted fear and uncertainty of what to do in their roles. Participants sought knowledge in pediatric palliative care

through networking with colleagues and mentors, attending conferences and reading on their own. Three practitioners described their organization promoting and funding training opportunities in the field for them. Practitioners spoke to the desire for more funded training opportunities to improve their competencies and keep their skills relevant. Training in both palliative care competencies and coping skills are vital resources to be provided for practitioners inexperienced in the field of palliative care (Chan et al., 2015). The importance of providing additional training in palliative care for health care practitioners has been reported throughout the current research in the field (Peng et al., 2017; Plante & Cyr, 2011; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2013). The importance of training and education in the field of end of life and palliative care for practitioners has been emphasized in the literature as a means to improve confidence and compassion satisfaction and reduce levels of compassion fatigue and burnout (Slocum-Gori et al., 2013). Providing ongoing training is vital in supporting the confidence and skills of health care practitioners providing end of life and palliative services.

Participants offered the most suggestions for improvement in the areas of providing additional emotional and practical supports. Participants suggested adding facilities such as a gym on-site, and private spaces where practitioners can destress and recoup. Providing spaces where health care practitioners can participate in non-job-related activities to reduce stress such as meditation, yoga, and reading is one-way hospitals can support their employees in reducing compassion fatigue (Perregrini, 2019). Several participants noted a lack of private spaces within the hospital. Participants indicated that having additional private spaces would not only allow opportunities to find quiet in the busy of the hospital; additional spaces could potentially create private spots to meet with families.

Most participants within this study indicated they participate in debriefing sessions following difficult cases and identified these as helpful strategies. Concerns around debriefing sessions were about their location or the size of the group in attendance. One participant noted when debriefing is open to practitioners within a clinic as well as the broader care team including floor nurses and anyone else in staff who may be impacted it becomes more challenging to be vulnerable and open up. Others identified feeling comfortable getting support from other members within their team where they would have an informal debriefing. Additional support in the form of networks, rounds, conferences and debriefing sessions were found to be helpful and informative by health care practitioners. These types of support can improve both the confidence and the competence of health care practitioners in this field to provide the best care and support their own well-being (Rushton et al., 2006).

Given the under-emphasized nature of health care practitioners grief, implementing formal services which acknowledge this grief, and give individuals an outlet to discuss these feelings and experiences is essential. The importance of debriefing sessions is noted in the literature for its ability to provide education, support, collaboration, and understanding amongst teams (Keene et al., 2010; McCloskey, & Taggart, 2010; Papadatou, 1997).

One of the biggest challenges noted amongst most participants was the difficulty associated with working with a team in conflict. Overlapping in services between teams and roles and relationships with families can be misunderstood. Participants responses explained the discomfort of working with teams in conflict and the added complexities of providing the best care within a team with communication challenges. Keene et al., (2010) highlight the ability of debriefing sessions to aid in providing an opportunity for teams to communicate together about a

difficult case to better understand perspectives. Facilitating these types of sessions for communication and support can assist teams in open communication and understanding, generating a more positive team environment. Furthermore, health care practitioners being able to manage their grief experiences is critical in their ability to continue providing care to families undergoing tragic experiences and losses.

Chapter 6: Conclusion

Summary

The participants within this study declared beliefs of privilege working in their respective fields. The ability to provide support and make a difference in the lives of children and families during painful, vulnerable experiences made participants work rewarding. Although participants felt privileged to work with families during such difficult times, they reported feeling the impact of the loss of their patients. Some participants described difficulty in leaving work when patients were declining, including staying at the hospital for days at a time, calling in to check on patients and checking mail and voicemail on off-hours. Working significant overtime hours and working for extended periods without breaks can lead to emotional exhaustion and increased rates of burnout (Koh et al., 2015). Moderate rates of psychological impairment have been shown in health care staff working in pediatric intensive care (Rodríguez-Rey et al., 2019). Health care workers in all pediatric settings report rates of burnout up to 56% and rates of PTSD up to 20.1% (Rodríguez-Rey et al., 2019).

