The Parental Experience of Unexpectedly Losing a Child In the Pediatric Emergency Department

by

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Abstract

Background: Losing a child is the most traumatic experience a parent can face in their lifetime. Unexpected loss in the unfamiliar environment of the Emergency Department only increases this trauma, putting parents at risk of negative outcomes such as complicated grief. Understanding the parental experience in these loss situations would enable healthcare providers to improve communication and support of parents, and would enable them to tailor interventions to optimize parental support.

Methods: The qualitative research design of interpretive description was used to enable parents to describe their experience of losing their child in their own words. In total, 8 parents from 5 families were recruited. Data collection included open-ended interviews, demographic questionnaires, and field notes. Data analysis was performed using a constant comparative method, and revealed four main themes along with subthemes to describe parents' experiences of loss.

Results: Four main themes of grief as waves, being the good parent, coping through the waves of grief, and the new normal were identified. Grief as waves described how parents' grief changed over time and the meanings they ascribed to their loss. Being the good parent described parents' need to do right by their child and ensure they would not be forgotten. Coping through the waves of grief included descriptions of the coping mechanisms parents used throughout their loss experience. The new normal described the reality parents were suddenly faced with after the death of their child, and how they adapted to that new normal.

Conclusions: Overall, parents described the unexpected loss of their child as a life-altering event that will continue to affect them for the rest of their lives. They struggled to find ways to cope with their grief, to maintain their role as the good parent, and to go on living. Parents identified many areas in healthcare where more supports are needed, from the Emergency Department to follow-up care at home. These findings can help educate healthcare professionals on the parental experience of loss and can help to guide resource development to optimize their support throughout the loss experience.

Keywords: parent, child loss, unexpected death, Pediatric Emergency Department

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Chapter I - Introduction

Background

Childhood death has become a rare occurrence in most developed countries, with only about 1% of total deaths in Canada occurring in those under the age of 19 (Statistics Canada, 2011). Even for clinicians who practice exclusively in pediatrics, it is no longer an expected event and may only be experienced a handful of times in one's career. This can make childhood death an even more traumatic event, because it is so unexpected and unfamiliar. In the first year of life the majority of childhood deaths are due to congenital malformations, but from age 1-19 the leading cause is unintentional injuries (Statistics Canada, 2008). Unintentional injuries include events like motor vehicle accidents, drowning, and poisonings. The majority of these deaths are sudden and unexpected, making an already traumatic event even more challenging for parents.

Losing a child is the most traumatic event that a parent can experience in their lifetime. Even when compared to other types of loss, parental loss of a child is more difficult and carries with it an increased risk of complicated bereavement (D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008; Rini & Loriz, 2007). It challenges a parent's identity, relationships, worldview, and fundamental beliefs in the natural order of life (Bucaro, Asher, & Curry, 2005; Garstang, Griffiths, & Sidebotham, 2014; Meert, Thurston, & Briller, 2005). When death is sudden and unexpected, these challenges can be complicated by feelings of guilt over not fulfilling their role as protector of their child. This can put them at increased risk for complicated bereavement and negative outcomes like depression and post-traumatic stress disorder (PTSD) (Rini & Loriz, 2007; Truog, Meyer, & Burns, 2006).

The majority of children die in hospital, with most of those deaths occurring in the Pediatric Intensive Care Unit (PICU) (Meert, Briller, Schim, Thurston, & Kabel, 2009). The high stress situation of having an ill child and the unfamiliarity with the hospital is challenge enough for parents, but the atmosphere of the PICU brings into play its own unique challenges. The PICU is a technological and fast-paced area with a focus on restoring children back to health (Meert et al., 2012; Truog, Meyer, & Burns, 2006). Parents must adapt to rapidly changing conditions and struggle to build trusting relationships with their child's healthcare team. Qualitative studies examining the parental experience of losing a child in the PICU have revealed several parental needs during their process of bereavement. The needs identified include: honest communication, trust, compassion, professional support, and enough time (Garstang, Griffiths, & Sidebotham, 2014; Meert et al., 2012; Steele et al., 2013). Sometimes it is in the clinician's power to meet these needs, as more than half of the deaths in the PICU occur after parents and the healthcare team decide to withdraw life-sustaining treatments (Meert et al., 2009). Sometimes, however, the child's clinical situation does not allow time to meet parents' needs, and this is often the situation with deaths in the Emergency Department (ED).

Approximately 20% of childhood deaths occur in the ED (Knapp & Mulligan-Smith, 2005). The ED shares many challenges with the PICU, in terms of unfamiliarity, technology, and dynamic nature. But the ED also poses some unique challenges for parents, which can make their experience of loss even more traumatic. Deaths in the ED tend to be sudden and unexpected, which does not allow parents any time to anticipate death and can limit their participation in patient care and decision making (Knapp & Mulligan-Smith, 2005; Rini & Loriz, 2007). Parents may not even be present for the death, which is a challenge for them and clinicians, as then decisions must be made with little information about the patient or family care wishes. Often the clinical picture is also unclear or incomplete, and this lack of information can make clinicians leery of updating parents with potentially mistaken or incomplete information. Workload demands of the ED also often mean the healthcare team is pulled to other tasks immediately after the death of the child (Lawrence, 2010). This leaves the parents feeling abandoned and gives the impression that the death was not of importance to the healthcare team. Even the parent’s time with the patient after death can be compromised, as most cases of unexpected death within 24 hours of entrance to the hospital are considered coroner’s cases (Bucaro, Asher, & Curry, 2005). This means that medical equipment cannot be removed and family is allowed very limited physical contact with the body as their actions could potentially destroy evidence regarding cause of death.

One of the most significant events in parent’s bereavement outcomes can be their interactions with hospital staff (O’Malley, Barata, & Snow, 2014; Rini & Loriz, 2007). However, surveys performed with ED physicians in the United States revealed that only 14% of physicians felt prepared to support parents after the loss of their child, and some even admitted to prolonging resuscitations beyond all hope in order to avoid having to tell the parents that their child had died (Bright, Huff, & Hollon, 2009). This situation is further complicated by the lack of a relationship between the ED healthcare team and parents, as they are trying to communicate with no concept of the parents’ level of understanding or their needs (Meert et al., 2008). Nurses also avoid contact with the parents after the child dies, as they are struggling with their own emotional reactions to the event and fear the loss of control that parents may experience. The healthcare team tries to maintain a sense of calm to keep the situation under control and to maintain their own composure so they can function in their roles. But this calm can be mistaken as cold and uncaring by parents, and goes against the open and empathic relationship that parents want with the healthcare providers involved in their child's care (O'Malley, Barata, & Snow, 2014; Truog, Christ, Browning, & Meyer, 2006).

The central role of the ED healthcare team is to care for the patient, but part of caring for a child is also supporting the parents. Research on childhood death has shown that healthcare provider support can have a very positive impact on parental bereavement, from reducing their grief symptoms to reducing their risk for long term negative outcomes like complicated bereavement (Meert et al., 2012). But there is a lack of research in this area, with no studies occurring specifically in pediatric EDs, few studies focusing on the unexpected loss of a child, few studies that isolate mothers' and fathers' loss experiences, and few studies that examine the parental experience of unexpectedly losing a child. Loss of a child, unexpected loss, and loss in the ED are all factors that have been identified in the literature as increasing parents' risk of complicated grief. Research is needed to understand the unique challenges faced by parents who unexpectedly lose a child in the ED, as this would allow for tailoring of care and resources to best support parents during their time of loss.

Purpose of the Study

The purpose of this qualitative study was to explore the parental experience of unexpectedly losing a child in the pediatric ED, and how that loss experience changed in the first five years after the death. This study provided insight into the parental experience of unexpectedly losing a child in the pediatric ED, and aided in the understanding of their experience, perspective, meanings, and how those factors changed during the first five years after the loss.

Research Objectives

The research objectives of this study included the following:

1) To identify how parents characterized the experience of unexpectedly losing their child in the pediatric ED, and how that characterization changed in the first five years after the death
2) To identify the meanings that parents ascribed to the unexpected loss of their child in the pediatric ED, and how those meanings changed in the first five years after the death
3) To identify how parents coped with the unexpected loss of their child, and how their coping changed in the first five years after the death
4) To identify parents perceptions of supports provided or not provided by healthcare clinicians during the unexpected loss of their child in the pediatric ED and through the first five years after the death

Particular attention was given to parental presence at the time of death, degree of parental participation, parents' needs during the time of the loss, and what resources were needed to meet their needs.

Definitions of Major Constructs

For the purpose of this study, the major constructs were defined as follows:

1) *Parent(s)* – Parent or parents refers to the child's primary caregiver(s). This included biological parents, foster parents, grandparents, or any other caregiver who provided primary care for the child.

2) *Pediatric Emergency Department* – A pediatric ED was an ED that exclusively saw pediatric patients under 18 years of age.
3) *Unexpected Death* – Unexpected death included any acute death that was not attributable to an underlying chronic condition. This excluded deaths due to SIDS and those that occurred as an expected end to life-limiting conditions or palliative care.
4) *Coping* – Coping was the ways in which parents deal with the unexpected death of their child, including during the death and afterward.
5) *Meaning* – Meanings were lived and referred to the way a person experienced and understood his or her world as real and meaningful (van Manen, 1990). Meanings attached to experiences and events were positive, negative or neutral, and changed as changes occurred in situations and relations (Woodgate, 2001).

Assumptions and Preliminary Work

My experience as a pediatric ED nurse has provided me with an understanding of what it is like to care for parents that have lost a child in the ED. Most children seen in the ED are treated and go on to make full recoveries. But the experience of being seen in the ED can still be a highly stressful event for parents, as it often involves uncertainty and fear around the wellbeing of their child. The atmosphere of the ED is highly technological and dynamic, with an aggressive focus on returning children to a positive state of health. Parents bringing their children into this atmosphere must try to navigate an unfamiliar location and communicate with a team of staff that are completely unknown to them. The situation is often complicated by heightened emotions, a lack of information, and a lack of time with which to consider treatment decisions. In some cases, parents are not immediately present with the child or may be completely unaware that a medical crisis has occurred. This may lead to them being unable to participate in medical decisions, and can compound their guilt over not being present to support and care for their child.

For some parents, there is no recovery, and they must face the loss of their child in the unfamiliar atmosphere of the ED. The loss of a child is one of the most traumatic events that a parent can face in their lifetime. Death in the ED is often sudden and unexpected, and parents must struggle to come to terms with an event that they never expect to happen to them. They can get lost in a sea of unfamiliar people, with a healthcare team that is so cure driven that the parents may be completely unaware that death is even a possibility. The child's condition and information available on which to base prognosis and treatment decisions can change very rapidly. This can make it extremely challenging to keep parents up to date on the situation and may preclude the time necessary for them to participate in care and treatment decisions. At the time of death, parents crave a connection to those who were present in the last moments of their child's life. But the healthcare team struggles to balance supporting the parents with managing their own emotions and responding to the other workload demands of the department. Often the healthcare team is immediately assigned to other tasks, leaving the parents feeling abandoned and alone in their time of crisis.

As a pediatric ED nurse, I have struggled to emotionally cope with the death of a child in the ED. As a mother, I cannot begin to imagine the depth of that loss for parents. There is a loss of one's identity as a parent, guilt over failing as a protector, loss in the belief of a just world, and a shattering of the belief in the natural order of life. No parent ever expects to outlive their child. No parent ever thinks their previously healthy child will not recover or cannot be fixed by healthcare providers. Even as a pediatric ED nurse, I can only imagine the fear of the unfamiliar in the ED, and the distress over handing care of your child over to strangers. Add the challenge of a non-medical person trying to understand a rapidly evolving situation enough to participate in life and death decisions, and you can see how this constellation of factors can complicate their bereavement process. Parents are often left with guilt, unanswered questions, and a long list of "what ifs" that can never be answered. Understanding how the atmosphere of the ED affects their experience of loss can help us to better support parents and ensure there are resources in place to meet their needs. We cannot take away the trauma of their loss, but understanding the experience from their perspective may help identify ways for us to positively impact their bereavement outcomes.

In interpretive description there needs to be an "explicit awareness of the investigator as interpreter" (Thorne, Kirkham, & Flynn-Magee, 1997, p.3). Underlying assumptions must be explicitly identified in order to provide an understanding of the lens through which the themes and meanings were viewed. For this research study, assumptions were based on the philosophical underpinnings of naturalistic and qualitative inquiry. The underlying assumptions include the following:

1) There are multiple constructed realities that can be studied only holistically. Thus, reality is complex, contextual, constructed, and ultimately subjective.
2) The inquirer and the "object" of inquiry interact to influence one another, indeed, the knower and known are inseparable.
3) No *a priori* theory could possibly encompass the multiple realities that are likely to be encountered; rather, theory must emerge or be grounded in the data.
4) Parents who have experienced the loss of a child in the emergency department are experts on explaining the experience of their loss.

Significance of the Study

This study had many potential positive outcomes, both in terms of helping parents who have experienced the loss of a child and in terms of informing clinical practice. Telling their stories could be cathartic for many parents, as it allows them to speak out about their loss experience and honor the memory of their child. Hearing stories from parents that have experienced the loss of a child could also help other parents to realize they are not alone, and may give them hope for incorporating the loss into their life. Understanding the parental experience of losing a child in the ED may also help to inform clinicians on how to best support parents during this time. And understanding parents' needs during their loss could help to guide policy and resource provision, enabling better support of parents during and after their time in hospital.

Chapter Summary

Chapter one provided an overview of the challenges faced by parents who unexpectedly lost their child in the ED. The majority of literature on child loss was focused on the PICU and palliative care, both areas that often include a degree of anticipation of death that is not often found in the ED. Much of the literature alluded to loss of a child being more difficult in the ED due to the sudden and unexpected nature of the death, but little research has been done in this area. Understanding this experience has the potential to improve care and impact how health care providers support families during this time. Following chapter one, chapter two will explore the literature and present the groundwork that will underpin this research study.

Chapter II: Literature Review

Introduction

This chapter will provide a critical review of the current research around parental loss of a child. It includes an overview of the following: childhood death, the impact of child loss on parents, the unique features of mothers' and fathers' perspectives, childhood death in hospital, the effect of childhood death on healthcare providers, and the unique circumstances of childhood death in the pediatric ED. It also identifies limitations within the literature and suggests areas for further study.

Childhood Death

More than half of all childhood deaths occur in children under one year of age, with the leading cause of death being congenital anomalies. After the first year, and up until 19 years of age, the leading cause of death is unintentional injuries, including things like motor vehicle accidents, drowning, and poisonings (Statistics Canada, 2008). Deaths from unintentional injuries tend to be sudden and unexpected, with many of these children dying out of hospital or shortly after arrival in the ED. From 1-14 years of age, the second leading cause of death is malignant neoplasms (Statistics Canada, 2008). These deaths are more likely to occur in hospital, often come at the end of a period of significant illness, and are most likely to involve palliative or ICU care. In this sense, these deaths may be more expected or anticipated, and the grieving process may have already begun at the time of diagnosis. There is often time for parents to begin to prepare for the death, and death may even be seen in the positive light of release from suffering (Arnold, Gemma, & Cushman, 2005; Proulx, Martinez, Carnevale, & Legault, 2015). From age 15-19, the second leading cause of death is suicide or intentional self harm (Statistics Canada, 2008). These deaths are also often unexpected, and may be complicated by the tumultuous relationship that often exists between parents and teenagers (Davies, 2001; Schonfeld, 2012). Suicide also carries with it a degree of social stigma, and parents may feel like their competency is being judged or that they failed as parents in some way leading to added guilt and emotional distress (Arnold & Gemma, 2008; Davies, 2001)

Regardless of the cause of death, childhood death is characterized as one of the most traumatic events that one can experience, and has been identified as more difficult than other types of loss due to the unique nature of the parent-child bond (D'Agostino, Berlin-Romalis, Jovcevska, & Barrera, 2008; Garstang, Griffiths, & Sidebotham, 2014; Woodgate, 2006). Death in childhood goes against the natural order of life, as the young are supposed to outlive the old, and parents do not expect to outlive their children (Bogensperger & Lueger-Schuster, 2014; Garstang et al., 2014). But it is more than just the loss of a person, rather it is the loss of all the hopes and dreams attached to the child, like graduations, weddings, and children of their own (Bucaro, Asher, & Curry, 2005; Woodgate, 2006). And the death of a child requires a restructuring of the parent-child relationship, moving from an external, physical relationship to a more internal one based on honoring and cherishing memories of the child (Meert, Thurston, & Briller, 2005; Proulx et al., 2015; Truog, Meyer, & Burns, 2006a). It is not about forgetting, rather memories of the child are cherished and can be a great source of comfort to parents that are grieving (Truog et al., 2006a; Woodgate, 2006).

Impact on Parents

Parental bereavement encompasses the entire journey from anticipation of death, through the death itself, and the subsequent adjustment to living without the deceased (Denhup, 2015). It can start as early as the time of diagnosis of a life-limiting condition, and is described by many parents as a new state of being that they have been thrust into and will exist in for the rest of their lives (Denhup, 2015; Schonfeld, 2012). While many bereavement theories focus on performing a set of tasks in order to come to a point of resolution, a study by Denhup (2015) revealed that parents consider bereavement to be a lifelong state. In her phenomenological study of parents that had recently lost a child to cancer, she interviewed six parents to gain an understanding of the meaning they attributed to their experience of loss. Parents identified a distinction between bereavement and grief, describing grief as the emotional component of bereavement. And while grief intensity could change over time and be affected by other life factors, bereavement would always be a part of their life. As one mother described "I will always be a bereaved mother…but [the intensity of] my grief will vary" (p.11).

Bereaved parents are at increased risk of many negative outcomes of loss, including mental, physical and spiritual domains. In the physical domain, bereaved parents have been found to have greater risk of myocardial infarction (MI), multiple sclerosis (MS), and overall higher mortality rates from natural and unnatural causes. Li, Hansen, Mortensen, and Olsen (2002) performed follow-up studies based on national registers in Denmark comparing approximately 20,000 parents that had lost a child to approximately 290,000 parents with similar familiar structures whose children were still alive. They found that parents who had lost a child had an increased relative risk of fatal MI and first time MI from the 7th to the 17th year post loss. Parents who lost a child unexpectedly, especially from Sudden Infant Death Syndrome (SIDS), had an even higher relative risk of fatal or first time MI. They also found an increased mortality rate from both natural and unnatural causes in mothers and fathers that had lost a child. Mothers had increased mortality from unnatural causes throughout the study, with the highest rate recorded in the first three years after their loss. They also had increased mortality rates from natural causes in the 10th to 18th year post loss, with unexpected losses increasing their mortality rates from both natural and unnatural causes. Fathers showed only an increased mortality rate from unnatural causes in the first few years after the loss. Li et al. (2004) also performed a follow-up study based on national registers in Denmark comparing 21,062 parents that had lost a child with 293,745 matched parents that had not lost a child. They found parents that had lost a child had an increased risk of developing MS, with unexpected loss linked to even greater risk.

In the mental domain, parents have shown high levels mental distress, post-traumatic stress disorder (PTSD), depression, and increased rates of first time psychiatric hospitalizations. Murphy, Johnson, and Lohan (2002) performed a study with 173 parents that had lost a child to accident, suicide or homicide. Parents were assessed for mental distress and PTSD at 4, 12, 24, and 60 months post-death. The study found that five years after the death, 61% of mothers and 62% of fathers met the diagnostic criteria for mental distress, while 28% of mothers and 13% of fathers met the criteria for PTSD. When compared to parents bereaved by non-violent causes, parents bereaved by violent causes scored two to five times higher for mental distress and PTSD, with mothers showing significantly higher levels of PTSD than fathers. Similarly, a population based survey performed by Kersting, Brahler, Glaesmer, and Wagner (2011) showed that female gender and loss of a child increased a person’s risk of developing complicated grief.