One of the main strategies participants reported using to prevent becoming consumed by their work, including establishing firm boundaries. Boundaries such as not checking work email at home, and not talking about work at home allowed participants an ability to create some disconnect from these experiences to be fully present in their personal lives. However, these strategies still appeared to be challenging to maintain for many participants during times when clients were declining. Relationships formed with colleagues were a reliable source of support for many participants in this study. Participants highlighted the inability to share their experiences at home for fear of upsetting family or disclosing confidential information. Participants also emphasized taking breaks as a way to cope with their work experiences.

Another theme that emerged from participant responses was the need to find closure. Participants honoured the deaths of their patients in different ways, such as attending the funeral, going to a memorial ceremony, or having a private ritual of their own. The IWK hosts an annual event honouring the patients lost in the last year that many participants attended. Some participants could attend funerals and believe in the importance of them attending both for their closure and to support the family. Attending a funeral can provide health care practitioners with the opportunity to find symbolic closure at the end of their relationship with their patient (Papadatou, 2000). Some participants wanted to attend the ceremonies, however, were not provided supported by their organization to participate during work hours, while others would prefer to honour in private ways of their own.

Strengths and Limitations

There are several strengths and limitations to this study, including the use of a qualitative research design. Using a qualitative research design allowed participants to share their experiences in the field and how they cope with these experiences. Analysis of qualitative interviews is difficult with larger groups of participants (Crouch & McKenzie, 2006). Keeping to a small sample size allowed for rich accounts, and the generation of meaningful narratives. Using a narrative approach enables a focus on exploring the stories of participants, and how social, cultural and institutional narratives shape them (Clandinin & Rosiek, 2006, as cited in Clandinin, 2006, p. 45). A narrative approach allows for researchers “to present experience holistically in all its complexity and richness” (Bell, 2002, p. 209). Conducting this research with a narrative approach provided further insight into the perceptions of health care practitioners experiences in the field, the coping strategies they currently use and ways they can be better supported.

Narrative research has limitations as well and is critiqued for its subjective nature. Narrative research is rooted in multilayered stories that are interpreted through the lens of the researcher (Bell,

2002). These individual stories are generated into a larger narrative and themes are developed attributing meaning to participant's experiences (Bell, 2002). Narrative researchers inevitably influence the representation of data when choosing what stories are important to include and which are left out. It is essential to recognize narrative research illuminates the participant and researcher equally (Bell, 2002).

This study also incorporated a variety of different professional backgrounds, including social work, nursing, medicine and physiotherapy. Incorporating interdisciplinary approach to recruitment was purposeful as most research in the field of pediatric palliative care is done through a nursing lens (Erikson & Davies, 2017; Maunder, 2006; McCloskey and Taggart, 2010; Treggalles & Lowrie, 2018). Pediatric palliative care is an interprofessional field and families within it will interact with several different professionals. Incorporating multiple different professions in the participant sample allowed for a variation in voices and experiences in the narrative.

Reflecting upon the interviews, there were missed opportunities to further deconstruct narratives around the collaboration between health care practitioners. One of the biggest challenges noted was team conflict, and it would have been interesting to explore in what was practitioners see themselves collaborating with other professions in this field. Another area that could have been further elaborated on in the interview process is whether or not participants had children, and how this impacted their experiences. While these narratives arose naturally in some participant's stories, the question was not within the interview guide and not asked to participants. Asking these questions would have allowed for further analysis of the impact of having children on the experiences of healthcare practitioners in the field of pediatric palliative care and would be an exciting area to explore further.