A study by Li, Laursen, Hansen-Precht, Olsen, and Mortensen (2005) comparing approximately one million non-bereaved parents to 17,000 bereaved parents, found that bereaved parents had an increased overall risk of first time psychiatric hospitalization for any disorder. Mothers showed a higher relative risk than fathers, with the highest relative risk occurring in the first year after the death but elevated levels of risk remaining for the first five years after the death. Rogers, Floyd, Seltzer, Greenberg, and Hong (2008) performed a Wisconsin Longitudinal Study comparing 428 parents of deceased children with 428 parents of similar backgrounds whose children were still alive. They found that bereaved parents reported more depressive symptoms, poorer well-being, more depressive episodes, and more marital disruption than non-bereaved parents.

And in the spiritual domain, parents have shown increased levels of guilt and existential crisis, as they try to make sense of their child's death within their own worldview and belief in the natural order of life. Bogensperger and Lueger-Schuster (2014) performed a mixed methods study involving interviews and questionnaires with 30 bereaved parents to explore their meaning reconstruction. They found that 36.7% of parents could not make sense of their child's death, and 26.7% of parents could not find any benefit in their child's death. This lack of sense-making or benefit-finding was linked to an increased risk of complicated grief and low levels of post-traumatic growth. Proulx et al. (2015) identified similar results in their phenomenological study of 13 bereaved fathers, with a lack of sense-making and benefit-finding linked to an increased risk of complicated grief and low levels of post-traumatic growth.

The majority of parents are able to manage their grief over time and learn to incorporate their bereavement into their new state of being (D'Agostino et al., 2008; Denhup, 2015). Some, however, fail to adjust to life without the deceased and go on to develop complicated grief. Complicated grief is characterized by extreme and persistent sadness that fails to lessen over time, and can develop into suicidal or homicidal ideation or intentions (Schonfeld, 2012). It can involve a preoccupation with thoughts of the deceased, so much so that it begins to affect daily activities and interpersonal relationships, and may even develop into maladaptive coping techniques like alcohol or substance abuse (D'Agostino et al., 2008; Meert & Eggly, 2011;

Schonfeld, 2012). Death of a child is a known risk factor for developing complicated grief, as is bereavement due to unexpected, violent, and traumatic causes (Schonfeld, 2012). Inability to find meaning in their loss and having their needs unmet also significantly increases parents' risk of developing complicated grief (Bogensperger & Lueger-Schuster, 2014; Meert et al., 2012).

Throughout the literature, several themes emerge to describe parental bereavement from the parents' perspective. The themes identified are: A) a new state of being, B) maintaining a connection to their child, C) finding meaning, and D) invisibility.

A New State of Being

Denhup (2015) undertook a phenomenological study with parents that had lost a child to cancer to describe their lived experience of that loss. Six parents (one father, five mothers) participated in the study, with the time that had passed since the children's deaths ranging from just over one year to 41 years. Parents in the study described bereavement as "an entirely new state of being into which parents are immediately propelled after the death of a child and in which they exist for the remainder of their lifetime" (p.8). Life was described as being completely different than it was before, and parents acknowledged that there was no possibility of returning to their previous state of "normal". They compared this new state of being to the aftermath of a tsunami, in that the drastic landscape changes that follow a storm were like the drastic changes that occurred in their own lives. Similar to findings by Arnold & Gemma (2008), some of these drastic changes involved personal relationships, in that the family unit had to be completely restructured to accommodate the loss of one of its members. Strain was also experienced in the relationship between parents, which has been attributed by other authors

(Arnold et al., 2005; Schonfeld, 2012) to the fact that parents grieve differently and may be so overwhelmed with their own grief that they are unable to be there to support their spouse.

Along with the external changes such as restructuring relationships and the physical absence of the deceased child, this new state of being also involves many internal changes. Meert, Briller, Schim, Thurston, & Kabel (2009) conducted a three phase qualitative study to examine the needs of bereaved parents in the Pediatric Intensive Care Unit (PICU). Phase one involved interviews with 33 bereaved parents, phase two involved focus groups with 13 parents, and phase three involved triangulation of data from the first two phases. In each case, interviews and focus groups took place approximately one to three years after the death of the child. In most cases, cause of death was a chronic illness with approximately half of deaths involving a decision to limit or withdraw life support. In approximately a third of cases, cause of death was acute illness or injury occurring within 48 hours of the death, with a third of deaths occurring after unsuccessful CPR. Parents’ needs were assessed in the time before death, at death, and after death, and one of the main themes identified was “Who I Am”.

The theme of “Who I Am” involved a need to honor the parent-child relationship right up to the time of death, and then to find ways to forge a connection that would go beyond death. Parents cited a need to be present with their child, even after death, and to fulfill their role as caregiver and protector. For many parents, their relationship to their children is central to their identity, and so parents struggle to maintain that connection even beyond death. Loss of their child means a loss of part of themselves, and they must find ways to restructure their own identity and their role as a parent to now accommodate that loss.

A phenomenological study by Woodgate (2006) uncovered a similar theme of “Being a Good Parent”, which identified that parents needed to feel they had been good parents in order to move on after their child’s death. Twenty-eight parents that had lost a child to various medical conditions participated in the study, with the time since the loss varying from seven months to 18 years. Parents identified a need to fulfill their role as parents, including doing everything possible to ensure their child lived a happy life with as little pain and suffering as possible. Some parents reported resentment over treatments that stole precious time with their child away from them, as they placed great importance on being physically present, emotionally supportive, and advocating for their child. Others reported that healthcare providers made them feel inadequate as parents, and undervalued their expert knowledge of their own child. Being able to be present for their child and having their decisions respected by healthcare providers made parents feel like they had been good parents, and this helped them to go on living after the death of their child. Overall, parents acknowledged that the loss of their child changed their whole world, and that the change was permanent. They would never again return to the state of “normal” that was present before their loss. However, many parents identified that their deceased child was very much a part of this new state of being, if only in the sense of memories and mementos.

Maintaining a Connection

The second theme identified by parents was that of maintaining a connection to their child, including at the time of their death and beyond. Arnold and Gemma (2008) performed a mixed methods study to examine parents’ grief, how it evolved over time, and the effect that grief had on them. The sample was drawn from nursing alumni at a single institution, and included 74 parents that had lost a child at some point in their adult life. The age range in the deceased children was from birth to 48 years, with 40% of deaths occurring under the age of one. Causes of death were varied, with 38% due to congenital or birth related complications and 40% due to unexpected causes. One of the themes identified by parents was that of maintaining a connection to their child even after their death. Memories became very important, and were maintained and cherished through sharing stories, family rituals, and images such as photographs. Some parents identified the need to carry a tangible memento or create a visual memorial, while others remembered by nurturing or helping others. Some parents also identified a strong desire to replace the deceased child by adopting or having other children, a factor which has been found to decrease parents' grief significantly (Wijngaards-de Meij et al., 2005).

Similar to findings by Arnold and Gemma (2008), Woodgate (2006) found that parents who had experienced the loss of a child placed great importance on keeping memories of their child alive. Memories helped them to maintain a connection with their deceased child, and having good memories helped them to go on living after the death. Parents who had few memories, such as those who lost their child only hours or days after birth, struggled to maintain that connection. And those who had negative memories surrounding their child's illness or care at the time of death also struggled with sadness and regret, whether over lost opportunities to spend time with their child or being unable to relieve their pain and suffering. Good memories provided comfort to parents, and many established rituals around special days or events that allowed them to relive those good times and thereby strengthen their connection to their child.

Meert et al. (2009), Widger and Picot (2008), and Garstang et al. (2014) also found that parents placed great importance on having mementos by which to remember their deceased child. These reminders could include things like a lock of hair, handprint or footprints, or a favorite object like a blanket or toy. These items act as anchors for the parents, who fear that without these things the child's memory will fade and they will truly be lost forever (Meert et al., 2009). These multiple ways of maintaining a connection with their child all become part of the transition in the parent-child relationship that is brought about by the death of the child. Rather than forgetting and letting go, the relationship is shifted from an external, physical relationship with the living child to an internal relationship with the deceased child (Truog et al., 2006a; Proulx et al., 2015). Parents continue to share memories of the child, imagine their opinion on life events, and may even continue to converse with them about family happenings and personal emotions that parents are experiencing around their loss. Overall, parents place great significance on maintaining a connection with their deceased child, whether through tangible reminders or personal memories. The parent-child bond is not broken by death, rather it is changed to accommodate a more internal relationship between the two.

Finding Meaning

The third theme identified by parents was that of finding meaning in their child's death, both in terms of making sense of the loss and finding benefits in the loss. Bogensperger and Lueger-Schuster (2014) performed a mixed methods study with parents that had lost a child at least one year prior to the study. The study included in-depth interviews around meaning reconstruction with a distinction between sense-making and benefit-finding concepts, and standardized questionnaires to assess post-traumatic growth and complicated grief. Thirty parents participated in the study, with the children ranging in age from 4 days to 40 years and the mean length of time since the death being almost ten years. Half of the deaths were identified as traumatic (ex. accident, suicide, or homicide) and half were non-traumatic (ex. illness), with 16.7% of parents reporting that the death was expected. Parents struggled to make the death more comprehensible, with 50% of parents citing sense-making concepts around the purpose of life and death. Some parents identified ways in which their child had fulfilled their purpose in life, as one parent reported that her time with her child taught her to work with disabled children which then enabled her to help others. However, 37% of parents reported being unable to find any meaning in their child's death. In terms of benefit-finding, almost half (46.7%) of parents identified a theme of personal improvement, including things like being more tolerant and developing personal potential. Almost as many parents identified a benefit of changed priorities, with a renewed focus on family and relationships rather than work and money. For 26.7% of parents, however, there was no benefit to be found in the death of their child.

The idea of needing to find meaning in their child's death is found throughout the literature, with authors identifying a multitude of ways that parents try to understand or make sense of their loss. Meert et al. (2009) looked at the needs of bereaved parents over time, and found that parents often spoke of their struggles to make sense of their child's death. They would often examine their own lives to try and find a reason why this had happened to them, as if they had done something wrong to cause the death. Some tried to find an "ultimate good" that could come from the loss, an idea which was cited by other authors in their discussion around parents' reasons for choosing organ donation (Widger & Picot, 2008). Some parents also made their own benefit by speaking out about their loss to others, reporting that some good could come from their loss if they were able to help others through theirs (Bogensperger & Lueger-Schuster, 2014; Steele et al., 2013). The benefit-finding aspect of meaning was also found by Proulx (2015) in her study of fathers' experience of losing a child. Fathers found it easier to identify benefits in their experience, such as changing priorities, rather than making sense of their loss. Finding these benefits helped them give meaning to their experience and helped them find a degree of peace that they identified as important to help them adapt to the loss and go on living.

Overall, parents have a need to understand why their child died, not just in a physical sense but also in an existential sense. Finding meaning or finding benefit in their loss helped parents to move forward, and helped them find some peace in order to go on living.

Invisibility

The last theme identified by parents in the literature is that of invisibility, both in terms of isolation and feeling as if their distress is invisible to others. The term invisibility was identified in a phenomenological study by Denhup (2015) in which she examined the meaning of the lived experience of parental bereavement. Six parents (five mothers, one father) took part in the study, each of whom had lost a child to cancer at least one year prior to the study. The length of time since the child's death ranged from one year, four months to 41 years. Parents described their bereavement as living in a fog that was invisible to others. They felt isolated by the fact that others seemed unaware of what they were experiencing. But this concept is not new in the literature, and, in fact, has been identified by several authors over the years using slightly different terminology.

Bucaro et al. (2005) wrote a description of a hospital-wide bereavement program implemented in a children's hospital in the United States. One of the central concepts used to describe parental bereavement was isolation, and it was described as being two-fold. On one hand, other parents avoided the bereaved parents because they embodied every parent's worst fear of losing their child. On the other hand, bereaved parents were also isolated from their strongest supports, such as family and friends, because those people were also struggling from the same loss and so were unable to provide support. Similarly, Arnold and Gemma (2008) and Arnold et al. (2005) found a theme of isolation in their study of bereaved parents. 25% of parents reported feeling ignored by others, while 10% reported feeling shunned during their bereavement. Parents in this study, as in that of Thompson et al. (2011), also reported that they wanted to share their grief with others, but few people asked them about their grief and few were willing to listen when they did speak up. And, as identified by Bucaro et al. (2005), almost half of parents reported relationship changes like strained marital relations, decreased communication with spouses, and distancing that resulted in divorce. These relationship changes take away one of parent’s most central supports, their spouse, leaving them even more isolated and struggling to cope with yet another loss.

Meert et al. (2009) also found that bereaved parents described a sense of disconnection from family and friends. The topic of the child’s death was avoided, and parents were likewise expected not to bring them up. This completely goes against parents’ need to speak about their child to maintain a connection with them after death and to honor their memory. One mother in the study described talking about her child as an essential part of her healing process. In fact, parents reported finding solace and understanding when talking to other bereaved parents about their loss. Talking about the experience helped them to make sense of the event, and helped to express some of their heightened emotions, thoughts, and fears. Some described it as “permission to grieve”, and reported feeling pressure from others to get over their grief and move on by no longer talking about their child or putting away the child’s belongings. This caused great distress to some parents, with one reporting she did not know how she could cope without having her child’s things around her as tangible reminders of all the good times. Overall, parents feel isolated in their bereavement, as others do not seem to understand what they are experiencing. They need to talk about their child, the death, and their grief as part of the healing process to go on living. They also need support from others to help them through this process, with an acknowledgement that everyone grieves in their own time and in their own way.

Fathers' Perspectives

Throughout the literature, the majority of parental perspectives have been those of mothers. Few studies have truly examined the perspective of fathers, although it has been suggested that fathers experience fewer grief symptoms and therefore are at less risk for complicated grief. Wijngaards-de Meij et al. (2005) performed a longitudinal study that examined the impact of specific variables on predicting adjustment among bereaved parents after the death of their child. 219 Dutch couples were involved in the study, all of whom had lost a child under the age of 30. Almost half (47.7%) of the deaths were related to illness or disorder, while 36.1% were due to unexpected causes such as accidents, SIDS, suicide, and homicide. The couples were contacted at 6, 13, and 20 months after the death of their child, and were assessed for grief using the Inventory of Complicated Grief scale and depression using the subscale of the Symptom Checklist-90. These results were then examined in context of shared parent variables, such as the age of the child and the unexpectedness of death, and individual factors, such as gender and education. The authors found higher levels of depressive symptoms in mothers compared to fathers, with mothers showing consistently higher levels over time. They hypothesized that the difference could be due to the different ways in which the genders classically experience distress, with fathers being seen as more stoic or less emotionally involved. But they also proposed loss-specific reasons for the difference, in that mothers invest more in their children and so are more attached to them. The loss of this stronger attachment would then lead to more grief symptoms for mothers as compared to fathers.

Proulx et al. (2015) undertook a phenomenological study of only fathers to understand their experiences following the death of their child. Interviews were conducted with 13 fathers that had lost a child between the ages of 1-17 within the previous 6 years from a life-limiting illness or unexpectedly in a PICU. They found that, rather than experiencing fewer grief symptoms, fathers experienced a balance of emotional and cognitive aspects of coping with loss. Fathers themselves identified that they did not experience more or less grief than their spouse, but rather grieved differently. And it was respect for these differences that kept the couple together and, in fact, strengthened their relationship. This individual nature of grief was also identified by Thompson et al. (2011), and they found fathers cited their spouses as being their strongest source of support, which makes the strength of that relationship all the more important. In the study by Proulx et al. (2015), fathers identified the difficulty in balancing the need to maintain a relationship with their deceased child, with all the emotional pain that involved, and moving forward with their life. Similar to Thompson et al. (2011), fathers reported feeling that their child would want them to go on living their life. In this sense, fathers were more likely to identify benefits in their experience rather than making sense of it. They focused on how the change in their priorities improved their daily life, or how the end of a prolonged illness meant that their child was no longer suffering. They also found peace and understanding with the knowledge that some good had come from the death, and were thereby able to find meaning in their loss. They were, however, quick to identify that moving on did not mean acceptance of the loss, but rather they had learned to live with their grief.

Losing a child is one of the most traumatic events that a parent will ever face in their lifetime. It is a highly individual experience, and involves a multitude of changes that will affect parents for the rest of their lives. Research has begun to scratch the surface of this experience, with parents identifying several common themes that underlie their bereavement. But many studies include a wide variety of causes of death, the loss of adult children, a majority of mothers' perspectives, and extended periods of time since the death. Each of these factors has been shown to effect parents' grief, so when taken together it is difficult to identify the effect of any one factor. More research is needed on parents' perspectives of the death of their child in the context of these specific factors. That research could arm healthcare providers with a better understanding of parental bereavement and optimal ways to support parents during their loss.

Childhood Death in Hospital

The majority of childhood deaths occur in hospital (Meert et al., 2009; Truog, Christ, Browning, & Meyer, 2006b). For some parents, the hospital can be a familiar and comforting place where they have been many times before and have received high quality care for their child. This can be the case for parents of children with chronic conditions that may require frequent treatments or hospitalizations due to complications of their conditions. They often develop strong and supportive relationships with their healthcare team, which they can then trust and rely on in crisis or loss situations. But for many parents, the hospital is an unfamiliar and overwhelming place where they can become physically and mentally lost. In a time of crisis, they must put their child's care in the hands of strangers and trust that they will do everything possible to return their child to health. Parents struggle to communicate with a healthcare team that is unknown to them, access basic resources such as food and a place to sleep, and navigate hospital policies and procedures to be with their child. And, when the outcome is the death of their child, they must face that ultimate loss adrift in a sea of strangers.

Childhood deaths in hospital can be characterized as expected or unexpected in terms of parents' awareness of death being a possible outcome of their child's medical situation. In the case of expected deaths, parents are aware that the death of their child is a possibility, or in some cases a certainty. This knowledge may come at the time of diagnosis of a life-limiting condition, and may only be the beginning of managing years of chronic illness before the reality of death must be faced. Or it can come mere hours before the death itself, with the decision to limit or withdraw life-sustaining treatment when all other medical options have been exhausted. Regardless of the amount of time, any degree of anticipation of their child's death allows parents to begin to grieve and prepare before having to face the event of death itself (Rini & Loriz, 2007). This anticipation has been shown to decrease their grief symptoms, and can reduce the risk of negative outcomes like complicated grief (Rini & Loriz, 2007; Wijngaards-de Meij et al., 2005).

Anticipatory grieving/mourning is described as the emotional preparation leading up to the time of death (Rini & Loriz, 2007; Schonfeld, 2012). It allows parents to "practice" grieving in a safer context before having to actually face the death of their child. If they get overwhelmed by grief at any time, they can shift focus back to their child and take comfort in the fact that they are still alive (Schonfeld, 2012). Rini & Loriz (2007) performed a qualitative study with 11 parents who had experienced the death of a child during the child's hospitalization. Almost all (10) of the deaths took place in the PICU, with the oldest child being 20 years old and the length of illness ranging from 24 hours to 20 years. The authors tried to determine the presence and the role of anticipatory mourning in the parents' grieving process. Seven of the parents reported they knew their child was dying and they had begun to mourn the loss before the actual death. All of them felt this knowledge was helpful because it gave them time to complete important tasks, such as saying goodbye, and time to prepare themselves for the loss. Some parents identified that it was not enough to know that death was a possibility or even a probability, they also needed to know when death was imminent. Sixty-four percent of parents reported they would have done things differently if they had known death was imminent, like gathering loved ones and ensuring they were at their child's bedside. And time frame did not seem to matter, as even parents who only had a few hours to prepare felt that time allowed them to make the experience more meaningful for them and their child. For some, however, no amount of time was enough, as two parents reported that nothing could have prepared them for the death of their child.