This study contributes to a field of research that is limited but growing. Keene et al. (2010) indicate research about practitioner's experiences and coping strategies is still very limited. This study will contribute to this literature and provide valuable information about the way organizations can

support their staff working in the area of pediatric palliative care. This research is important to protect health care practitioners from feelings of compassion fatigue and burnout, which can result in increased staff turnover and increased absences from work. Additionally, properly supporting health care staff reaffirms the importance of their service and invests in their abilities to continue providing quality care (Klassen et al., 2012).

Implications

All participants within this study noted they are affected when their patients are declining, and when they pass. This research can draw attention to the need for increased recognition of the impact of patient death for health care practitioners. Organizations can support the wellbeing of their staff by providing appropriate supports and resources to meet their needs. Health care practitioners highlighted the desire for additional training and continuing education to improve their skills and stay up to date in the field. Increased education can boost health care practitioners confidence and reduce their anxiety in working with patients who are dying (McConnell et al., Peng et al., 2017).

Participants also noted the difficulty in finding places to take breaks within their workplaces. Creating spaces for breaks away from the workplace can support employees in reducing compassion fatigue (Perregrini, 2019). Allowing for places where employees can rest, have quiet and seek comfort demonstrates recognition of the difficulties faced by health care practitioners in their working environments and promotes practices of wellbeing. Promoting the wellbeing of employees can also be reflected in supporting the attendance of funerals and ceremonies and rituals as a way for employees to find closure in their loss.

Areas of Further Exploration

The findings and implications of this study may spark several other areas of future research. Future studies should include a broader geographical area. Halifax, NS, is a small area, with few

practitioners working in the field of pediatric palliative care or working with children with life limiting illnesses. Including participants from multiple hospital locations would allow for a larger sample, including additional areas of practice. Participants in this study emphasized the impact of their first experiences of loss, highlighting another area of important future research. Many health care practitioners suggested being fearful and lacking confidence in their initial skills indicating that further research would be helpful in determining supports specific to starting work in this field.

Another critical area to research would include interprofessional collaboration with health care practitioners in the field of pediatric palliative care. Knowledge of interprofessional collaboration could generate knowledge on how to better support a reduction in team conflict, which participants noted to be one of the most significant causes of difficulty in their practice. Many health care practitioners formal roles in this study were not in the area of pediatric palliative care; however, they provide end of life care in their roles. For this reason, further research in pediatric palliative care must include areas of practice that provide this care in their roles informally.

Final Reflections

This study provided a greater understanding of the experiences of health care practitioners working with children with life limiting illnesses. Their stories illuminate the difficulties and rewards in their work and the strategies they use to cope with these experiences. Their narratives highlighted important ways organizations can support employees' efforts to maintain their wellbeing while working in environments where at times, they witness and experience repetitive traumatic events. It has been a privilege to conduct this research and gain further insight into the experiences of those working in pediatric palliative care, further solidifying my interest in this field.

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Appendix A: Recruitment Email

Dear _____,

My name is Victoria Ellison and I am currently completing a thesis project for my Masters of Social Work degree. I am writing to invite you to participate in the study I am conducting under the supervision of Dr. Catrina Brown at the Dalhousie School of Social Work and Todd Currie, MSW, RSW at the IWK Health Centre. I am looking to talk with health care practitioners who work with children with life limiting illnesses to explore their experiences and how they cope with difficult experiences in their practice. I am looking to complete one on one interviews that will take approximately one hour to complete. The interview would occur in a location of your choosing and at your convenience. If you would like to participate in this research or have any questions please contact me by email: vc404464@dal.ca or phone: (902) 292-9508. Additionally, if you know of anyone you feel might be interested in participating in this research it would be highly appreciated if you could forward this email onto them. Thank you for your time and consideration. I hope to hear from you.

Kind Regards,

Victoria Ellison, BSW, MSW(c)



Appendix B: Informed Consent Form

CONSENT FORM

Project Title: An Exploration of the Impact of Childhood Life Limiting Illness on Health Care
Practitioners and Their Coping Strategies

Lead researcher: Victoria Ellison, MSW Student, Dalhousie University School of Social Work,

Tel: (902) 292-9508, Email: vc404464@dal.ca

Supervisor: Catrina Brown, Associate Professor, Dalhousie School of Social Work

Email: catrina.brown@dal.ca

Site Supervisor: Todd Currie, Health Care Social Worker, IWK Health Centre

Email: Todd.Currie@iwk.nshealth.ca

In order to receive more information or clarification about the study at any time, or to report any potential difficulties related to the research, please contact at the following:

Victoria: (902) 292-9508 or vc404464@dal.ca

Introduction

You are invited to take part in a research study conducted by Victoria Ellison who is a Graduate student at Dalhousie University, as a part of a Masters of Social Work degree. Deciding whether to take part in this research is completely your choice. There will be no impact on your employment if you choose not to participate in this study. If you do choose to take part in the study, you may leave at any point for any reason. The following information will provide you with an outline of what is involved in the research, what you will be asked to do as well as any benefit, risk, inconvenience or discomfort that you might experience.

You can discuss any questions you have about this study with the lead researcher. Please ask as many questions as you like.

Purpose of the Study

The purpose of this research is to gain an in-depth understanding of practitioner's experiences providing care to children with life limiting illnesses and how they cope with the difficult experiences they encounter. This research will contribute to the small but growing body of literature in pediatric palliative care and provide insight into the experiences of health care practitioners in Nova Scotia specifically. The hope is that this study will contribute information that may be useful for organizations to consider implementing in supporting pediatric palliative care professionals in their experiences.

Study Design:

As a participant in this study, you will be asked to share your knowledge and experiences about working with children with life limiting illnesses. The information will be collected in one on one interviews approximately 90 minutes in length. You will be asked to participate in one interview in a location of your choice and convenience. Interviews will be seeking information on how health care practitioners describe their experiences working with children with life limiting illnesses and coping strategies practitioners use to cope with difficult experiences in their practice. Participants will be asked to describe any organizational supports available to them in their agency as well as any suggestions for improvement to current organizational supports. This study is hoping to have 6 - 8 health care practitioners participate. The overall results of this study will be shared with participants upon the completion of the project.

Who can Participate in the Study?

To participate in this study you must identify as a health care practitioner who has worked with children with life limiting illnesses in Halifax, Nova Scotia.

Who will be Conducting the Research?

The primary researcher in this study is a graduate student, Victoria Ellison. The supervising professor is Dr. Catrina Brown at the School of Social Work. Todd Currie, MSW, RSW is the supervisor at the IWK. The primary researcher will be the only one conducting and transcribing the interviews. Only the above-mentioned researchers would have access to the data transcripts.

What you will be asked to do:

I would like to ask you some questions about your experiences working with children with life limiting illnesses. I will ask you some questions about how you cope with difficult experiences in the area as well as organizational supports that are available to you to help you cope. You will be asked about sensitive and difficult experiences which may have arisen at work focusing on what it was about the experience that made it difficult. The interview will take approximately 90 minutes with the possibility of a follow up post-interview to clarify information. The interview will be conducted by the lead member of the research team. If you agree, I would like to audio tape the interview. I will conduct the interview in an agreed upon location of your choice, such as your place of work, a public place or a meeting room at Dalhousie School of Social Work. You may also be asked if you know other practitioners who could be potential participants in this study. If you agree, I may ask you to pass on the information about this study.

Possible Risks and Discomforts:

The risks associated with this study are minimal, however the nature of some of the questions may trigger difficult memories and contribute to emotional or psychological distress. There may also be potential discomfort in discussing organizational supports available to participants in their agency of employment. There is potential you could experience discomfort following the interview if you feel you have shared more personal or organizational information than you desired. At all times, you will be treated with respect, dignity and sensitivity. You also have the right to refuse or skip questions based on your personal comfort level with the material being discussed or withdraw your participation at any time. To mitigate these risks there will be time available at the end of each interview, unrecorded, to debrief about comments or concerns participants may have. If you should become distressed due to your participation in this study you encouraged to contact the primary researcher to debrief or be directed to alternative local services that can provide support.