In the case of unexpected deaths, there is no time for anticipatory mourning and parents may not even be aware that death is a possible outcome. They can experience profound anxiety, as Wijngaards-de Meij et al. (2005) describe "for the person who has experienced loss without forewarning, there is no situation that feels safe – loss can come again out of the blue" (p.621). Their sense of trust and belief in a good and just world is shattered, leaving them struggling to understand why and how this happened to them (Truog et al., 2006b). Whereas adjustment to death after a prolonged illness can occur over time or be "softened" by the perspective of death as an end to suffering, unexpected deaths are often sudden, traumatic, and occur with no forewarning at all (Arnold et al., 2005; Proulx, 2015; Wijngaards-de Meij et al., 2005). This not only increases parents' initial symptoms of grief, but can also increase their grief over time (Truog et al., 2006a). It can also increase their risk of complicated grief, especially when the death is traumatic, violent, mutilating, or random, as these factors make it difficult for parents to find meaning or understanding in their loss (Schonfeld, 2012). Unexpected loss can also lead to the complicating factor of parents not being present at their child's death, and this too increases their grief symptoms and their risk for complicated grief (Arnold & Gemma, 2008; Garstang et al., 2014; Meert et al., 2005; Meert et al., 2009; Rini & Loriz, 2007; Woodgate, 2006).

The majority of in-hospital childhood deaths take place in the intensive care unit, a place traditionally thought of as restoring critically ill children to good health (Copnell, 2005; Meert et al., 2009; Truog et al., 2006a). But in some cases, children may be admitted to the ICU in anticipation of death, or death may come as an unwelcome outcome when all other avenues have been exhausted (Copnell, 2005). For parents whose children are experiencing an acute event, the ICU may be an unfamiliar place full of strange noises, bright lights, and a constant stream of strangers moving through their child's room (Meert, Briller, Schim, & Thurston, 2008a). For those whose children are suffering from chronic conditions, the ICU may be familiar from previous short stays, but unfamiliar in terms of prolonged hospitalization (Meert et al., 2008a). Regardless of familiarity, the fast paced, dynamic, and highly technological environment of the ICU can leave parents feeling displaced, vulnerable, and ashamed for not know what to do for their child (Meyer, Ritholz, Burns, & Truog, 2006). They want and need to fulfill their roles as parents, but may feel awkward approaching unknown healthcare providers or unable to perform basic tasks like holding their child due to unfamiliar equipment or hospital policies.

A large part of the research around childhood death has focused on loss in the ICU and how unique aspects of this environment affect parental grief and bereavement. There have been studies around the physical environment, spirituality, communication, follow-up, and the provision of high quality end of life care (Copnell, 2005; Meert et al., 2005; Meert et al., 2007; Meert et al., 2008a; Meert et al., 2008b; Meert et al., 2009; Meert & Eggly, 2011; Meyer et al., 2006; Truog et al., 2006a). And many of these studies included recommendations from parents and siblings about how the ICU staff could best meet their needs. Overall, the literature identifies six themes of parental needs when parents are facing the death of their child in the ICU. Those six themes include the following: a) communication, b) compassion, c) professional support, d) maintaining a relationship with their child, e) enough time, and f) moving forward.

Communication

The theme of communication is cited consistently throughout the literature, and is considered one of parents' most important needs when facing the death of their child. Communication with healthcare providers is key to parents understanding the situation and being able to participate in decision making and care of their child. Good communication also builds a sense of trust, which may not be present if there is no previous relationship between parents and the healthcare team. Widger and Picot (2008) surveyed 38 families that had lost a child within 12-24 months of the study to describe their perspective of the quality of care they received before, during, and after the death of their child. Half of the deceased children were under 72 hours of age at the time of death, with prematurity and congenital anomalies accounting for the cause of death in 45% of cases. 40% of parents reported knowing that death was a likely outcome for their child for more than eight months prior to the actual death, while only a quarter had no knowledge of death as a possible outcome. The authors found that communication was key to parents, with almost all (95%) reporting that they had opportunities to ask questions and that staff was willing to repeat the information as needed. However, there were also several complaints about communication with healthcare providers. Seven families reported they received less information than they wanted, and ten families reported having difficulty understanding the information provided or received contradictory information from different members of the healthcare team. One family identified how one specialist had told them they would be able to take their child home soon, while another told them the child’s death was imminent.

The need for honest and straightforward communication has been identified by other authors as well, with Bright, Huff, and Hollon (2009), Meert et al. (2007), and Meert et al. (2009) all reporting that parents wanted honest disclosure about their child’s outcome. They felt betrayed and a loss of control when that information was withheld, as they were acting without full knowledge of the severity of the situation. Parents identified that “bad news” may have been withheld to protect them or spare them distress, but felt they would have been better served by knowing the truth so they could properly prepare for what lay ahead. They felt that by giving them false hope, healthcare providers only caused unnecessary pain and suffering for both the child and the family.

Bright et al. (2009) and Meert et al. (2008b) conducted studies that specifically examined bereaved parents perceptions of communication with healthcare providers around the time of their child’s death. They identified similar themes around communication, with parents voicing the importance of honest communication, not withholding information, not giving false hope, and not providing contradictory information. At the same time, parents identified several specific concerns around communication with their child’s physician, including physician availability, attentiveness, body language, complexity of language, and giving information too quickly. Parents often identified feeling ignored by physicians, or left out of conversation by the use of highly technical language. They wanted physicians to be available for repeated conversations so that they could discuss things as they came up and take time to digest the information provided at their own pace. They also reported a need for physicians to display compassion and emotion, and to know that the physician understood the magnitude of their loss.

Cold and callous conversations around the time of their child's death caused immense pain for parents, and created negative memories that stuck with them for years. Overall parents wanted honest and up-to-date information in a language that they could understand and at a pace that they could manage. Communication was key to them being involved in their child's care and fulfilling their role as parents. And being aware of the gravity of the situation allowed them to prepare themselves, to complete important tasks such as saying goodbye, and to ensure they were at their child's side when they were needed there the most.

Compassion

The second theme identified by parents was the need for compassion, and this was very closely linked to communication as often the actions of healthcare providers spoke just as loudly as their words. Compassion for parents included healthcare providers treating the child as a person rather than illness, and recognizing how important the child was to the parents. Meert et al. (2005) performed a qualitative study with 33 bereaved parents to gain an understanding of their spiritual needs around the time of their child's death. All of the deaths had occurred in the PICU, with the majority of the children dying from chronic illness and more than half dying after life support was limited or withdrawn. Many parents described quality interactions with healthcare providers, relating stories of praying together or staff stopping by to check on them even after their shift was finished. But this was not always the case, as some parents identified callous remarks from staff that seemed to think of their child as already gone or as less than a person. Parents were very thankful for the little things that healthcare providers did to show they care, like giving a hug, offering a prayer, or even shedding a few tears with the family. Those little things reassured the parents that the healthcare team saw their child as a person and that they too were affected by the loss.

The concept of the child being treated as a person rather than just another patient was also found in a study by Steele et al. (2013). The authors interviewed mothers, fathers, and siblings from 40 families to obtain their advice to healthcare providers on how to improve care during the death of their child/sibling from cancer. All three family members consistently reported that they wanted to see the child treated like a real person. They wanted them to be seen as more than just their illness, and felt healthcare providers who understood this were really providing compassionate care. The family wanted the healthcare team to understand that they too needed support, not in terms of false promises, but in terms of reassurance that they would get through this. Siblings specifically identified a need to be acknowledged by healthcare providers, and to have access and opportunities to spend time with their sibling. And, interestingly, they cautioned the healthcare team to be compassionate but not to get too involved, or they would experience the sadness of the loss as if it were their own. Overall the families wanted to know that their loved one was being cared for by people who cared, and that they were not seen as just another number or task to be completed. They wanted the healthcare team to understand how special and important that child was, as if knowing that would make them work that much harder to provide the best care possible. And they wanted the healthcare team to show emotions, such as shedding tears or a supportive hug, not only to support them through their loss, but also to create a loving and caring atmosphere for their child.

Professional Support

The third theme identified by parents was that of professional support, including the time before, during, and after the child’s death. Garstang et al. (2014) performed a systematic literature review to identify what bereaved parents wanted from professionals after the sudden death of their child. In the study, sudden death included any unexpected death that qualified as a coroner’s case, and professionals included police, social workers, nurses, and physicians. Parents identified a need to be supported by professionals, in terms of emotional support, professional support, and follow-up after the death. Emotional support was described in terms of healthcare providers visibly showing emotion, such as shedding tears at the time of death or when breaking bad news. Many parents identified this emotional support as being quickly withdrawn after the death itself, with several describing being left on their own to find a way back home. Professional support was described as constant presence during the time of death, to which they could turn for information or practical support in managing follow-up care or funeral arrangements. Meert et al. (2009) had similar findings, in that parents identified a need for staff to help them find their way literally and figuratively, in terms of navigating paperwork, rules, and the logistics of the hospital system itself.

A need for professional follow-up after the death has been identified in many studies as something parents want, but few receive any follow-up from healthcare providers. The systematic literature review by Garstang et al. (2014) found follow-up for bereaved parents was variable, with studies reporting rates anywhere from 16-92%. Follow-up in their review included everything from phone calls or sympathy cards from healthcare providers to post-death conferences with the entire healthcare team. Some of the highest rates were found in SIDS and neonatal deaths, which could be due to those areas having well established policies for care after a loss, including collection of mementos and offering bereavement support information. Meert et al. (2007) performed a study on parents’ perspectives regarding a physician-parent conference after their child’s death in the PICU, and found that parents identified follow-up with healthcare providers as very important. Despite this level of importance, only 59% of parents reported they wanted to meet with their child’s physician. Of those who did not want to meet, the most common reason cited was that parents felt satisfied with the information provided to them during their child's hospitalization. Of those who did want to meet with the physician, the most common reasons cited were to gain further information about their child's death, to provide feedback to physicians, and to suggest areas where healthcare providers could improve their care of the children and support of parents during their time of loss.

Meert and Eggly (2011) looked into this connection further with their study on whether or not follow-up after a child's death in the PICU could improve family outcomes. They found families that did not receive follow-up care reported feeling abandoned by physicians, and speculated this was due to an unmet need for closure of the physician-parent relationship. The authors also suggested that a good physician-parent relationship during the child's illness made the physician more willing to continue interacting with the parents after the child's death. Overall, parents consistently cited a need for professional support before, during, and after their child's death. Regardless of the length of time spent in hospital before the child's death, the healthcare team members were identified as key sources of support and were often instrumental in enabling parents to be present for their child as parents and advocates. They viewed follow-up with the healthcare team after their child's death as very important, although provision of this follow-up care was very inconsistent. Their reasons for follow-up varied from wanting support and sharing memories to providing feedback and learning further details about their child's death. Follow-up allowed for closure of the relationship between the parents and the healthcare team, people that had gained vast importance due to their presence during the child's death.

Maintaining a Relationship

The fourth theme identified by parents is that of needing to maintain a relationship with their child, both by being present at the time of death and through remembering them after their death. Meyer et al. (2006) performed a qualitative study with bereaved parents to understand their priorities and recommendations on how healthcare providers could improve end-of-life care in the PICU. 56 parents that had lost a child in the previous 12-45 months after a decision to forego life-sustaining treatment participated through anonymous questionnaires. Similar to Meert et al. (2009), one of the priorities reported by parents was that of preserving the integrity of the parent-child relationship. They described this in terms of being allowed to fulfill their role as caregivers, protectors, decision-makers, and providers of love and physical tenderness. And, similar to Meert et al. (2005), parents wanted to participate in their child's care, be present at the time of their death, and have time after death for intimate communication with their child. As one parent described: "after she passed away one thing that helped us to say our good-byes was that we were able to hold her…we knew she was gone but just to have that closeness with her one more time" (p422).

Thompson et al. (2011) found a similar theme of continuing bonds with the deceased child in their longitudinal study of parents and siblings that had lost a child to cancer. 36 mothers, 24 fathers, and 39 siblings participated in the study. Families were interviewed at home approximately one year after the death, and were asked to identify their advice to others on managing grief before, during, and after the death. All family members clearly stated that grief is very individual, and that what worked for them would not necessarily work for others. So, rather than offering advice, they explained what had helped them through their loss in the hopes that their stories would potentially help others. Their theme of continuing bonds focused on the time after death, and involved cherishing memories and keeping tangible reminders of the deceased child around them. Mothers, fathers, and siblings all identified ways that they incorporated memories or symbols of the deceased child into their everyday lives to ensure they were never forgotten. This idea of finding new ways to incorporate the deceased child into their lives connects to the idea of moving from an external, physical relationship to an internal relationship described by other authors as characteristic of parental bereavement (Meert et al., 2005; Proulx, 2015; Truog et al., 2006a). Overall parents identified a need to fulfill their role as parents, and to maintain that bond with their child for as long as possible. Physical presence gained importance as parents needed that physical connection to communicate their love and create the memories that would sustain them through their grief. Fulfilling their role as parents, in terms of protecting and advocating for their child, also became important as parents aimed to give their child a “good death”. Even after death, they found ways to maintain that connection and honor their child by continuing to include them as part of the family unit. Death did not lead to forgetting, rather it made remembering all the more important.

Enough Time

The fifth theme identified by parents is that of having enough time with their child before, during, and after their death. This included time before the death to fulfill final wishes and prepare for the death, and having full access to their child during their hospitalization, death, and after their death. Rini and Loriz (2007) and Schonfeld (2012) both examined the concept of anticipatory grief and how having that time to prepare themselves before death could positively impact parents’ grief outcomes. Parents appreciated having that time, no matter how long it was, to begin grieving and to begin saying goodbye within the safety net of knowing the child was still alive. This meant that if they became overwhelmed by the grieving process, they could take a step back and just be with their child for a time without having to face what lay ahead. This theme was strongly connected to the need for honest communication from healthcare providers. Meert et al. (2009), Rini and Loriz (2007), and Steele et al. (2013) all found that parents felt cheated out of time with their child when healthcare providers withheld information on prognosis or gave them false hope making them believe they had more time.

Meert et al. (2008a) also found a theme of time in their phenomenological study of parents' environmental needs during the loss of their child in the PICU. Here time was identified partly as parents needing to have full access to their child at all times. Parents voiced distress over having to phone PICU staff to be allowed into the unit, and felt that there should be no limits placed on being with their child, especially when they knew time was precious and in short supply. Some parents also described being excluded from life-threatening or resuscitation situations, with subsequent regrets over not being present during those moments to comfort their child. These barriers to parents spending time with their child goes against their need to be present and need to be involved in their child's care (Meyer et al., 2006). It can make them feel as if they've lost their role of being a parent at the exact time that their child needs them the most (Woodgate, 2006). On the other hand, Meert et al. (2009) found parents were grateful when staff did not rush them through decisions or put a limit on the time they got to spend with their child even after death.

Overall, parents need to spend as much time as possible with their child before, during, and after their death. In the PICU, approximately 60% of childhood deaths occur after a decision to limit or withdraw life-sustaining treatments (Meert et al., 2009). In these situations, healthcare providers may be able to give parents the benefit of more time with their child. However, in unexpected death situations, time may be dictated by the clinical situation rather than healthcare providers. Regardless of the situation surrounding the death, parents need time to prepare, provide comfort, and say goodbye, without having to navigate barriers from hospital policy or the decisions of healthcare providers. When time is limited by the knowledge that death is on the horizon, it becomes the most precious thing in the world to parents and their child. And while there may never be enough time, every effort possible needs to go into making the most time.

Moving Forward

The sixth theme identified by parents was that of needing to move forward, which included the concepts of acceptance, finding meaning, and continuing to live. Acceptance is a controversial topic in the literature, with Arnold and Gemma (2008) finding two distinct concepts of acceptance in their study examining the process of grief over time. The study involved a retrospective survey of 74 nurses that had experienced the death of a living child using their own survey instrument "Grief Over a Lifetime: A Study of the Lifelong Effects of Child Death on Parents". They found that some parents identified acceptance as inevitable, and equated it to resignation over the fact of death, the fact that the child was gone, and the unalterable reality of life without their child. Similarly, Thompson et al. (2011) found family members identified acceptance as being a necessary part of moving forward. They encouraged acceptance as a way to not dwell on the past, as the past could not be changed. One sibling in the study was careful to make the distinction that acceptance did not mean getting over the grief, but it did help to lessen the grief over time. Other parents in the study by Arnold and Gemma (2008) refused to accept their child's death, and equated acceptance with getting over the loss which was something they felt they could never do. Proulx et al. (2015) found similar results in their study of bereaved fathers, as fathers reported they could never accept their loss but rather had learned to live with their grief.

For many parents, finding meaning in their child's death was also an important component of moving forward. Meert et al. (2005) and Bogensperger and Lueger-Schuster (2014) in their studies of bereaved parents found many felt a need to identify the child's purpose in life or the meaning in their death before they could move forward. They needed to have a "why" in order to move on from the death, and many refused to believe that there was not a reason or purpose to be found. Despite this refusal, 30% of parents in the study by Bogensperger and Lueger-Schuster (2014) reported finding no benefit or meaning in their child's death. Meert et al. (2005), Bogensperger and Lueger-Schuster (2014), and Proulx et al. (2015) all found that parents attributed a variety of meanings to their child's death. Some identified a change in priorities, others felt their child had positively touched the lives of others, while some felt their child had fulfilled their purpose in life despite the short time they had lived. This need to find meaning connects back to the idea of parents needing to restructure their worldview after the loss of their child. They must make sense of their new reality, which can be quite challenging with unexpected and traumatic deaths, as they can seem senseless due to a lack of pre-existing illness or medical condition on which to blame the death.

The final component of moving forward is that of going on with life or continuing to live. Thompson et al. (2011) and Proulx et al. (2015) both found that fathers specifically identified a need to keep going. This was partly to prevent themselves from breaking down, and partly because they felt it was what their deceased child would have wanted them to do. Fathers were careful to identify that going on with life included maintaining a relationship with the deceased child, and that memories of them were not only a part of moving on but were sometimes the inspiration to do so. As one father described "we're not looking back, we're looking forward, and we feel that's what he would want us to do" (Thompson et al., 2011, p.165). Overall parents identified a need to find ways to move forward after the death of their child. For some this meant accepting the death, for others it meant finding meaning in their loss, and for some it simply meant making the decision to keep going. Although not all parents were able to accept their child's death or find meaning in their loss, most parents acknowledged that life would go on, the past could not be changed, and that their child would want them to continue to live. Their child's death had propelled them into this new state of being, and there was no option to return to the previous state of "normal". But moving forward did not mean forgetting their child or their loss experience, rather it involved finding ways to bring their child with them through the rest of their life.

Effect on Staff

The death of a child is traumatic for everyone involved, and that includes the healthcare providers involved in that child's care. Physicians and nurses must strike a balance between caring for the child and supporting the family, all the while managing their own emotions around caring for a critically ill child. The healthcare team tries to respond to crisis situations with calm and efficiency, partly to inspire confidence in the family and partly to protect themselves from the heightened emotions around the care of critically ill children. However, this calm demeanor can be perceived by parents as cold and lacking compassion, which goes against their need for empathy from those caring for their child (Knazik et al., 2003; O'Malley et al., 2014; Truog et al., 2006b). There is also a belief among healthcare providers that children are healthier and more resilient to illness and injury. This coupled with the ever increasing curative potential of medical technology can mean that many healthcare providers see death as a personal failure (Knazik et al., 2003). This can lead to feelings of guilt, failure, and unworthiness, all of which make it difficult to face the family after the death of a child (Knazik et al., 2003).