Possible Benefits:

Participants may not benefit directly from their participation in this study however there are several potential benefits that could arise from this study. Possible benefits of this study include allowing participants to contribute to the current growing body of literature in pediatric palliative care. Specifically, this research could contribute to a lack of current research on this topic in Nova Scotia. Additionally, this study allows practitioners an opportunity to explore their own experiences and coping strategies as well as learn from the practices of others. The discussion of coping strategies and suggestions for improvement of organization supports could initiate conversations about training, education and supervisory support that is provided to health care practitioners working in this area.

Compensation and Reimbursement:

There will be no compensation or reimbursement for your participation in this study.

Confidentiality and Anonymity:

Your identity will be known to the researcher and therefore not anonymous however any personal and identifying information you provide to the research team will be kept confidential and secure. Personal and identifying information will not be disclosed to anyone outside of the research team unless obligated to do so by law. In the unlikely event that this occurs, you will be informed if it is necessary by law to breach confidentiality. With your agreement, your interview will be audio-taped and you will be asked to choose pseudonym to be used in place of your name to ensure your anonymity and privacy. Your name will not be recorded on digital recordings or transcript files, and this information will be stored on the researcher's password protected computer. The only people who will have access to transcripts will be members of the research team. Data will be stored for five years following the completion of the study, after which paper containing identifying information will be shredded and computer files will be deleted as per IWK research policy. Transcripts, which contain a participant pseudonym as an identifier, may be kept following completion of this for potential knowledge transfer purposes. The data shared in the final report of this project, journal articles or public presentations will not contain any

identifying information (i.e. name, job title etc.). Any direct quotes used within the sharing of this data will not be identifiable.

If you Decide to Stop Participating:

Your participation in this study is completely voluntary and you have the right to withdraw your participation at any time without consequence. If you should choose to stop participating at any point, you can contact the lead researcher at vc404464@dal.ca or 902-292-9508. If your data has already been collected, you can decide whether you would like to have the data you have contributed to be used or removed. You have the ability to decide to remove your data up to one month post interview.

How to Obtain Results:

Following the completion of the study I will provide you with a final report on the study findings. No individual findings will be provided. These results can also be obtained by contacting the researcher in approximately nine months.

If you would like to receive the results of this study please provide an email and/or mailing address that results can be sent.

Questions:

I am happy to talk with you about any questions or concerns you may have about your participation in this research study. Please contact Victoria at (902) 292-9508 or vc404464@dal.ca at any time with questions, comments, or concerns about the research study. You may also contact Dr. Catrina Brown at catrina.brown@dal.ca. At the beginning of the study you will be provided a copy of the consent form for your records and there will be time before the interview begins to ask any questions as well.

Problems or Concerns:

If you have any concerns about your participation in this research or general research questions the Research Office of the IWK Health Centre can be contacted at (902) 470-8520, Monday to Friday between 8:00a.m. and 4:00 p.m.

Appendix C: Signature Page
Signature Page

Project title: An Exploration of the Impact of Childhood Life Limiting Illness on Health Care Practitioners and Their Coping Strategies

Lead Reacher: Victoria Ellison

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to take part in an interview that will occur at a location acceptable to me. I agree to take part in this study. I realize that my participation is voluntary and that I am free to withdraw from the study at any time, until the time of publication.

I agree that my interview may be audio-recorded. Yes No

I agree that direct quotes from my interview may be used without identifying me. Yes No

I agree I may be contacted after my interview is completed for follow-up questions and/or to review sections of my transcribed interview for accuracy. Yes No

Participant Name	Signature	Date
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Researcher Name	Signature	Date
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Appendix D: Interview Guide

Setting the scene- not recorded

- Welcome and introductions.
- Reiterate confidentiality and informed consent.
- Encourage participant to ask questions throughout the process and remind that they do not need to answer any questions they do not feel comfortable with.
- Emphasize that data will be anonymized.
- Inform that recording will only start when interviewee ready and comfortable. [SEP]

Interview- begin recording

1. Let's start with your name, profession and place of work?
2. Can you tell me a bit about how you began to practice in this area?
Prompt: How long ago? What made you choose this area? Did you always have an interest in this field?
3. What type of training did you already have or were provided prior to working in your position?
4. Could you describe to me the different aspects of your role?
Prompt: What are some aspects of your role which you find rewarding or make the job worthwhile? What are some aspects which make your job more difficult or challenging?
5. Can you share with me a time you had an emotional response to a difficult situation at work?
Prompts: What was it about this experience that you found challenging? Is there anything that makes this more difficult? Is there anything that makes these experiences less difficult? Are there other times you have had this type of response? Is this a common experience for you? How do you cope with these experiences?
6. Can you share with me a time you were affected by your work experiences at home?
Prompts: Are there other times you have had this type of reaction? Is this a common experience for you? How do you cope with these experiences?
7. Can you tell me about how you are supported by management and available organizational resources in these experiences?
Prompt: Does this affect your practice? If so, how?
8. Could you share with me any self-care practices you use to cope with your work experiences?
Prompt: How often do you partake in self-care activities? Do you feel self-care affects your practice?

9. If you could design the support system available in your place of work what might you change or add to be in place for yourself and your colleagues?

Prompt: Formal supervision, training, informal debriefing, etc.

10. Is there anything else you would like to share that has not been covered?

11. Do you have any questions?

Appendix E: Ethics Approval



Approval – Delegated Review September 27, 2017

5850/5980 University Avenue
PO Box 9700, Halifax
Nova Scotia B3K 6R8
Canada
tel: 902-470.8888
www.iwk.nshealth.ca

Principal Investigator: Victoria Ellison
Supervising Investigator: Dr. Catrina Brown & Mr. Todd Currie
Title: An Exploration of the Impact of Childhood Life Limiting Illness on Health Care Practitioners and Their Coping Strategies
Project #:1022645

On behalf of the IWK Research Ethics Board (IWK-REB) I have reviewed the documents included in this study. I am pleased to confirm the Board's full approval for this research study, effective today.

Best wishes for a successful study.

Yours truly,

Adam Huber
Co-Chair, Research Ethics Board

This approval includes the following study documents:

Document Name	Version Date
Protocol	2017/09/26
Information and Consent Form	2017/09/26
Script - Interview	2017/09/26
Script - Recruitment	2017/09/26

The Board's approval for this study will expire one year from the date of this letter (September 27, 2018). To ensure continuing approval, submit a Request for Continuing Review to the Board 2 - 4 weeks prior to the renewal date. If approval is not renewed prior to the anniversary date, the Board will close your file and you must cease all study activities immediately. To reactivate a study, you must submit a new Initial Submission (together with the usual fee, if applicable) to the IWK-REB and await notice of re-approval.

Please be sure to notify the Board of any of the following:

- Proposed changes to the initial submission (i.e. new or amended study documents)
- Additional information to be provided to study participants
- Material designed for advertisement or publication with a view to attracting participants
- Serious adverse events experience by local participants
- Unanticipated problems involving risks to participants or others

- Sponsor-provided safety information
- Additional Compensation available to participants
- Upcoming audits/inspections by a sponsor or regulatory authority
- Closure of the study (within 90 days of the event)

Approved studies may be subject to internal audit. Should your research be selected for audit, the Board will advise you and indicate any other requests at that time.

Important Instructions and Reminders

Submit all correspondence to Ethics Manager Bev White or Ethics Coordinator, Joanne Street at the address listed at the top of this letter (do not send your response to the IWK-REB Chair or Co-Chair)

Be sure to reference the Board's assigned file number, 1022645 on all communications.