Unexpected death can intensify these emotions, especially when the cause of death is a preventable illness or injury, or due to criminal violence (Knazik et al., 2003). In this case, healthcare providers and parents may face similar struggles of trying to make sense of the loss and accommodating it into their own belief in a just world and the natural order of life. Overall healthcare providers are not immune to the distress caused by the death of a child, regardless of years of experience or location of employment. They too must face the challenge to their worldview and the belief that children simply should not die. In the time of crisis, many healthcare providers try to project an outward calm and efficiency to reassure the family that their child is receiving high quality care. It also helps the entire team to focus on the task at hand when emotions are temporarily set aside, to be dealt with later when there is time and space to do so. And balancing support of the family with care of the child can be difficult, especially when there is no previous relationship between parents and healthcare providers. Aggressive care focused on cure often leaves little time and attention for family, which can leave them feeling abandoned and displaced during a time of great need.

The death of a child in hospital can leave parents facing many added challenges, including communicating with healthcare providers that may be previously unknown to them, being physically present with their child, and carving out time for important tasks such as saying goodbye. Parents can feel overwhelmed by the atmosphere of areas like the PICU, displaced by the authority of healthcare providers, and ashamed of not knowing how to help their child. Research has begun to uncover parental needs during the death of their child in the PICU, but approximately 60% of deaths in the PICU are due to a decision to limit or withdraw life-sustaining treatments. This decision often affords parents a certain amount of time that is not possible with sudden and unexpected deaths. Although the literature identifies that sudden and unexpected deaths are the most difficult in terms of grief symptoms and the risk of developing complicated grief, few studies isolate unexpected deaths in order to assess how this factor affects parents' experience of their loss. Further research is needed around the parental experience of the unexpected death of their child, both in terms of how this factor affects their experience and their needs during their time of loss.

Childhood Death in the Emergency Department

The final section of this literature review explores the complex nature of the death of a child in the Emergency Department and the unique challenges that parents face in these situations. The main areas of focus are: a) the nature of emergency care and b) parental challenges.

Nature of Emergency Care

The ED is a dynamic, fast-paced, and highly technological environment that often experiences rapid patient turnover. Healthcare providers in this area often work under the strain of a lack of time, lack of information, and lack of relationships with patients and families. The majority of children that enter the ED are treated for a minor injury or illness and are released home in good health. However, approximately 20% of childhood deaths occur in the ED, including those who are pronounced dead on arrival and those who die after failed resuscitation attempts (Knapp & Mulligan-Smith, 2005). The majority of these deaths are sudden and unexpected, though studies have shown that up to 20% of deaths in children with known life-limiting conditions also occur in the ED (O'Malley et al., 2014).

Regardless of the cause of death, the death of a child is a rare occurrence in the ED (Knapp & Mulligan-Smith, 2005; O'Malley et al., 2014). Children are generally otherwise healthy, and so are very resilient to illness and injury and respond well to resuscitative efforts. This means that children are generally not brought into the ED in anticipation of their death, and care provided is often very aggressively cure focused (Rini & Loriz, 2007). Death is often seen as failure by the healthcare team, leaving them struggling with their own emotions and guilt at a time when the parents most need their support (O'Malley et al., 2014). The nature of sudden and unexpected deaths means the healthcare team often works against a lack of time, information, and sometimes even parental presence. Sometimes they are alone in making sense of the situation with rapidly changing conditions, incomplete medical information, and no prior relationship with the patient or family on which to base care decisions, identify needs, or assess understanding. Other times they are trying to balance building a relationship with the parents, treating the child, and working with team members toward a positive outcome (O'Malley et al., 2014).

This balancing act does not end after the child's death, as workload and time pressures in the ED often pull staff immediately away to other tasks (Lawrence, 2010). This leaves them unable to fully support the family, or offer them time for answering questions or reviewing events. And most often, in the case of unexpected death or death within 24 hours of entering the hospital, these deaths must be investigated by a coroner (Bucaro et al., 2005). This means that medical equipment cannot be removed from the body, parents cannot handle the body, mementos cannot be collected, personal effects cannot be returned, and family may either be interrupted or delayed in terms of spending time with the child after death. Overall the ED is a challenging environment for parents, especially those facing the death of their child, as it often involves a rapidly evolving situation that requires constant adaptation to keep pace. Healthcare providers often have to work with little information, little time, and a lack of previous relationship with the patient and family. This combined with cure-focused care can complicate communication, family participation, anticipation of death, and follow-up care. These factors can all affect a parent's grief and their risk of negative outcomes such as complicated grief, but sometimes these factors are dictated by the medical situation and not by healthcare providers.

Parental Challenges

The very nature of emergency care can cause many challenges for parents facing the loss of their child in the ED. The lack of a relationship with healthcare providers can complicate communication and the sense of professional support. And the nature of unexpected death further complicates the experience as it often includes a lack of information and lack of time for parents to prepare, make decisions, or even be present. Ahrens, Hart, and Maruyama (1997) surveyed 37 families whose child had died or been pronounced dead in the ED to examine their experience and to elicit information that would help ED physicians tell parents that their child had died. All of the children had undergone autopsies, and in 34 cases the cause of death was listed as SIDS. In terms of communication, most (76%) parents wanted the attending physician to notify them of the child's death, rather than a nurse or a chaplain. But as Lawrence (2010) identifies, ED staff have many competing demands for their time and must balance support of the family with fulfilling other obligations.

In terms of being present, only 34% of parents reported they wanted to be in the room for resuscitation, yet 88% found viewing the child's body helped them to accept the death. Knapp and Mulligan-Smith (2005) reported that family presence during resuscitation could help them to accept the death and had been related to more positive grieving behaviors. Similar to Garstang et al. (2014), Meert et al. (2005), and Meert et al. (2009), most parents would have liked a physical memento of their child, such as a lock of hair or hand prints, but few parents had these offered to them. However, as Bucaro et al. (2005) identified, most deaths in the ED are coroner cases and so collection of mementos must wait until after the investigation of the death is complete. And in terms of professional support, 65% of parents reported that it would have been helpful to have follow-up from healthcare providers, although only 6 parents received any kind of follow-up. This is similar to findings by other authors (Garstang et al., 2014; Meert et al., 2007; Meert & Eggly, 2011), who identified that parents cite follow-up with healthcare providers as being very important and yet rates of follow-up vary greatly among studies. Meert and Eggly (2011) also suggest that a lack of physician-parent relationship, as is found in the ED, makes follow-up care more difficult and less likely to occur.

Garstang et al. (2014) found very similar results in their systematic review examining what parents wanted from professionals after the sudden death of their child. The review looked at bereaved parents' interactions with professionals including physicians, nurses, police, and social workers after the death of their child. And, though all deaths were considered sudden and unexpected, the location of those deaths included both in-hospital and out-of-hospital settings. Similar to Ahrens et al. (1997), parents identified themes of communication, time, and professional support. In terms of communication, parents wanted information in a language they could understand and at a pace that gave them time to process it. They also wanted to feel listened to, whereas some reported they were dismissed, avoided, or even judged by healthcare providers. Parents identified a need for information about their child's death, whether from autopsy results or follow-up appointments with healthcare providers. Knowing the details of the death reassured them that everything possible had been done and that their actions were appropriate, which helped to lessen their guilt. Not knowing the cause of death could be a great source of distress for parents, as it left them struggling to understand why their child died. This was especially true in the case of SIDS deaths, as there seemed to be no underlying medical condition on which to blame the death. Lack of information also led to parents believing information was being deliberately withheld, which could lead to mistrust of healthcare providers and concern over the quality of care that their child received. In the case of unexpected death in the ED, cause of death may not be known until after an autopsy is performed. And trust between parents and healthcare providers can be difficult due to the lack of a prior relationship.

In terms of time, parents wanted to see and hold their child, and found not being able to do so increased their grief. As found in the study by Meyer et al. (2006), these actions were part of the process of saying goodbye to their deceased child. Even with traumatic deaths, Garstang et al. (2014) found that most parents wanted to see their child, as often the injuries they imagined were far worse than the reality. And, in terms of professional support, parents felt supported when healthcare providers showed visible emotion, with parents reporting an appreciation of the little acts of care and compassion from those involved in their child’s care. Something as simple as a hug or calling their child by name let the parents know that their child was important to the healthcare team as well. Many identified that support was quickly withdrawn after the death of the child, with some parents reporting they were left to find their own way home. And although many parents wanted continued contact with the healthcare team, whether to share memories or as a support system, few received follow-up care.

Overall, parents found the lack of a relationship with ED healthcare providers and the lack of time and information associated with unexpected death to be the most significant challenges around losing a child in the ED. The inability to be present with their child and to maintain that parent-child bond caused great distress among parents, as did the many unanswered questions that often accompany sudden and unexpected deaths. Although healthcare providers may feel uncomfortable facing families after the death of their child due to feelings of guilt and heightened emotions, their support is one risk factor for parental bereavement that can be altered.

Chapter Summary

Death in children under the age of 19 accounts for only 1% of the total number of deaths in Canada each year (Statistics Canada, 2011). This is an extremely rare occurrence compared to a century ago when 30% of all deaths occurred in children under the age of 5 (O'Malley, Barata, & Snow, 2014). Parents facing the death of their child must navigate a completely new state of being, in which their worldview, relationships, and even their identity has changed. They struggle to maintain a parent-child bond and to find meaning in their child's death, all the while acknowledging that they need to keep moving forward. Losing their child unexpectedly in the ED can complicate this process with a lack of information, time, and relationship with healthcare providers. All of these factors increase parents' risk of negative bereavement outcomes, such as complicated grief.

Despite identification of these risk factors in unexpected child loss in the pediatric ED, the majority of research has focused on loss in the Intensive Care Unit (ICU). Many ICU focused studies include a wide variety of causes of death, including deaths after a decision to limit or withdraw life-sustaining treatment, stillbirths, SIDS, acute injury or illness, and chronic or life-limiting conditions. Some studies have examined factors that affect the grief process, including the nature of the death, age of the child, and family support systems. Others have tried to identify parents' needs during their child's illness and death in order to provide recommendations for healthcare providers on how best to support them during their loss. But there is very little research that focuses on the parental experience of losing a child, especially within the context of unexpected loss in the Emergency Department (ED). Understanding the parents’ perspective on their loss experience will help to inform healthcare providers in the ED on how best to support parents and what interventions they can implement to positively impact bereavement outcomes. This literature review provided the support for an exploration into the parental experience of unexpectedly losing a child in the pediatric ED. The next chapter explores the conceptual framework that will guide this interpretive description study.

Chapter III: Analytic Framework

Introduction

Chapter three outlines the Theory of Chronic Sorrow created by Eakes, Burke, and Hainsworth (1998), and how it was used to inform this interpretive description study. In interpretive description, an analytic framework is constructed based on critical review of the existing knowledge (Thorne, Kirkham, & O'Flynn-Magee, 2004). This framework then orientates the study, provides a rationale for its anticipated boundaries, and makes explicit theoretical assumptions, biases, and preconceptions that will drive the design decisions (Thorne, Kirkham, & MacDonald-Emes, 1997). The Theory of Chronic Sorrow provided a framework for understanding responses to loss situations, coping methods, and the overall bereavement experience. This section provides a brief overview of the Theory of Chronic Sorrow.

Theory of Chronic Sorrow

Chronic sorrow was first identified in the literature over 30 years ago, and was used to describe recurring waves of grief experienced by parents of children with mental disabilities due to their loss of a "perfect child" (Eakes, Burke, & Hainsworth, 1998). Subsequent research found the occurrence of chronic sorrow in many different types of loss, and identified it as a normal response to an abnormal situation. The defining characteristics of chronic sorrow include: a) a perception of sadness or sorrow over time in a situation with no predictable end, b) sadness or sorrow that is cyclic or recurrent, c) sadness or sorrow that is triggered internally or externally and brings to mind a person's losses, disappointments, or fears, and d) sadness or sorrow that is progressive and can intensify (Eakes et al., 1998). These characteristics combined with a concept analysis, critical review of the literature, and validation through multiple qualitative studies formed the foundation for development of the Theory of Chronic Sorrow.

The Theory of Chronic Sorrow offers an explanation of how people respond to single or ongoing losses, and includes a model of chronic sorrow as a framework for understanding those responses and the bereavement experience as a whole (Eakes et al., 1998). The primary antecedent to the onset of chronic sorrow is the experience of a significant loss, including ongoing losses such as living with a disabled child or more finite loss like the death of a loved one. Although the definition of significant loss is very individual, research has shown that loss of a “perfect child”, such as children with physical or mental disabilities, places parents at high risk of chronic sorrow (Eakes et al., 1998). The second antecedent to the onset of chronic sorrow is the experience of unresolved disparity due to the loss, meaning the gap between reality and the ideal situation. In terms of the loss of a child, this disparity can include the gap between the desired relationship with the living child and the reality of life without them. Trigger events are closely tied to disparity, as they are the situations or conditions that exacerbate or renew focus on the disparity caused by the loss (Eakes et al., 1998). They are highly individual, and depend on the nature of the loss and the nature of the individual’s relationship to that loss. In bereavement situations, the disparity that triggers chronic sorrow is the absence of a loved one, and so common triggers in these situations are memories or anniversary events surrounding the deceased individual.

Management methods include both internal coping strategies used by the individual and external interventions implemented by professionals (Eakes et al., 1998). Use of effective coping strategies and appropriate interventions can help those experiencing chronic sorrow to find emotional balance, increase comfort, decrease the number of trigger events, and reduce the degree of perceived disparity (Eakes et al., 1998). Effective internal coping methods can include focusing on the positive aspects of life, staying involved in personal interests, and talking with others that have experienced a loss. Effective external coping methods can include offering support, providing information, and taking time to recognize and acknowledge feelings around the loss. In terms of parental bereavement, many parents have cited the importance of internal coping methods such as finding meaning in their loss, maintaining the parent-child relationship, and speaking about their loss with others (Bogensperger & Lueger-Schuster, 2014; Meert et al., 2009; Meyer et al., 2006; Steele et al., 2013; Thompson et al., 2011; Widger & Picot, 2008). Effective external coping methods that have been identified by bereaved parents include follow-up with healthcare providers, receiving information about their child's death, and compassionate care (Bright et al., 2009; Garstang et al., 2014; Meert et al., 2007; Meert et al., 2008b; Meert et al., 2009; Meert & Eggly, 2011; Widger & Picot, 2008).

Overall, the Theory of Chronic Sorrow provided a framework for understanding the responses of individuals to loss events. This combined with the model of chronic sorrow, allowed for a greater understanding of the entire bereavement experience. Although no single theory can possibly encompass the multiple realities of parents that have unexpectedly lost a child in the pediatric ED, this theory provided a base of knowledge on which more in-depth understanding of the loss experience could be built. Healthcare providers need to recognize the occurrence of chronic sorrow in those who have experienced single losses or ongoing losses, and understand that this is a normal response to an abnormal situation. There needs to be support not only at the time of loss, but also during trigger events when recurrence of sadness and symptoms of grief can occur. This theory and the model provided an appropriate framework in which to guide this study, as they provided a greater understanding of the ongoing nature of loss and the overall process of bereavement.

Chapter Summary

The Theory of Chronic Sorrow provided a framework for understanding responses to both single and ongoing losses. Eakes et al. (1998) developed this theory to not only explain individual responses to loss, but also to acknowledge chronic sorrow as a normal response to an abnormal situation. This theory and the associated model provided a framework for this study, and guided understanding of the experience of parental loss and the process of parental bereavement as a whole. Understanding the ongoing nature of loss and the recurrent episodes of grief symptoms can assist healthcare providers in supporting parents, not only through interventions during their loss and trigger events, but also in normalizing their response to their loss. This knowledge can then enable improved interventions and resources for parents during their time of loss and beyond. The following chapter describes the methodology of this research study.

Chapter IV: Methodology

Introduction

This chapter describes the research methodology that will be used to guide this qualitative study, and provides details of the research method. Thorne, Kirkham, and MacDonald-Emes' (1997) interpretive description comprised the methodology, and method details discussed include: research design, sample criteria, recruitment procedure, research setting, data collection methods, data analysis methods, strategies to maintain methodological rigor, and ethical considerations.

Philosophical Framework

Interpretive description is an inductive, analytic approach that allows for new viewpoints on clinical phenomena, which can then generate new insights and applications to practice (Thorne, 2008; Thorne, Kirkham, & O'Flynn-Magee, 2004). It recognizes that healthcare clinicians are not satisfied with research that purely creates a description of a clinical phenomenon. Rather, they want to identify associations, relationships, and patterns with the phenomenon which can then be used to inform clinical practice (Thorne, 2008). Thorne, Kirkham, and MacDonald-Emes (1997) developed interpretive description to fill a methodological gap, as there was a need for an applied qualitative approach that could both generate better understanding of clinical phenomena and applications for practice. This new methodology drew from the substantive histories of ethnography, grounded theory, and phenomenology, while adding its own unique characteristics to the mix.

Methodological Ancestry

Ethnography is a qualitative design in which the researcher describes and interprets the shared and learned patterns of behaviors, values and beliefs within a culture-sharing group (Creswell, 2013). It views cultural variation as a way to understand social organization, cognitive function, and human complexity (Thorne, 2008). Ethnography strongly identifies the importance of fieldwork, participant observation, and immersion of the researcher in the culture in order to truly understand the cultural group and their way of life (Creswell, 2013). Although understanding cultural influences is important, healthcare research is often more concerned with a shared illness experience among participants rather than a shared cultural background.

Grounded theory is a qualitative research design in which the researcher generates an explanation for a process or action from the data generated by those who have experienced the process or action (Creswell, 2013). It involves interviewing and memoing to begin to sketch out the flow of the process itself, and then the data is coded so that relationships and intersections can be identified and built into a theory to explain the process (Creswell, 2013). This method is highly structured, and requires the researcher to set aside their own ideas about the process so that theory emerges from the data alone. It can be useful when seeking to understand a process or causal relationships, but it does not acknowledge the individual experience.

Phenomenology is a qualitative research design which generates a description of the common meaning for participants of their lived experience of a concept or phenomenon (Creswell, 2013). It involves gathering individual experiences with a phenomenon, and reducing those into a description of the "essence" of the experience of that phenomenon (Creswell, 2013; Thorne, 2008). The researcher is required to "bracket" their own experiences with the phenomenon in order to ensure the description comes from the participants rather than their own beliefs (Creswell, 2013). This method focuses on the subjective experience while bracketing the context surrounding the phenomenon. But in healthcare, context can be a very important component in the clinical situation and must be considered when making patient care decisions.

Although each of these qualitative methods has components that fit well with healthcare research, none are a perfect fit for applied health research because they lack the final link back to practice. Interpretive description evolved to fill this methodological gap, and finally gave applied health researchers a way to link theory and practice within one methodology (Thorne, 2008). The researcher begins with a practice goal and a firm grounding in what is already known about the research topic. Then they go into the field to uncover what is beyond the known or what other possibilities may be present. As Thorne (2008) describes: “[interpretive description] offers the potential to deconstruct the angle of vision upon which prior knowledge has been erected and to generate new insights that shape new inquiries as well as applications of ‘evidence’ to practice” (p.35). It allows for critical interpretation of current knowledge and an understanding of context that can be used to guide practice decisions.

Appropriateness of Interpretive Description for this Study

Interpretive description was an appropriate methodology for this study because there was knowledge around the parental experience of losing a child, but it lacked contextual grounding within unexpected loss in the ED. Applying this methodology not only allowed for a critical review of the current knowledge, but also provided a greater understanding of the parental experience within that specific context. Interpretive description also allowed the researcher to contribute personal experience to current knowledge, and provided an opportunity to enhance that knowledge into a greater understanding of the parental experience.

Research Design

A qualitative interpretive description study was performed to explore the parental experience of unexpectedly losing a child in the pediatric ED. Qualitative methodology acknowledged that parents are the experts of their own experience, and enabled parents to use their own words to describe their experience, coping methods, and the meanings they attributed to their loss. This allowed for a greater depth of understanding of the parental experience from the perspective of the parents themselves.

The aim of interpretive description is to take qualitative description and filter it through a disciplinary lens. It allows for the careful and systematic analysis of a phenomenon to then be put back in the context of clinical practice where it can be used to inform and guide patient care (Thorne, 2008). Interpretive description was the chosen methodology for this study because it enabled a critical review of the literature and previous knowledge with the aim of discovering new information or new perspectives around the phenomenon under study. This new knowledge can then be taken back into the clinical context and can be used to guide practice decisions.

Sampling and Recruitment

This study initially included a purposive sample of parents that unexpectedly lost a child in the pediatric ED between six months and five years of this study. The strength of purposive sampling was that it allowed for selection of participants that had a specific angle of experience that allowed for greater understanding of the phenomenon under study. A sample of 10-15 participants was proposed, however only 7 participants were recruited for the study. Several steps were taken to try and increase recruitment for this study, including resending letters of invitation in case they had been lost in the mail or delivered incorrectly, advertising in the newsletter of a local parental bereavement support group, and increasing the time frame of loss from 6 months to 10 years. There was some concern that expanding the timeframe since the loss could dilute the memory of the grief experience, but many parents described the peak of their waves of grief as feeling just as raw as the day their child died. Inclusion criteria for parents included: (1) parents who unexpectedly lost a child in the pediatric ED in the previous six months to five years, (2) parents from both rural and urban areas within Manitoba, (3) and parents who were able to speak, read, and write English. Exclusion criteria for unexpected death included: (1) children with life-limiting conditions who died from expected complications of those conditions, (2) children receiving palliative care, and (3) any cases in which the researcher was involved in the child's medical care.

Recruitment of participants began with the Clinical Resource Nurse at the Health Sciences Center Children's Emergency Department reviewing deaths in the pediatric ED over the previous six months to ten years. Participants who qualified for the study were then sent a letter of invitation (Appendix A) to participate in the study. The letter instructed parents who were interested in participating to contact the researcher by phone, email, or returned mail. Due to low recruitment numbers and multiple letters being returned to sender, a second round of letters was sent out approximately one month after the first round. An invitation to participate in the study was also placed in a local parental bereavement support group newsletter, which was circulated to members of the group and available on the group's webpage. Interested parents were then contacted by the researcher by phone to allow for further discussion about the purpose of the study and an exploration of parents' willingness to participate (Appendix B). Those who agreed to participate in the study then had an interview arranged with the researcher at a time and location that was convenient for them. Study information and consent forms (Appendix C) were distributed to participants prior to the interview, and demographic forms (Appendix D) were provided at the beginning of the interview allowing parents' time to voice any further questions or concerns. All interviews were conducted by the researcher according to an interview guide (Appendix E), and were audio-taped with permission from the participants. After the interview, parents were provided with a list of community resources to support them through their grief (Appendix F), and a letter of invitation from the department head of the Pediatric ED to meet to discuss their loss experience (Appendix G). Field notes were also written after each interview, and were used with transcribed interviews for data analysis concurrent with data collection.

Research Setting

Interviews were conducted at a location and time that was convenient for the parents. The researcher tried to ensure an environment that was free from distractions and minimized interruptions. Most interviews took place in the homes of the participants, as the home environment was a familiar and comfortable location for conversations around such personal information as the loss of a child. Being able to visit the participants' homes also allowed for a greater understanding of their context, in terms of surviving children, family structure, and the overall home environment. And it allowed parents to share personal memories such as photos, shrines, or personal objects that belonged to their deceased child.

Data Collection Methods

Three primary sources of data collection were utilized within this study. These included personal interviews, demographic questionnaires, and the researcher's field notes.

Interviews

Interviews were open-ended and semi-structured to allow parents to describe their experiences in their own words. Each interview lasted approximately one to three hours and was digitally recorded to allow for accurate transcription and review of the data for identification of underlying themes. During the interviews, parents were asked to describe their experience of unexpectedly losing their child in the pediatric ED. They were also asked to describe the coping methods they used during their time of loss (Appendix D). Open-ended probes, such as “can you tell me more about that…”, were used to elicit further details about the parents’ experience when needed. Three couples chose to do their interviews together, one single mother had a support person present who did not partake in the interview, and one mother chose not to involve her spouse in the interview. A second interview session was offered to give participants an opportunity to add or clarify any information provided in their initial interview. This also gave the researcher the opportunity to clarify any previous information and to validate themes as they emerged from the data. The second interviews lasted approximately 30 minutes to one hour, and were digitally recorded other than one that was completed by email. Two couples chose to complete their second interviews together, one mother interviewed alone but had her family present for support, one couple completed their interview separately by emailing responses to a list of questions provided by the researcher, and one mother did not feel she had further information to add so she did not complete a second interview.

Demographic Questionnaire

The second source of data was a demographic questionnaire developed particularly for this study. Parents were asked to fill out this questionnaire prior to being interviewed. Included in this form were questions on the participants’ age, sex, marital status, number of children in the household and their ages, home location, age of the deceased child at the time of death, and cause of death for the deceased child. The form took five to ten minutes to complete and any questions asked by participants were answered by the researcher while the form was completed.

Researcher's Field Notes

The final source of data collection was from field notes written by the researcher after each interview. Observations were recorded from each interview, along with thoughts, feelings, and potential themes arising from the data collection. Personal assumptions and beliefs about the research topic were also recorded to ensure the researcher remained aware of personal perspective, and to help ensure that the themes arose from the data and from the perspectives of the parents' themselves. These field notes also allowed the advisor to monitor the researcher's assumptions and beliefs, thereby preventing any bias from influencing the data collected.

Data Analysis

All interviews and field notes were transcribed verbatim and analyzed by the researcher. Data analysis was performed using a constant comparative method, which involved taking one piece of data, such as an interview or theme, and comparing it with all other data collected in order to identify possible relationships between various pieces of data (Thorne, 2000). This method allows the researcher to identify how pieces of data may be different and how they may be related in order to identify themes and patterns within the human experience (Thorne, 2000). It also allowed for an understanding of phenomena within the context in which they were experienced, creating a deeper understanding of the phenomena as a whole. Collaborative analysis between the researcher and advisor was ongoing throughout the study, and provided the researcher with guidance and expertise in thematic analysis. This assisted with interpretation of the data and clarification of themes, and ensured that the results clearly reflected the parents' characterization of their experience of loss. Moreover, the advisor provided expertise with the refinement of the study's themes and subthemes.

Methodological Rigor

In interpretive description, rigor is maintained through consideration and evaluation of four general principles. These general principles include: epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 2008).

Epistemological integrity means that the research questions and interpretation of data sources is consistent with the stated epistemological standpoint (Thorne, 2008). In this study, the research question and interpretation of the data were guided by a critical review of current knowledge on the topic and an understanding of individual responses to loss based on the Theory of Chronic Sorrow. And, in keeping with interpretive description methodology, the researcher approached the study with the knowledge that no one theory can encompass the multiple realities of parents that unexpectedly lose a child in the pediatric ED, parents are the experts of their own experience, and new insights or perspectives are possible on the research topic.

Representative credibility means that the theoretical claims made by the study are consistent with how the phenomenon under study was sampled (Thorne, 2008). Interpretive description aims to identify patterns and themes within experiences of a phenomenon, and then to use that information to change the way that phenomenon is understood (Thorne, 2008). In this study, the sample was specific to parents that had unexpectedly lost a child in the pediatric ED. The patterns and themes identified from their experiences can be used to inform healthcare providers in terms of general knowledge, but will also be able to help guide practice decisions in terms of providing support to parents. There is also potential for this knowledge to inform clinical practice in other loss situations when parallels between the cases are identified.

Analytic logic means the reasoning of the researcher will be made explicit throughout the research process, from study development through data analysis to the discussion of final results (Thorne, 2008). In this study, assumptions of the researcher were made explicit during study development, and personal reflection in the field notes shared with the researcher's advisor, helped to ensure those assumptions and the decision making process remained explicit.

Interpretive authority means ensuring that a researcher's interpretations are trustworthy, and that they reveal a truth that is unbiased by the researcher's previous knowledge or experience (Thorne, 2008). In this study, interviews and field notes were transcribed verbatim in order to ensure the data was reflected in the parents' own words. Second interviews also allowed for emerging themes to be confirmed with participants, thereby ensuring they appropriately captured the parental experience. Discussion with the researcher's advisor throughout data collection and analysis also helped to ensure that themes reflected parents' characterizations of their loss experience.

Ethical Considerations

Every research methodology faces ethical dilemmas, especially when dealing with human participants. Within qualitative research, the ethical dilemmas of informed consent, anonymity and confidentiality, researcher-participant relationships, and risks and benefits of participation in the study must be considered. This section details the ethical issues that were considered.

Ethics Review

An ethics review was performed in order to ensure that the research study was performed in an ethically responsible manner. This review involved many steps, the first of which was to obtain approval for the study from the thesis committee. Ethical approval was then sought from the University of Manitoba Education/Nursing Research Ethics Committee and the Health Sciences Center. Ethical approval from these governing bodies not only ensured the protection of research participants, but it also ensured that the research was conducted in an ethically sound manner. In addition to being the primary researcher in this study, the researcher was also a Registered Nurse, and was bound by the Canadian Nurses Association Code of Ethics and the Privacy Health Information Agreement. These guiding ethical principles helped ensure the protection of research participants and that the research was conducted in an ethical manner.

Informed Consent

The focus of qualitative research is human subjective experiential knowledge, which means the researcher cannot fully predict what will happen during the interview process (Thorne, 2008). This creates difficulties for achieving informed consent, as the researcher can only predict what an interview might entail rather than being able to fully disclose all details of the research process prior to participation. For the purpose of this study, informed consent entailed the researcher ensuring the participants were fully informed about the purpose of the research study, were able to comprehend the information provided, and were capable of making the decision of whether or not to participate. Consent forms were distributed prior to the first interview, and consent was verbally confirmed with participants throughout the study.

Anonymity and Confidentiality

Issues surrounding anonymity and confidentiality were discussed with participants during the informed consent process. Anonymity involves ensuring the participant's identity is not revealed through the data results, which can be difficult to achieve in qualitative research due to the personal in-depth nature of the interview process. Confidentiality involves ensuring the participant's information remains private and protected throughout the research process. In this study, confidentiality was maintained by keeping all audio recorded interviews, transcribed data, and field notes in a locked location or on a password protected computer system. Data sources were only shared with the researcher's advisor for the purpose of data analysis, discussion around emerging themes, and grading of the final thesis project. All participants were assigned number codes for demographic forms, transcribed interviews, and field notes, so that no personal identifiers were attached to the data sources. And consent forms were kept in a locked cabinet separate from all the other participant data, as they were only documents that contained both the participant names and their assigned number codes.

Researcher-Participant Relationships

Research in healthcare can be complicated by the power differential between patients and healthcare providers, and researchers must be aware of the effects this relationship can have on participants and study results. Participants may feel pressured to participate in the study for fear that refusal will affect the healthcare they receive in the future. They may also feel pressured to not discuss negative experiences, as the person conducting the research may be affiliated with an institution that they access for medical care. In this study, researcher participation in the deceased child's medical care was an exclusion criterion for participation in the study. The researcher also informed participants that this study was part of the requirements for attainment of a Master’s Degree in Nursing through the University of Manitoba, and that their personal information would be carefully protected throughout the research process. Participation in the study was voluntary, and the researcher reiterated this to participants so they understood they could choose to withdraw from the study at any time with no risk of negative consequences.

Risks and Benefits

In addition to the risks discussed previously in this section, there was a risk that discussing the experience of unexpectedly losing their child would be distressing for parents. To address this concern, the researcher observed parents for any signs of emotional distress and was prepared to pause or reschedule the interview in order to provide emotional support or to give participants time to decide if they are able to continue. Parents that experienced emotional distress during the interview process were provided with emotional support by the researcher and by support people they had present during their interview. Only one father requested contact information for a personal counselling service that he could access, and that was openly provided by the researcher at the time of his interview. Despite the above-mentioned risks, there were also benefits to parents sharing their experiences of loss. In the literature, parents have identified talking to others about their deceased child as one way they can maintain a connection to their child after death (Arnold & Gemma, 2008). Sharing their experience in order to help other parents through their loss can also be a way to find meaning in the child’s death, and can be part of the healing process for bereaved parents (Bogensperger & Lueger-Schuster, 2014; Meert et al., 2009; Steele et al., 2013). Increasing knowledge of this topic also has the potential to improve the care and support of other families experiencing the unexpected loss of a child in the pediatric ED, both through educating healthcare providers and identifying parents' needs during their time of loss.

Chapter Summary

A qualitative, interpretive description study was done to explore the parental perspective of unexpectedly losing a child in the pediatric ED. Participants were recruited based on inclusion and exclusion criteria, with a final sample of 8 parents. Data was collected through in-depth interviews, demographic questionnaires, and the researcher's field notes. Data analysis occurred through a constant comparative method, and involved coding of all data sources until themes began to emerge from the data. Methodological rigor was ensured through adherence to epistemological integrity, representative credibility, analytic logic, and interpretive authority. Ethical dilemmas were addressed through an ethical review and consideration of informed consent, anonymity and confidentiality, researcher-participant relationship, and the potential risks and benefits of participation in the study. The next chapter will describe the sample of participants and the findings of the research study.

Chapter V: Demographics and Findings

Introduction

The first section of this chapter describes the demographics of the participants and their children, including details of the timeframe since the loss. The second section summarizes findings from this qualitative interpretive description study examining the parental experience of unexpectedly losing a child in the Pediatric Emergency Department. Themes that emerged from the participants' descriptions of their experiences are identified, including direct quotations from participants enabling them to use their own words to describe their experience, coping methods, and the meanings they attribute to their loss.

Description of the Participant Sample

There were eight parents from five families who participated in this study. Four of the five families were from within the city of Winnipeg, with only one family living rurally in a community just outside the perimeter highway. In total, eight interviews were completed, with all but two families choosing to take part in two interviews. One family chose to complete their second interview in written form and one parent did not feel they had any further information to provide in a second interview. Participants ranged in age from 25-56 years. Two interviews were completed by mothers alone, one was a single parent and the other mother chose not to have her husband participate. The rest of the interviews were completed by both parents, all married couples who are still married at the present time. Four of the couples have surviving children, and two are expecting children in the coming year. Time elapsed since the death of their child ranged from 15 months to 8 years. Each family lost one child (n=5, 2 girls and 3 boys) with ages at the time of death ranging from 1 month to 16 years of age. All but one of the deceased children had siblings at the time of their death, although one child did not live with her siblings at the time of her death. For three of the children a clear cause of death was found, but the other two children had no identifiable cause of death.

Findings

This section focuses on the findings of this interpretive description study. Four main themes emerged from parents' interviews, including grief as waves, being the good parent, coping through the wave of grief, and the new normal. The theme of grief as waves was described by parents as an initial shock wave they experienced, leaving them set adrift and struggling to face the reality of their loss. This initial wave was quickly followed by waves rippling through the entire family, leaving relationships strained as family members each dealt with their loss in their own way. In the end, parents had to face the reality that those waves of grief would always be present in their lives to some degree. The theme of being the good parent was described by parents as their struggle to maintain their role as parents and to do what was right for them and their child. Coping through the waves of grief involved finding ways to cope with the changes in their role as parents and learning to adapt their lives to a new, internal relationship with their child. The theme of a "new normal" was how parents described their lives after the death of their child, as the death completely changed their reality. Parents identified a critical shift in their worldview, a fear of subsequent loss, and the balancing act between moving forward with their lives and remembering the child they lost.

Grief as Waves

The analogy of grief as waves was a common theme among parents of this study, as they described how their grief would come and go without warning, or would be triggered to recur by things like anniversaries or birthdays. For those who did not use the analogy of waves, parents still described their grief as cyclical, recurrent, and often intensifying based on the presence of triggers. Most parents had believed their grief would be like a tsunami, a single wave to be survived which would then fade away over time. Few expected recurrent waves, many of which came without warning, that were as strong as the first wave and left them feeling just as raw in their grief as the day their child had died. Over time, some parents learned the warning signs that a wave was coming, and they could brace themselves for the impact. Other times the wave would sneak up on them, being triggered by random events such as seeing a child that looked similar to the child they lost. These random waves were often more difficult to manage because they were unexpected, leaving parents with no time to prepare or put supports in place to help them swim through the waves. One father described how just when he thought he was mastering the waves, he would get a big one that would overwhelm his coping mechanisms:

> "I was noticing that before like I noticed how [the waves] were getting not quite as extreme and then once in a while you'd get a really big wave come in and you wouldn't really be prepared for it…but you're right, the smaller ones did come…it's almost like there's a, trying to dam it and if you were to use the wave analogy, they're crashing instead of everything going all over." (04B, 429-438)

Some parents felt they would always be at the mercy of their waves of grief, and did not believe time would even change those waves. Over time, others found they were able to predict many of the waves, either by learning and overcoming their triggers or by learning the warning signs that a wave was coming. One father described how he learned to predict his waves and so found he was better able to swim through them when they came:

> "it's not going to stop. There's going to be the ups and downs, ups and downs…at the beginning like the waves seemed to be further apart right, and then now you'll get them but they peak, you can peak it faster right, you get back up to where the normal people are again, out of that grieving cycle." (01B, 4073-4079)

Most parents described their waves of grief as changing over time, and these changes were separated into subthemes of the first wave, ripples through the family, and waves are never-ending. Many parents described the first wave as overwhelming and their emotions washed over them with such force that they were unable to control them at all. Parents were left in a state of shock, during which time many had difficulty even processing the reality of their loss. Over time, those waves rippled through the family, affecting each person in unique ways and causing strain on relationships between spouses and surviving children. Many parents found it difficult to relate to one another because they were each grieving in their own way and in their own time. And the central support system of the family unit was impaired, as each member of the family was grieving the loss making it difficult for them to offer support to one another. Eventually, parents came to realize that the waves of grief are never-ending, and that they would have to find ways to incorporate that grief into their lives in order to go on living. For one father, these recurring waves of grief were a reminder to him that he had loved his son very much:

> “somebody had a poem about grief was like crashing of waves and sometimes they were little waves and sometimes they were big waves and I always thought that was very apt analogy…some days you pretty much feel nothing and I remember thinking to myself, wow I’m getting over this really quickly, I, I’m a little surprised you know, did I not care enough about my son and then all of a sudden I got a bunch of grief that just was like harder than any other day and it’s like okay, well yeah there’s the waves.” (04A, 4105-4115)

Some other parents strongly asserted that they were not going to let those waves of grief submerge them. They worked hard to develop coping mechanisms to manage their waves of grief, and over time most found they were able to ride out the waves and keep themselves afloat. These subthemes of the first wave, ripples through the family, and waves are never-ending will be discussed in the following section.