Highlight all changes on revised documents and remember to update version numbers and version dates, include a clean copy of all revised documents.

Research Ethics Board Committee Members		
Victoria	Apold	Lay Representative
Tricia	Beattie	Pediatric Psychology
Kimberly	Brewer	BIOTIC
Kelly	Cameron	Lay Representative
Jill	Chorney	Pediatric Psychology (Clinical Researcher)
Eleanor	Fitzpatrick	Nursing (Clinical Researcher)
Isabelle	French	Legal Representative
Ron	George	Women's Anaesthesia (Clinical Researcher)
Kevin	Gordon	Pediatric Neurology (Clinical Researcher)
Linda	Hamilton	Obstetrics and Gynecology, Co-Chair
Adam	Huber	Pediatric Rheumatology (Clinical Researcher)
Francois	Tremblay	Pediatric Ophthalmolgy

*REB members are not in attendance during review of their own proposed research involving human subjects or where there is conflict of interest with the proposed research

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *The Research Ethics Board for the IWK Health Centre operates in accordance with:*

- Food and Drug Regulations, Division 5 "Drugs for Clinical Trials involving Human Subjects"
- The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS(2)
- International Conference on Harmonization - Good Clinical Practice Guidelines - ICH-GCP
- FWA #: FWA00005630 / IORG #: IORG0003102 / IRB00003719

Appendix F: Ethics Renewal 2018



5850/5980 University Avenue
PO Box 9700, Halifax
Nova Scotia B3K 6R8
Canada
tel: 902.470.8888
www.iwk.nshealth.ca

Approval – Annual Renewal September 27, 2018

Principal Investigator: Miss. Victoria Ellison

Co-Principal Investigator:

Title: An Exploration of the Impact of Childhood Life Limiting Illness on Health Care Practitioners and Their Coping Strategies

Project #: 1022645

On behalf of the IWK Research Ethics Board (IWK-REB) I have examined the application for annual renewal. This request for annual renewal was considered at the September 18, 2018 REB meeting. I am pleased to confirm the Board's approval to continue the study.

The IWK-REB approval will expire on September 27, 2019.

Adam Huber
Co-Chair, Research Ethics Board

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *The Research Ethics Board for the IWK Health Centre operates in accordance with:*

- Food and Drug Regulations, Division 5 "Drugs for Clinical Trials involving Human Subjects"
- The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS(2)
- International Conference on Harmonization - Good Clinical Practice Guidelines - ICH-GCP
- FWA #: FWA00005630 / IORG #: IORG0003102 / IRB00003719

Appendix G: Ethics Renewal 2019



5850/5980 University Avenue
PO Box 9700, Halifax
Nova Scotia B3K 6R8
Canada
tel: 902.470.8888
www.iwk.nshealth.ca

Approval – Annual Renewal September 27, 2019

Principal Investigator: Miss. Victoria Ellison

Title: An Exploration of the Impact of Childhood Life Limiting Illness on Health Care Practitioners and Their Coping Strategies

Project #: 1022645

On behalf of the IWK Research Ethics Board (IWK-REB), I have examined the application for annual renewal. This request for annual renewal was considered at the September 17, 2019 REB meeting. I am pleased to confirm the Board's approval to continue the study.

The IWK-REB approval will expire on September 27, 2020.

Eleanor Fitzpatrick
Co-Chair, Research Ethics Board

This statement is in lieu of Health Canada's Research Ethics Board Attestation: *The Research Ethics Board for the IWK Health Centre operates in accordance with:*

- Food and Drug Regulations, Division 5 "Drugs for Clinical Trials Involving Human Subjects"
- The Tri-Council Policy Statement: *Ethical Conduct for Research Involving Humans - TCPS(2)*
- International Conference on Harmonization - *Good Clinical Practice Guidelines - ICH-GCP*
- FWA #: FWA00005630 / IORG #: IORG0003102 / IRB00003719