The First Wave

The first wave of grief struck parents when they realized their child had died, and it was described as an overwhelming shock to their system. The loss of a child was not something parents ever expected to face, and was described by parents as going against the natural order of life. Parents expected to watch their children grow up and to celebrate the milestones of life with them. They dreamed of a multitude of firsts, such as first steps, first loves, and first grandchildren. Nowhere in that dream did they imagine saying goodbye to their child or trying to navigate a world without them. As one mother described, "honestly I never thought any of my kids would die, I figured they'd bury me…that's what they're supposed to do" (02B, 2607-2612). She described the loss of her son as "the roughest thing that any mother has got to go through. It's the worst fear that any mother has" (02A, 362-364).

The sudden and unexpected nature of their child's death also meant parents were completely unprepared for the first wave, leaving them floundering in a sea of strangers with a life that had been torn to pieces. The loss of their child affected every aspect of their life, from their core family structure to their own personal identity. For some, the initial reaction was one of shock and a complete inability to face the world or the reality of their loss. The first few hours were described as a blur and many identified waking the next morning believing their child was still alive. One father described the morning after his child's death as a "perpetual state of shock…it's like surreal, you can't even, you can't even fully absorb what's going on" (03A, 2612-2614). He felt he had to function, despite this state of shock, because there were decisions to be made and notifications to be done. His spouse, on the other hand, described her experience quite differently, "I don't know how you did it because all I wanted to do is put a sheet over my head and just never get up" (03A, 2621-2622). This inability to face the world was echoed by another mother as well, as she related “I didn’t want to leave the house…lasted for about a year” (02A, 586-588). She also described waking the morning after her son’s death with the impression that he was not dead, but simply away at his father’s house. It was not until the funeral that she truly began to face the fact that he was gone.

> “In the very beginning, I didn’t have anything…I didn’t cry, I didn’t have emotion, I had nothing. It was like he wasn’t even dead. I could eat, I could sleep, do all my regular stuff…pretty much in my head he was just at his dad’s and I would go pick him up after. Once the funeral hit, I think that night…that’s when, like I said, it kind of went all downhill…like the grieving and everything.” (02A, 603-610).

Another mother described a similar experience the morning after her child’s death, when she woke up and realized the whole experience had not been a dream.

> “you wake up and it hits you again right, you’d forgotten about it while you were sleeping and you wake up and then the second it comes into your mind you just feel sick, it’s like that didn’t really happen.” (06, 1079-1081)

She described a similar state of shock in the initial days after her daughter’s death, and felt unable to face anyone, rather relying on her husband to make all the necessary decisions.

> “the whole thing afterwards is just a blur right, suddenly family’s in town, you’re having a funeral, I just remember being in shock, like the whole idea of where to bury a baby, I just could not even speak, like my husband handled all of that, I went into a shock zone…I couldn’t even answer, I was just like I don’t care, I cannot think.” (06, 777-783).

Other parents recalled a desire to cling to what was “normal”, so they tried to continue to fulfill their role as parents by taking on the tasks of notifying family and making funeral arrangements themselves. Despite being in the midst of their own grief, they needed to fulfill these tasks for their child, even if sometimes they wondered how they would manage it all.

> “you’re in this sort of perpetual state of shock right, it’s like surreal, you can’t even, you can’t even fully absorb what’s going on. I mean can you, I mean I can’t even believe I had the wherewithal to do it but like our son dies, pronounced at 8 p.m. and the next morning I’m already, the next morning literally 12 hours later I’m on the phone you know making funeral arrangements, contacting the priest, you know doing all these

> things that you know you can’t even imagine yourself even doing, I don’t even know how I was able to do it.” (03A, 2612-2619)

Ripples through the Family

Though parents seemed to be the hardest hit by the first wave, it did not take long for the waves of grief to ripple through the entire family. And though everyone experienced those ripples of grief, they affected each person and each family in unique ways. Even between spouses who had experienced the loss of their child, many described very different grief experiences from their spouse. While some experienced physical symptoms, others were very emotional, some coped by focusing on tasks or work, while others hid from the world. One mother recalled how her grief affected her physical health, describing the loss of her daughter as a shock to her system that she continued to struggle to recover from.

> “losing her was like losing a part of me. And I’ll tell you something, I believe that my health went downhill because of that. I think it was such a shock on my system that when I actually came out of shock that everything fell apart.” (01A, 180-183).

She went on to describe how her grief was “darker” than her spouse’s, so she chose to focus on individual counselling so her grief would not negatively impact his ability to cope with his own.

> “my dark place is a lot darker than his dark place…I talk to a psychologist because I don’t want to bring him to my dark place...when I started talking to my psychologist I realized that I can’t tell him what I tell my psychologist…it’s not ‘cause I don’t trust him, it’s because I don’t want him going down into that deep hole.” (01B, 1453-1469)

Most parents were able to understand that different people grieve differently, even within a single family unit. But for some, the differences in grieving were extreme and led to a lot of hurt feelings and animosity between spouses. One mother recalled how she had trouble relating to her spouse because he was grieving so differently, and how much it upset her because he did not seem to share her grief over the loss of their daughter.

> "I don't think he was fine but he appeared to be fine right afterwards…it just propelled him into action mode. I've got to do something, do something, do something. I can't fix it so I'm going to do, do, do…I found it very hard to relate to." (06, 2705-2717)

> "Maybe we're grieving differently…I will try to give him the benefit of the doubt then that he is upset about this and this is just how he's expressing it. I said but you know from my point of view, from all what he said previously, I almost feel like he's happy." (06, 3485-3491)

She struggled to make sense of how her spouse was grieving, and tried desperately to understand his viewpoint so they could connect and support one another through their loss. Unfortunately, their relationship had already been undermined during her pregnancy as her spouse had not wanted to have another child. She associated his lack of desire to have another child with his lack of overt grieving over the loss of their daughter, as if her death meant he had gotten his wish to not expand their family.

> "I don't know how he dealt with her dying because it seemed like he didn't want to have her pretty big time, so maybe it was easier for him, I don't know. I mean you think you'd feel pretty bad, I would think you'd feel, he never said this, but I would think you'd feel pretty darn guilty…considering he went around the whole time suggesting he never wanted to have her." (06, p.66)

One mother described how her coping mechanisms differed from her spouse, but she attributed much of that to her cultural background and their propensity to being emotional and open about death. She found she needed to give herself time to grieve rather than fighting back the emotional response, and she found that allowing for that emotional release made her better able to be present and supportive for her surviving daughter.

> "So if I need to cry I cry. And I immerse myself in it because I feel like I let it go during that time and I don't hold it in…and I can be a better parent afterwards I give myself that time 'cause I, I understand myself well enough to know I need that time to grieve for him so that I can be a better parent for 'G' ." (04B, 350-357)

Several parents attributed these differences in grieving and coping mechanisms to differences in societal expectations for each gender. Fathers identified feeling like it was their responsibility as males to stay focused and composed in order to complete tasks such as planning the funeral or providing support to the rest of the family. One mother described her spouse taking charge of the situation as part of his coping mechanism, "he did everything, he did all the arrangements which was good because I think that was his way of coping with things was to be in charge of things" (06, 790-792). Two of the fathers felt it was their responsibility to hold things together for the rest of their family, and both identified how this may have actually helped them to cope with their grief.

> "you're in this survival mode I guess you can kind of call it that, is how do you basically, and you got to keep it together because especially me as kind of a you know I guess the male of the family if you want to put it that way, the husband, I mean trying to just keep it all together for my other son, but also for everybody else just so that it's all kind of, doesn't look like we're falling apart." (03A, 2654-2659)
>
> "I think sometimes for me it felt more like my biggest source of strength was the fact that I had to be strong…I kind of had to do a lot more of the logistic stuff generally and I had to worry about the other stuff, the mundane things that happen, whether you're grieving or not." (04A, 1756-1765)

Some parents acknowledged that respecting differences in grieving and allowing their spouse to cope in their own way was crucial to their relationship surviving the grieving process. They understood that there was no right way to grieve and no exact timeline for grieving. Judging others for not grieving the "right way" only led to hurt feelings and damaged relationships, and this further deteriorated the family's support system.

> "I think it's respecting each other and where you are in the process…not judging each other…'cause if you don't respect each other for where you are and don't, and you start judging each other…you're finished." (01B, 1357-1365)
>
> "he's going through grief too…he may be processing it differently than you…it was good that she said that, because it was like, okay I will try to give him a break, because from my point of view I didn't feel like I was being supported…it helped, it helped to soften when I thought he was doing bizarre things." (06, 1010-1022)

Regardless of how any one member of the family was affected by the waves of grief, the family unit was disrupted as a whole due to the loss of one of their members. This change in structure left an imbalance within the family and compromised their ability to support one another because they were all grieving and struggling with the loss. Their most essential source of support, their family, was not necessarily available or intact at a time when they needed each other the most.

> "Everybody goes through their grief in their own way and I think because we're all grieving related to the same situation, people tend to withdraw into themselves a little bit and each person goes and does their own thing when they're feeling sad…and I think that it's really difficult for us to draw on each other's support as a family." (03A, 317-325)

Waves are Never-Ending

Parents understood that the waves of grief would be intense in the beginning, and would affect every aspect of their lives. However, most parents believed that over time the waves would change and become less intense and intrusive in their daily lives. But when time passed and things did not change it wore down their hope and seemed to refresh their feelings of loss.

> "you're thinking things are going to get better you know, you're looking forward to feeling better…But when you get there you're not…Which tends to just multiply all your feelings you know. And it takes you for a ride like you wouldn't believe...the pain seems deeper, everything, every time you turn around you see a child, you see a crowd of children, you're looking for her face you know." (01B, 895-911)

They came to realize that their grief would never really end, but rather would always be a part of their lives in some way. One couple described their grief as haunting them, "it was…and still…even now it's tough…it haunts us…it still haunts us, and it always will" (01A, 319-320). The same was true for another couple that described their grief as a constant pain in their hearts, "we'll always have that terrible pain in our hearts, always" (03A, 2737).

One couple clearly identified that they did not think their grief was going to improve, regardless of how much time passed. The father described his grief years later as the same as it was the day his son died, “there’s certainly not some turning point or anything like that, I think it’s just always there. I don’t think there’s any less, it’s no less painful now than it was then” (03A, 2809-2810). The mother, on the other hand, described her grief as getting worse as time passed, “the best analogy I can think of in relation to missing him is adding one additional stone each day to a backpack that is always carried” (03C, 285-286).

Most parents, although they acknowledged grief would always be a part of their lives, identified ways in which their grief had changed over time. They did not expect their grief to come to an end, but many described changes in intensity and frequency over time. For some parents, these changes began when they accepted that their grief was never going to end. One mother recalled the point when she acknowledged that she would always grieve the loss of her son, but also made a conscious choice not to dwell on her loss.

> “I’m always going to miss him, I’m always going to love him and I’ll always remember him, but I’m not going to dwell on it…people who are just like, I miss you, like they’re doing it every day and they’re just like, I can’t live without you and blah, blah, honestly you’re killing yourself, you need to tell yourself that he’s dead… And that he’s gone and that he’s not coming back…but it’s not like he’s not there with you, you just got to think of it in a different way…but if you keep thinking he’s alive that’s where you’re killing yourself and that’s when you’re just, you’re going up the hill but you’re just literally throwing yourself back down.” (02B, 1675-1705)

She acknowledged that she still had good days and bad days, a fact that was echoed by most other parents as well. On her good days she celebrated her son’s life and appreciated all the positive things that she still had in her life, like the baby that she was expecting in the near future. On her bad days, she allowed herself to feel sad over the loss of her son but did not let that sadness stop her from moving forward with her life.

> "I have my days where it's like I'm down the hill kind of thing you know like why did God take him, there's so many other parents out there that are worse that their children should have been you know, but it's just shit happens…I can't dwell on it, I can't fix it, so what's the point of being sad about it…just slowly start to move on, do what you need to do to help you move on." (02B, 3845-3858)

Accepting that grief would always be a part of their lives was not easy for parents. They struggled to find a way to incorporate that grief into their lives without letting it control their emotions or their relationships with others. One mother described how she struggled to face things that triggered her grief, such as being around children the same age as her son or taking part in activities that her son had loved to do.

> "find your triggers, know your triggers, figure them out. For me…if something triggers I don't like to…I don't like to get rid of the trigger, I like to own it. So instead of having that trigger make me cry, I'm going to keep going to that trigger until I stop crying and that trigger just becomes me instead. And then I work with it…or else you just end up with depression and end up going back down the hill and then you end up back to square one." (02A, 640-647)

Over time, most parents noted that their emotions became less intense, they had fewer triggers, and they felt more able to prepare for and control their emotions. One mother described how her feelings had changed over time, and how she felt better able to manage her grief symptoms as time passed.

> "when her birthday would come around, like the first couple of years, I was reliving the whole thing… the first couple of years to get through that was really horrible. The third year was like I know it's coming up and I can deal with this. The fourth year was like, not that I forgot, but it wasn't a big issue." (06, 2375-2387)

Though parents understood the never-ending nature of the waves of grief, one couple did identify a distinct turning point in their grief. Each parent recalled having a moment when they fully accepted that their daughter was gone, and they both described this as a point when the burden of their grief seemed to lighten. They knew that there would always be an undercurrent of grief in their lives, but that point of acceptance reminded them that they could go on living with their grief rather than stop living because of it.

> "It wasn't like a great big event, you know like an anniversary date or anything like that, it was more just you know what, I think I'm ready…your heart tells you when you're ready…this summer just you know what, yeah I can live, I've accepted now that she's gone, and she's never coming back, but we'll always have memories." (01B, 1311-1327)
>
> "coming back from [a trip] and I just started to cry…I realized my baby's never coming home. And I came to terms with that you know and I thought I still have other ones that still need me and its time that I give them some normalcy, because they haven't had normal since "G" passed away." (01B, 1411-1418)

While many parents longed for a time when their grief would not be so raw, one father described why he never wanted his grief to go away completely. To him, the intensity of his grief signified how important his son had been to him. He understood that his grief changed over time and became easier for him to manage, but he wanted it to remain as a constant reminder that his son had existed.

> "it's not as intense but it's there… it comes in waves…it's certainly changed, I mean like I said you can focus a little more on the happy parts and they're not quite as hard…I don't think I'd want my grief to go away completely…I feel like it needs to, it's like keeping a part of his memory alive…it should be painful…simply because he meant so much and if it wasn't painful then…feel like he never existed." (04A, 2801-2834)

Being the Good Parent

The concept of being the good parent has previously been identified in the literature, with Woodgate (2006) defining the good parent as "knowing that, as a parent, they had done everything possible to make their child live a life that was as happy, and with as little pain or suffering as was possible" (p.78). Every parent in this study described in their own words how important it was to be the good parent and exactly what that meant to them. The duties of being a good parent changed after the death of their child, and parents identified subthemes of before the death and after the death to describe these changes. Before the death of their child, parents fondly recalled memories of being together as a family and the close-knit relationship they had with their child. On the day their child was dying, most parents struggled to fulfill their role as the good parent, either due to a lack of presence or a lack of understanding of the severity of the situation. They tried to focus on doing right by their child, by ensuring their child did not suffer and by advocating for their own presence as parents to comfort and support their child in their last moments. Few parents understood before the time of death that they could possibly lose their child that day, and the death came as a shock and an abrupt transition in their role as the good parent. Several parents also had to struggle with the guilt of others insinuating that they had not been good parents, or had been involved in their child's death in some way. After death, the focus of being a good parent turned to ensuring their child would never be forgotten. For themselves, many parents clung to physical mementos, as these triggered positive memories of their child and allowed them to somewhat maintain that physical relationship. For others to remember, parents talked about their child and reminisced about happy times they had together. Many also created new traditions within the family to encourage remembering and to reaffirm their child's continued role in their lives.

The Day their Child Died: Doing Right by their Child

During the period when their child was dying, parents focused on being the good parent by doing right by their child. For some, this involved being so "in tuned" with their child that they recalled having a premonition that something bad was going to happen that day. For others, it involved being physically present with their child in the ED, to comfort them, advocate for them, and ensure their child knew they were loved. Parents felt it was their duty to ensure their child was not alone, that they did not suffer, and that they had the love and support of their parents for as long as possible.

Each parent in this study described their role as the good parent, recalling happy memories with their children and identifying a deep, binding love that tied the family together. The depth of this love and connection led some parents to question how they did not know something was wrong the day their child died. One mother described her feelings of guilt over not realizing how sick her son truly was, “it was my fault. I’m a mother…I should’ve known” (02A, 1495-1496). Parents felt that part of their role as the good parent was to protect their child and to know when something was wrong, even though the nature of unexpected death largely excluded this possibility.

Some parents did identify their close-knit relationship with their child as the reason why they felt something bad was going to happen the day their child died. One mother clearly recalled how she took extra care to tell her son she loved him because she had a bad feeling about that day, even going to the extent of trying to get him to stay home with her instead of going out.

> “I remember having a kind of a funny feeling that day, I said “E” you sure you want to go to your practice today. Why don’t you stay home with mom and, and just skip it, you’ve had such a busy day so far, and, and I don’t know why I felt like that… And I remember standing in front of the fridge with him and giving him a great big bear hug and telling him how much I loved him… we got out of the car and I told him I loved him and I, I wanted to give him a hug and I thought, you know he’s in such a hurry, he’s almost late already…I didn’t give him that hug and I thought I really should and I didn’t…that was the last time I ever saw my child alive.” (03A, 501-546).

Once parents entered the ED with their child, part of maintaining their role as the good parent involved the struggle to be physically present. Parents wanted to be there for their child, to comfort them, hold them, let them know they were loved, and let them know they were not alone. Some parents took comfort in knowing they had given that extra hug, said “I love you”, or were present at the time of their child’s death. For those who were not present when their child died, the struggle to maintain their role as the good parent was just as difficult. One mother recalled how she had to argue with the healthcare team in order to be present with her daughter in the resuscitation room.

> "We walked in, um, the nurse said you can't come in here. And I said oh yes I can. I know what I can and can't do, and I'm not leaving. And my daughter and I went in. We stayed back. We let them do their work, you know, but in here (points to her heart) I knew what was happening." (01A, 88-92)

Despite wanting to be present to comfort and support their children, some parents later came to regret this decision. Parents described being traumatized by watching the attempted resuscitation of their child, especially when they realized their child was already gone and so was beyond comforting. One mother described how she got in the ambulance with her daughter because she thought she was still alive, and so wanted to be present to comfort her and ensure she was not alone or frightened. Upon getting into the ambulance, she realized her daughter was already gone, and the ride to the hospital became a nightmare that has haunted her ever since.

> "Even me with all my training and all my psychology and everything, I suffer from post-traumatic because of that. And I've seen a lot of ugly things…but it's different when it's your own. It is so much different when it's your own, you know. It bothers you, it has to bother you as a [professional], but as a parent it just takes your soul away. It chews up every bit of anything, you know your faith, it chews up your beliefs, it chews up your heart." (01B, 1486-1494)

Another mother described similar feelings of distress over watching the healthcare team attempt to resuscitate her son. She knew before he ever got into the ambulance that he was already dead, so the resuscitation seemed to be a pointless violation of her son's body. She felt unable to be the good parent because she could not protect her son from that trauma, and did not feel like she had the power to tell them to stop. She stood in the resuscitation room alone and watched them "break" his body in what she knew was a futile attempt to save him.

> "I think he was dead pretty much before he got into the…like before he even left the house. So I think they were just trying for my sake. But I feel like they should've stopped a long time ago because I was in there by myself, and to watch what they were doing to my son was the worst fucking thing I ever had to go through. They broke him, and I heard his chest break and I saw his body flip…You're hurting my child more, just let him go, he's already gone." (02A, 287-295)

Some parents felt being the good parent meant they should not be present in the resuscitation room because they did not want to risk their grief reaction distracting the healthcare team from providing their child with the best care possible. As one father described, "I wouldn't want to be in the resuscitation room, I would be a distraction" (04A, 851-852). This was not an easy decision for parents, as they wanted to be present with their child to offer comfort and support, but they felt they needed to put their child's needs before their own. One couple seemed to feel their presence would have been an intrusion in the resuscitation room, and they did not want to risk compromising their son's care to satisfy their need to be present.

> "I would have liked to have held his hand, if, if there was room and, and that would not interfere with care…they don't need the distraction from the parents…it could have been potentially distracting to them to have grieving parents there." (03A, 1232-1248).

One of the most difficult things that parents had to face was the fact that someone else got to put an arbitrary end-point on their time as the good parent. For some parents this end-point came when other professionals, such as the police or the medical examiner, arrived to take "possession" of their child. For others, it occurred when they were taken away for police interviews and, on arriving back at the ED, were told they could no longer see their child because they had already been taken away to the morgue. Parents clearly identified that there would never be enough time with their child, but they wanted as much time as possible because these would be their last moments with them.

> "I remember when they took her away I was going like, are we going to see her again, and they're like, oh we're just taking her to do some handprints and some whatever, so it wasn't really like enough time, I mean you couldn't do closure in that amount of time

> anyways, but I remember feeling this panicked feeling of them taking her away and I would never see her again." (06, 576-581).

One couple recalled how the staff in the ED had told them they could stay with their son until the police arrived, and how thankful they were that the police did not arrive quickly so that they got to spend more time with him. When the police arrived, however, their son was taken from them as if he was evidence, an event that was terribly distressing to the parents.

> "When they were done him and they said we could stay until the police arrived, we wouldn't be allowed to touch him…the hospital staff let us…they said when the police arrived we wouldn't be able to…and the detectives came in…and said no you shouldn't have touched him and I was like, oh whoops well I touched his hair and his hand…it was a very hard stop to it I guess, does that make any sense, like it was okay the police are here now you, now your child is not yours its, he's evidence." (04A, 884-955).

Many families experienced feelings of guilt over their child's death, as they felt they had failed at being the good parent. This guilt, however, often stemmed from the treatment they received from the police officers involved in their child's case. Although police interviews are standard procedure in unexpected pediatric deaths, parents consistently described these interviews as being "interrogated" in order to uncover their involvement in their child's death. This insinuation that they had failed in their role as the good parent often left parents wracked with guilt, and their minds spinning with "what ifs" that often no one could answer. One mother described how she and her husband were separated for their interviews, as if the police were comparing their stories for consistency: "they took us immediately into two separate rooms and they had police officers interrogate us" (06, 388-390). One couple was even taken to a police station downtown so that their interviews could be recorded. Parents recalled how distressing it was to walk into that building because they associated it with criminals, and so felt as if they were guilty in some way for their child's death.

> "it was hard walking into the Public Safety Building 'cause you see on the door all the things that are in there that you know it's, 'cause they tell you what they do and you

> know child molestation and that sort of thing, and that's the first thing you see when you're going in there to get interviewed…I know I didn't do anything but at the same time it was still a little hard to see when you're kind of carted in." (04A, 638-647)

One mother in particular was questioned by the police about a life insurance policy that her son's biological father had for him. She was questioned about whether or not she was receiving any of the life insurance money, and she vividly recalled how upset she was over the insinuation that she could have killed her child for money.

> "they figured I was getting money for his death and they wanted to know how much I was getting…I told him off and told him he could keep his money, you give me my son. There's no one in their right mind that loves that child that much wants the fucking money…they all want their child to be alive and happy again." (02B, 1039-1047)

As distressing as it was for parents to believe others felt they had failed in their role of being the good parent, most parents actually identified the most distressing part of the police interviews as being the time they lost with their child. For those interviewed in hospital, there was less lost time but that did not make the lost time any less precious to parents. As one father explained, "when it was the very end I would have loved to say goodbye to her and not have to deal with those kinds of things [police interviews] right away" (01A, 311-312). For those interviewed out of hospital, the time lost was far greater and parents did not understand that they would not be able to see their child again after the interview.

> "the only part where I felt short-changed was like the time spent with 'D' in the resuscitation room was fine, I just thought after the interrogation, the interviews and it was, it was interrogation right, but after the interviews I thought I would be able to come back to see him one last time, but at that point he became evidence." (04A, 3704-3708)

Police presence also meant parents were not allowed to touch their children, though few parents recall this protocol being explained to them. Instead, parents felt they were being denied contact with their child because of their potential responsibility for their child's death. This lack of contact prevented them from fulfilling their role as the good parent, saying a last goodbye and left some parents with long-lasting regrets. One couple understood the police protocols around child death because of their own professional backgrounds, but they still recalled their regret over not being able to have a final goodbye, “I would have loved to hold my baby one last time. And I never got the chance…I understand there are certain protocols that do not allow you to do that…to say goodbye means so much” (01A, 189-201).

One mother recalled how her right to be the good parent was taken away when she was denied any physical contact with her son in the ED, even by the healthcare team. This not only took away her opportunity for a final goodbye, but essentially cut off her rights as a parent. She described her distress over not being allowed to touch her son one last time, “at the end if I want to pick up my little boy and give him a kiss I’m going to fucking do it. But they told me I couldn’t touch him…and it was so rough. Not to say goodbye to your son” (02A, 355-358). The reason for this lack of contact was never explained to her by the healthcare team or the police, making the situation even more distressing for her because she did not understand why she was not allowed to touch her son.

Missing out on those final moments was not the only regret that parents had, though many regrets centered on the lack of time they had due to the unexpected nature of their child’s death. Several parents identified ways they would have fulfilled their role as the good parent if they would have known they were going to lose their child, like spending more time with them or saying that final “I love you”. It was comforting for parents to recall positive final conversations, knowing that their child knew they were loved and cherished. One mother fondly described her last conversation with her son, acknowledging that she had the best goodbye she could have considering it was a goodbye.

> "I put my hand on him and I said 'I love you' and he said 'I love you too'. That's the last thing we ever said to each other. So, I mean, I got the best goodbye that I ever could've got. It's just not the one I really wanted…he was supposed to say goodbye to me and I was supposed to be an old fart and ready to go." (02A, 545-550)

For one couple, not being with their daughter on the day she died was a huge source of regret. Not only did they miss out on a chance to say a last goodbye, but they had to come to terms with the fact that their daughter died alone. They took comfort in knowing she was happy and knew she was loved, but that did not take away the ache to have that extra time with her.

> "I would have gotten to say goodbye…Or been with her when she took her last breath…She wouldn't have died alone…That's what I struggle with everyday…when my dad was dying I made sure I was at the hospital day and night with him because I didn't want him to die alone and I didn't want him to take his last breath alone. Less than a month later my little one dies and she's alone…it would mean so much just to be able to have said goodbye or held her hand while she was warm." (01B, 1867-1957)

After the Death: Keeping the Memories Alive

After the death of their child, the priorities of being the good parent shifted from doing right by their child to ensuring their child would never be forgotten. For many, this initially involved a strong reliance on physical mementos, as those items helped them to maintain their parent-child bond and acted as triggers for their memories. To help others remember, parents talked about their child, sharing the positive impact that their child had on their lives and the lives of those around them. These episodes of reminiscing not only honored their child's life, but also served to strengthen their role as the good parent and help them work through their grief. Over time, many parents focused on developing their own unique traditions that would honor their child's memory and reaffirm their role within the family. This encouraged others to remember their child, but also helped parents to re-define their role as the good parent.

After death, parents still wanted and needed to continue their role as the good parent. They could no longer have the external, physical relationship that they used to have, so they had to find ways to create a new internal relationship. In this way, they could keep the memory of their child alive, maintain their role within the family, and continue their role as the good parent. Many parents found this to be a difficult process and recalled how tightly they held onto physical reminders of their child. As one parent described, “at the beginning, do not dare take anything away from a grieving parent because they need that” (01B, 3277-3278). Many parents held onto items that their child had cherished, such as favorite items of clothing or stuffed animals, as these items were not only strong reminders of their child but were often involved in many family memories. One mother described how she kept her son’s favorite teddy bear as a constant reminder of him, “I keep his favorite teddy there in our room sitting on the, there’s a chair by the, in our bedroom” (03A, 4342-4344). She dressed the bear in his favorite sweater and has always kept it close to her, even years after his death.

For one couple, it was not about picking out a favorite item to remember their child by; rather it was not removing items from the house that acknowledged he had lived there. They found it comforting to have his things around them, from keeping his bedroom intact to leaving his highchair in the dining room. This created constant reminders of him around their home, but they were reminders of his life rather than having a memorial that would have only reminded them of his death.

> “his name’s still on the answering machine. His pictures are everywhere if you look closely…we even have diapers still in the washroom…we cleared up a few things but generally speaking his footprints still there…I used to wonder if it was people who couldn’t accept the fact that they lost someone…but we’ve kind of lived it, have experienced it, it’s more, its fully accepting the loss you’ve had but its more about the memories, the acknowledgement of my child was alive, he existed...he lived. And kind of a reminder when everyone else, when everything else just sort of moves on, and you can still see those things and be reminded and remember.” (04A, 2457-2477)

Though all parents kept some of their child's belongings, there seemed to be a balance between keeping items to maintain that connection and getting rid of some things in order to move forward. For some, having too many of their child's belongings around only intensified the grief because there was nowhere they could turn without being reminded of their loss.

> "it was easier not having his bed around…I found myself always in it. Um…some stuff I find easier not having…and some stuff I find I just…I can't let go. Like his puppy…I could never let that go…I carried that (pointing to the puppy in his shrine) around I think for like six months…wherever I went I carried it…I didn't care what people thought." (02A, 1105-1117)

The reliance on physical items did seem to lessen over time as parents were able to shift to a more internal relationship with their child. Often this meant parents were ready to go through their child's belongings and give them away to others, though a few special items were always kept. One couple described how they were forced to end their reliance on physical items when most of their child's belongings were accidentally destroyed. But rather than seeing this as a tragedy, they chose to believe it was their daughter telling them to move on with their lives.

> "we needed physical things…but I realize now that her stuff is gone that yeah, you know, it's, it's okay…he always said she packed it away for us…she packed it away for us so we didn't have to take care of all of that, and give it away." (01B, 3063-3103)

Another way that parents continued their role as the good parent was to talk about their child to others and to share all the wonderful memories they had of them. This allowed them to remember their child, celebrate their life, and to remind others that their child had existed and was an important part of their life. It also gave them an outlet for coping with their grief, as talking about their child inevitably involved talking about their loss as well. One father described talking to others about his daughter as a "need" in the beginning, as he wanted to ensure she would not be forgotten.

> "you still want to talk about her you know. Like I still want to talk about her but at the beginning I thought it was a need, a necessity to heal and just let everybody know who she was…and that she was gone but not gone in my eyes." (01B, 946-952)

His spouse identified this need to talk about her as part of his coping mechanism, "he needed to just keep talking about her because if he didn't you know she wasn't gone…he didn't want her forgotten…it was just his way of coping" (01B, 960-966). It was important to parents to be able to talk about their child, and even more important to know that they would not be forgotten. Though most parents had family and friends they could openly talk to, some struggled with talking about their child in more public situations. Discussing the death of a child made people uncomfortable at the very least, but it also sometimes brought up questions that parents did not necessarily want to answer.

> "one of the hardest things I run into is when you meet somebody and they ask you about your children and you always have to make the decision on whether you're going to deny that 'D' ever existed or not." (04B, 1409-1411)
>
> "you're in a spot where you're either, the child that brought you so much joy is making everyone really uncomfortable, or you deny that the child that gave you so much joy ever existed…you have to try and size somebody up real quick and to figure out what version you're going to give them…basically drop the my child died bomb on them. So you just kind of glaze over it." (04B, 1422-1436)

Some parents faced this same struggle within their own family, as talking about their child either made other family members upset or they did not want to talk about them at all. One mother recalled how she tried to talk to her daughters about their sister's death, "even now if I talk about 'C' they both maintain that they don't remember her" (06, 1475-1476). After a while she stopped trying to have those conversations and just accepted that she could not talk to them about it. Another couple faced similar struggles at family gatherings when people would avoid even mentioning their son's name, "people at important occasions don't even mention that he's not there, it's just like he was never there and that makes it harder" (03A, 2851-2852). Parents found these situations very distressing, as being unable to talk about their child completely undermined their role as the good parent.

Parents in this study reported that there were many other parents in local support groups that described similar struggles with finding people they could talk to about their child and their grief. One father described how this denial by family made the loss feel more permanent, and how his greatest fear was that his child's very existence would be denied by others and he would be powerless to prevent it.

> "some people would, their husbands would not admit that, they would never mention the name of their child again, the siblings would not even acknowledge that that child existed…that would be terrifying for me…that makes death even more, I don't know if I'd say more permanent, but it's certainly more, a…greatest fear." (04A, 4125-4141)

Over time parents came up with their own unique traditions to maintain their role as the good parent, and to honor their child and their role within the family. For most, this involved celebrating their child's birthday or the anniversary of their death. As one mother described, "we celebrate the day he died. We get together…we kind of have a…day for him on that day" (02A, 633-637). Some families started new traditions that reinforced their child's continued role within the family. These traditions not only ensured their child would not be forgotten, but also created new and positive memories to hold onto rather than only remembering the sadness.

> "We say goodnight to him every night with 'G'. We get her to…start our little mantra and, and every night we say goodnight 'D', I love you, I miss you very very much and blow kisses, even in my mind I imagine those kisses turn into bubbles and he runs around squealing and clapping at them." (04A, 2625-2631)

Some traditions were specifically designed to help siblings remember, and to help them focus on positive memories rather than the traumatic memory of the death. For parents that had more children after the death of their child, more creative solutions had to be devised because these children had no memories of their sibling at all. One mother described her plan to use family photos to establish that connection between her son and the child she was expecting, "there's little things I want to do, like when I, I want to get maternity photos and have him shadowed in, you know, touching the belly" (02B, 1833-1835). Another couple planned for their surviving daughter to tell stories of their son to the new baby, thereby reinforcing her connection to him and helping the new baby to establish a connection as well.

> "I had some ideas of just having 'G' tell stories…and of course going through pictures as we normally would…we have videos specifically for 'D' so we have that too…I had every intention of having this child know that there was another one, we did have a son." (04B, 1022-1034)

Most parents were able to find ways to maintain their role as the good parent, whether they did so individually or as a family. Encouraging their family to do the same was sometimes far more difficult though, as not everyone felt the need to maintain that kind of connection. Not having family support in these situations compromised parents' ability to maintain their role as the good parent, and left them feeling alone and unsupported in their grief. One mother described her frustration over her family refusing to celebrate her daughter's birthday. She tried to encourage them to maintain that connection, but they seemed to have no interest in it and so eventually she gave up.

> "for the first couple of years, like we would say oh its 'C's' birthday, we should have some cupcakes or whatever, and I would talk to the girls about you know you need to remember 'C' blah, blah, blah. But I just didn't feel like anybody was into it, except for me…No one seemed to want to do this and I thought you know what, why am I dragging us through the mud. Like the girls don't have a connection to this obviously, for whatever reason and my husband doesn't seem to be big about wanting to." (06, 2385-2407)

For many parents, part of maintaining their role as the good parent was ensuring their child would never be forgotten. They needed their child to be remembered, both by themselves and others. Parents could not comprehend how someone so important, that had brought so much joy to their lives, could possibly be forgotten and yet it happened. So parents went to great lengths to ensure their child would be remembered, not for their death but for the positive impact their life had on others. One couple described how they initially feared their daughter would be forgotten, but over time realized that they were the only ones that really needed to remember her.

> "important to know that she's not forgotten…That's why we started her fund… we wanted to make sure that she'll never be forgotten, that's her legacy, you know she loved the arts and she loved theatre 'cause she took the acting classes and dance…and that's her legacy." (01B, 1109-1123)

> "like I was afraid but I've realized so many people still remember her, but also too, I don't, it doesn't make a big difference to me anymore if they forget 'cause I won't forget…She'll always live on…I don't need to have other people remember her, it's nice, but as long as I don't forget, that's all that counts." (01B, 2980-2990)

One father admitted that he never considered the possibility of forgetting his son in the beginning, but that over time little things had made him fear that happening. He had spent time dismantling his son's room in order to prepare for a new baby on the way, and the thought of letting go of his son's belongings made him feel like he was losing his son all over again. Balancing maintaining his connection to his son with making room for the new baby was not an easy task for him or his spouse.

> "we're having a hard time letting go right of his room, of the things that we created in there, 'cause that nursery was like, we put a lot of effort into it and we thought a lot about him and then and creating and designing it…but now it's hard to let go of small things, like the hot air balloons that I made for his room…you want to keep some of it 'cause you don't want to lose the memories." (04B, 859-869)

The fear of forgetting was intense for him, and he clung to his grief because the pain reminded him that his son had existed. This idea was echoed by other parents as well, as if the degree of pain they felt over their loss symbolized the degree to which they had loved their child. This meant lack of pain suggested their child was not important, and that they had not been the good parent or had not loved them enough.

> “the fear of forgetting is huge, it’s always been big for me. And I think that sometimes overlaps with the fear of healing because what better way to be reminded of your child than this horrible vacant hole in your life. So I think there is a, a real distinction between healing and, and forgetting and that there’s somehow, you can’t have one without the other, but it’s, you can, it’s just not always, when you’re in the weeds it’s not always easy to see…something happens where something feels like its pushing in on that, that hole a little too much you kind of, I find I, I, I jump on my grief like it’s a life preserver and, and hang on to it because I’m afraid of…forgetting.” (04B, 3112-3128)

In his second interview, he disclosed that his memory of his son had become hazy. This caused him intense distress because he felt this was the first stage of forgetting his son. Several parents identified their memories changing over time, though this often involved a shift to remembering the positive moments and forgetting the negative ones. In this case, the father worried that time was fading his memories to where the possibility of forgetting his son was becoming real.

> “For me what’s been kind of alarming lately is I don’t remember specifics anymore. My vision has, my memory has blurred. I remember doing things but I don’t remember the moments as much and that’s only been kind of in the last little while… the feelings still there but sometimes the memory doesn’t seem to be so that’s been pretty upsetting… it could be time, but I don’t, like I said its, it’s tough because that’s all I have.” (04B, 252-282)

Coping through the Waves of Grief

Maintaining their role as the good parent while living through the waves of grief was not an easy task, and parents described a multitude of coping mechanisms that they employed to accomplish that task. Some parents drew strength from their faith, believing that they would one day be reunited with their children and so their role as parents would continue. Some searched for more concrete answers and an understanding of why their child died, allowing them to not only protect their surviving children but also to reassure them that the death had not been their fault. Others tried to find comfort in their loss, either by focusing on the positives that remained in their lives or by focusing on the fact that their child was not suffering. Many also tried to create positive memories from their child’s death, through activities such as organ donation, donating to charities in their name, or using their grief experience to help others. Throughout the loss experience, one of parents' most crucial coping mechanisms was having the support of those around them. This support began in the ED in their interactions with healthcare professionals, and continued on with professional counselling services, friends, and family. Parents needed this support to help them maintain their role as the good parent and to help them adapt to how that role had changed. Over time, most parents came to identify moving forward as part of being the good parent, as they knew their child would have wanted them to go on living despite their loss and they knew their role as parents had not ended with the death of their child. These coping strategies that parents employed are described in the following section.

Strength from Faith

Some parents drew strength from their faith in God, and the belief that they had been the good parent because they had faith and had instilled that faith in their children. They believed their children were safe in heaven, not only because they were children, but because they too believed in God. It comforted parents to know their child was not alone, and reassured them that they would be okay until the day they could be reunited. One mother explained how she took comfort in her faith and her belief that her and her spouse would be reunited with their child upon their death, "I'm a much more spiritual person…I think that has helped me enormously and I have faith that someday we're going to see our son again" (03A, 3281-3283)

The Search for Answers

For some parents, faith was not enough. They needed to understand why their child had died and the circumstances surrounding their death, not only to help protect their surviving children from the same fate but also to confirm they were not at fault for the death. This need to find answers began in the ED and was closely linked to the amount of information received from the healthcare team. Parents wanted complete and up to date information in order to understand the care their child was receiving and to be involved in decisions around their child's care. They also needed this information in order to prepare themselves for possible outcomes, including the death of their child. There were, however, many barriers to achieving this level of information, including the unexpected nature of their child's condition and the lack of a previously formed relationship with the healthcare team. Things happened quickly in the ED, which often meant there was little information to relay or little time in which to do so. And the lack of a pre-existing relationship between parents and the healthcare team made sharing such intimate and distressing information awkward and uncomfortable for everyone involved. Despite these barriers, one mother did identify being well informed and involved in her daughter's care during the resuscitation. In her situation, her professional background and previously established relationship with members of the healthcare team greatly enhanced her ability to get answers about her child.

> "The doctor came and I was talking to him, and he just looked at me and goes 'M…you tell me what to do…I can't…you need to tell me where to go from here'. And I said, it's okay, I'll make it easy for you. As soon as 'D' comes in, you can stop CPR." (01A, 107-110)

For most parents, there was minimal information relayed by the healthcare team, and they were left feeling completely unaware of what was happening with their child. Many parents were not present in the resuscitation room, whether by their own choice or by the choice of the healthcare team, which made answers even more difficult to obtain. They were left in the dark, wondering what was happening, how things were going, and if their child was even still alive.

> "When you're in a situation like that and your child is really ill and you know it and you don't know whether your child is living or dying, you have a lot of time to sit in that little

> room and ruminate well what's going on now, could it be this, is he dead, is he alive, what's going on." (03A, 2374-2378)

In fact, some parents described a myriad of possibilities going through their minds because they had no information to ground them and give them any indication of what was happening. One father identified this as "in the absence of information you just make up your own" (04A, 3853-3854). This lack of information caused parents a great deal of anxiety, guilt and frustration because they did not have a reason to pinpoint as to why they had just lost their child. For one mother in particular, the lack of information from the healthcare team led her to blame herself for her child's death.

> "I know I'm in shock, but at least give me something…you know, like okay, like 'you know what they're CPRing him, we're trying to get his heart back, he's going into cardiac arrest' or something. No…I didn't know anything until the autopsy came…which was rough because I thought I had killed him…nurses didn't tell me anything, so I went home thinking that I did kill him." (02A, 397-405)

For some parents, the search for answers came after their child's death when they dove into educating themselves about their child's condition. One couple, in particular, recalled how they turned to education as a way to make sense of their son's death. They even joined a support group made up solely of parents whose children had died of the same condition, and who were working toward improving care and outcomes for this patient population. The mother describes how she "buried [herself] in educating [herself] about [his condition]" (03C, 14), while the father acknowledged "it was a way of coping…we wanted to know what, if anything, could be done to prevent these types of tragedies in the future" (03B, 127-130).

Several parents echoed this need for answers in order to understand why their child died. This was especially true for those who did not have a clear cause of death, as they were left wondering what had happened and if their child's death could have somehow been their fault.

They were unable to cope with the “not knowing”, as this led to spiralling ideas about what might have happened.

> “You’ve only got theories then you know. But you do go a little bit crazy, ‘cause you’re like well did I dress her too warmly that day you know, or did I miss something, like did I accidently smack her head on something when I wasn’t looking, and you’re like, no I didn’t do any of those things, but you go a little bit cuckoo, you had to look for all those reasons right ‘cause you want to blame yourself…there was nothing signalling that there was anything wrong with her.” (06, 540-550).

For many parents the answers to all of their questions came when they were given a cause of death in the autopsy report. There was only one couple who knew their child’s cause of death before receiving the autopsy report. For them, the autopsy brought reassurance more than answers, as it let them know their daughter did not suffer when she died.

> “I wanted the autopsy report to read…and then we finally, we finally said no. When the…medical examiner told us that she didn’t suffer, then we thought, you know what, we don’t need to know [details of her injuries], we seen it.” (01B, 2074-2081)

The same was true for another couple where, rather than providing cause of death, the autopsy report reassured parents that they were not responsible for their son’s death. They wanted a cause of death to explain why their child died, and it was not easy for them to come to terms with not having an answer.

> “The autopsy was a big one…’cause it was finally allowing yourself…some closure…one of the hardest things to kind of walk away with is the fact that, that there was no reason I guess. There was, that it just really, for lack of a better word, was unlucky…and I guess that kind of senselessness felt sometimes, it was a little harder to grasp.” (04A, 2023-2050)
>
> “and I remember one of the first things they wrote was when they were talking about the initial examination…to say that he was a well-cared for child really meant a lot ‘cause you felt less like you did something wrong…for a long time I didn’t think I was fit to even be a mother.” (04A, 1036-1043).

The autopsy did, however, help to rule out many of the “what ifs” that had been weighing on their minds. As the father described, “I wanted to know why. It helped knowing that it wasn’t our fault…that did bring a lot of resolution” (04B, 2271-2277). The information from the autopsy eased their feelings of guilt over their son’s death and allowed them to move forward.

Understanding their child’s cause of death was part of coping with the situation for many parents. This knowledge took the weight of guilt off their shoulders and allowed them to begin to process their grief without wondering if their child had died because of something they had done or not done. They were reassured that they had not, in fact, failed as parents, but rather had been the unfortunate victims of circumstances beyond their control.

> “as a mother you’ve always got that, you know, in the back of your head…was there something I could’ve changed, like in my diet while I was pregnant, or done something different, or done something different in his diet or stuff like that, right. But…when it comes down to it, I did everything I could’ve done, and that’s all…that’s all you can do.” (02A, 1132-1138).

For one mother, the lack of answers from the autopsy report only brought frustration, as she had hoped that having a cause of death would help her to make sense of her daughter’s death. Not having an answer left her with all the “what ifs” and nothing on which to lay the blame for her daughter’s death.

> “we weren’t able to find anything…I said so what is it, what happened, and she said we don’t know, we’re just going to call it sudden infant death. I’m like but why, and she said sorry I can’t answer those questions, we don’t know why…it’s a little frustrating ‘cause you have nothing to, you know, pin it on.” (06, 521-530)

The Search for Comfort

For some parents, finding answers and understanding why their child died helped them to reconcile their child’s death with their role as good parents. For others, this involved a search for ways to find comfort in their loss. Several parents took comfort in the knowledge that their child was happy and knew they were loved by their parents. One mother described how she took comfort in knowing her son had a good life, “he was always happy…he knew what he had in life and he enjoyed it" (02B, 933-938). Even if there was no opportunity for a final goodbye, parents held onto conversations or memories that reminded them of how their child was surrounded by love and happiness in their life. One couple recalled taking comfort in the knowledge that their child knew he was loved, "I know we didn't get a chance to say goodbye but, you know what, in so many ways…he knew he was loved" (03A, 4099-4102). Another mother chose to focus on the positives in her own life in an attempt to find comfort after the loss of her daughter, "you have to go with all the positive things…we have more money for the two that we have, we probably would have had to move out of our home…I just tried to turn everything positive" (06, 1811-1814)

Others took comfort in the knowledge that death meant their child was no longer suffering. Quality of life was extremely important to parents and the thought of their children being severely disabled or suffering in some way after the resuscitation led some to acknowledge that death was the "lesser of the evils". They did not want their children to suffer or to live a life that they could not fully participate in. One mother described how she felt her son's resuscitation "broke" him and would have left him disabled and suffering if he would have survived, "where he would be if he was alive and he made it would devastate me, I'm sure he'd be paralyzed, broken, surgeries, brain damaged, like no parent wants to see their kid like that" (02B, 1742-1744).

Not all parents were ready to find comfort after their child's death, as some found the pain was still too raw. One mother wondered if she would ever be able to find comfort, or if her daughter's death would always be a senseless tragedy to her.

> "I could say things like, oh, God needed her more than I did…but at this point in time I'm not at that point yet where I can say this good came of that…or something good happened

> because of it…I may never be there, but at this point in time it just, it's still too raw." (01B, 4525-4544)

Creating Positive Memories

Many parents asserted their role as the good parent by creating something positive from their child's death, a legacy that would help others and ensure their child would never be forgotten. One couple chose to continue to support the causes that their daughter was passionate about. She had loved music and dance, and had actively fundraised for these groups while she was alive. To honor her memory, her parents chose to continue this support and created scholarships and fundraisers in their daughter's name.

> "the school…they planted a tree…and the school of dance has an, an award in her honor. The zoo has a couple of things with her name on it…I think when we're done we'll, we'll kind of feel she's still alive out there giving to somebody." (01B, 2687-2747)

One father chose to use his grief experience to help others by educating people on how to support those who were grieving. He began posting information about his loss and how he was feeling on social media, and then had people contacting him for support and advice on how to help their own loved ones through loss experiences. In this way, he found a positive outlet for his grief and brought meaning to his son's death by using his experience to help others.

> "telling these little stories periodically about how I'm feeling or things I've noticed to try and give, help the people there who are on my list understanding of what I'm going through but understanding of what others might be going through that can't articulate it as well as I can and also sometimes they might have some common thread and they can find some comfort in it too." (04B, 2851-2856)

> "the act itself is not therapeutic for me. It's to try and bring some meaning, a little bit of purpose, a little bit of…understanding. Something, some sort of silver lining…to all of it, I think that's why I, I do it and that's why it's important to me to keep doing it." (04B, 3020-3030)

Some parents were unable to create anything positive from their child's death, and they found this both frustrating and disheartening. Their child's death felt meaningless and senseless, and this was something parents could not cope with or accept. One mother recalled feeling disappointed over not donating her son's organs because this would have allowed him to help so many other people. Organ donation would have created something positive from her son's death, and this would have helped her to cope with her loss.

> "I was so messed up with his death I totally forgot to say I wanted to donate everything. I forgot to tell, I forgot to tell the doctor that and I kind of, I don't want to say I regret it now, but I'm kind of sad about it now 'cause I feel like other than the intestine he was healthy, I could have helped so many other kids." (02B, 1173-1177)

Another couple tried to set up a medical program in their son's name that would help other children with their son's condition. They wanted to prevent this tragedy from befalling another family, and this would have allowed them to create something positive from their son's death. Despite all their efforts, they were unable to get the program started, and this left them feeling disheartened and bitter toward the entire healthcare system.

> "when you lose a child you always hear people who, who they lose a child and they take on a cause in memory of their child and they, it's actually successful and you know and its obviously it's still bittersweet but at least they've had, had some satisfaction knowing that they've helped make some change in their community you know in memory of their child. For us its worse because we had that loss, we tried to do something, we know what, we know we're right because other jurisdictions are doing what we're recommending and met with such resistance basically, so it's like, it's almost like, it's even worse. I mean you go through a tragedy and then we tried you know to give of ourselves, volunteer our own time to make inroads and create awareness and just to have all these doors shut on us." (03A, 1713-1723)

They felt cheated out of their "happy ending" and, in a way, felt like they had failed their son by not creating something positive in his memory. They had extensively educated themselves on their son's condition, studied successful programs in other countries, and tried to use that knowledge to make positive changes in the healthcare system. Despite these efforts, they were unable to establish the program and were left with no outlet for their expertise, "we have this wealth of knowledge and expertise that we've developed and acquired on this topic since our son died and we don't have any real outlet to…to do anything with it" (03A, 4259-4263). Additionally, both parents identified how the inability to create something positive from their son's death made coping with their grief harder, "I think it would have helped to alleviate our grief somewhat knowing that a legacy could have been created in 'E's memory" (03B, 133-135).

The Need for Support

Despite the multitude of ways parents tried to maintain their role as parents, sometimes their strongest coping mechanism was leaning on the support of others. This need for support came even before their child died, and was first identified by most parents during their time in the ED. Parents looked to the healthcare team and other professionals, such as social workers and spiritual care providers, for support to help them through the traumatic time in the ED and to guide them through their loss experience. One mother, who was present in the resuscitation room with her daughter, clearly recalled the support she received from the healthcare team.

> "The staff was really supportive…they didn't make me leave the room…they weren't saying she was going to be okay, but they were trying to comfort me and say, it's going to be okay, like you're going to be okay." (06, 291-315)

This degree of support was not experienced by most parents; however, as many identified feeling ignored or even abandoned by the healthcare team and other professionals they came into contact with in the ED. Several parents recalled being shuffled into another room on arrival in the ED and being kept there the whole time the healthcare team was caring for their child. This physical separation from the healthcare team left parents feeling disconnected and unsupported by the very people who were witness to the worst moment of their lives. One couple remembered seeing a member of the team that treated their son at the desk as they were leaving the ED, and it surprised them that they were completely ignored by someone that had shared such an intimate and traumatic moment in their lives.

> "There was no summary or any follow-up visit like that like that while we were there, no that was basically it. I remember seeing her at the sort of nursing station or just kind of talking to the other people but there was nothing, there was no interaction with us." (03A, 2447-2450)

Support from the healthcare team also involved keeping the family informed about what was happening with their child, especially when they were not physically present for the resuscitation. Parents recalled their belief that as long as the healthcare team was still working on their child that meant there was still a chance they would survive. The longer the resuscitation lasted, the more parents started to believe that things were going well and that their child was critically ill but would survive this event. Three of the families recalled being kept in a small room beside the resuscitation room and receiving little information about what was happening with their child, other than being told that the team was still working on them. At one point, a member of the healthcare team came and told each family that they could finally come in and see their child. On entering the room, parents clearly remembered the healthcare team still working on their child, but within moments their child was declared dead. Parents were shocked that they were not prepared or warned in any way that time of death was about to be called.

> "The whole thing was just like surreal and it wasn't for very long, like they announced that she was, pronounced her deceased within probably five minutes…and then I was like, what happened, like why, you know so then your mind is racing, like well what happened, I just saw you guys trying to resuscitate her" (06, 327-335)

> "They brought us in to show us and I always held the opinion that they were kind of still working but it was more just to show us that they were, not because there's anything wrong with that or anything but just to let, kind of let you know that they were, were trying" (04A, 745-748)

One family in particular recalled the horror they felt when they entered the resuscitation room and watched the doctor pronounce their child dead. The demeanor of the staff member bringing them into the room had led them to believe their son was still alive.

> "at one time the doctor came in and said, you know we're going to give him his drugs for his heart, this is typically what we do in these situations… other than that there wasn't a lot of information… then finally after I don't know how long it was, not more than about 15, 20 minutes, half an hour maybe that we were, then they came and I remember them coming and saying, that same doctor came and okay you can come see him now… Based on her demeanor she seemed like almost as if you know pleasant about it, almost as if you know like they had resuscitated him and like okay he's kind of awake now you can come see him. And then so we all went in there with my other son as well, they worked on him for a few seconds more…in front of us she says they pronounced him dead…They basically said I'm sorry there's no more we can do for him. And I mean obviously I mean our world changed at that second right. And, and I mean we were just shocked because I, I just figured that based on her tone that, that they had somehow resuscitated him 'cause she seemed you know almost smiling and pleasant. I guess maybe she didn't want us to make a scene." (03A, 697-732)

Most parents that were not present in the resuscitation room received little or no support from hospital staff, as the healthcare team was busy working on their child rather than being present for the family. One couple, however, did have a social worker and a spiritual care provider in the room with them while they awaited news from the healthcare team about their child. They recalled feeling somewhat supported by the spiritual care provider, but then described how that support ended very abruptly when they left the hospital.

> "The social worker seemed really rushed that was in there, she was kind of…in and out and she was kind of all over the map. But the spiritual advisor was with us the whole time and more trying to make sure "J" in particular wasn't building things up in her head anywhere so yeah and more around guilt." (04B, 1999-2007)

The struggle for support did not end with the healthcare team, but rather continued with other professionals involved in their child's death. All parents were interviewed by police at some point after their child was declared dead, either in the hospital or at a police station downtown. Although this is standard procedure in all unexpected child deaths, only one family was aware of this process and their awareness came from their own professional experience rather than knowledge imparted by the healthcare team. Most parents were surprised or confused by police presence, and many felt they were being interrogated during their police interview as if their child’s death was somehow their fault. One mother recalled thinking the police were present in the ED because they had escorted the ambulance there, only to discover that they were there to investigate her daughter’s death.

> “Giving you a bit of a heads up that this is going to happen, and it doesn’t mean that we think you did anything, but this is just a process we have to go through, like a little bit more explanation rather than making you feel guilty on top of everything else… I thought they were just in the background to, to help out, you know make sure the ambulance got in there safe or to whatever, I didn’t really realize that’s what they were there for.” (06, 424-453)

> “Worst thing that happened that night in the hospital was I got arrested for the murder of my son. Three fucking hours I spent in a room while they interrogated me thinking that I got this for money and all this other shit. It was the worst thing ever.” (02A, 327-330)

One couple specifically recalled feeling “set adrift” when the police dropped them off at the hospital after their interviews, as they had received no instructions or follow-up as to what happened next, “when the police just dropped us off at the back of the Children’s Hospital and I just felt like abrupt…I have no idea what I’m doing now, like I’m just kind of set adrift (04B, 2110-2116). They were not allowed to go in and see their son again, and they were left to find their own way home with no follow-up or supports offered by anyone.

As much as providing information was a way for healthcare providers to support parents in their time of loss, information also needed to be delivered with tact and compassion. Several parents recalled negative interactions with professionals in which information was provided but was delivered abruptly and without emotion. This lack of sensitivity and understanding of the traumatic experience parents had just been through left them feeling unsupported and alone in their grief. Parents were shocked by how cold and uncaring some conversations were considering these were professionals that should be trained to handle such situations. The medical examiner, in particular, was identified by several parents as being unsupportive, both because there was a time delay of up to several months before they received any information and because parents contact with them was extremely limited. Only one couple had a chance to speak to the medical examiner on the day their child died, and they described this interaction as very cold, clinical and abrupt.

> "She came to the room and said "I'm done, you have five minutes". And she was very abrupt. And I looked at him (D) and I thought, you know, five minutes…but she didn't say anything else. You know, and I thought she's depersonalizing it, she's trying to keep her emotions intact." (01A, 650-653)

Another family had a similarly unsupportive experience with the transplant coordinator from the hospital. There had been no discussion with the family about organ donation while they were in the hospital, so the phone call they received on arriving home was very unexpected and distressing to both them and their surviving son. Parents felt forced into making a decision on the spot, and have since wondered if they would have made a different decision if the information was delivered with more compassion and consideration.

> "He just said to me, I'm calling and I'm, I'm with the Children's Hospital, I'm the transplant coordinator and, and he let us know that we could donate "E's" organ but that if we wanted to do this we, we had to do this very shortly… In any event "J" was right there, he heard this conversation, he was getting really, really upset on the phone, he was almost hysterical, he said to me, mom, don't let them cut "E" up, don't let them take, take anything out of him… Perhaps we would have, I would have liked to have you know offered something of "E" so that somebody else would, would have a better life, but, but the way it was handled especially on the phone like that…we're in our garage…such an impersonal area, to get a call like that and be told that you have 10 minutes to decide, instead of telling us while we were there and, and counseling us…if somebody had that, just that fundamental compassion." (03A, 1010-1091)

When support was not openly offered, several parents chose to seek out professional supports, such as supports groups and personal counsellors, on their own. For some, these supports were accessed when parents realized their existing support system was inadequate, while others sought them out as an option to supplement their existing coping mechanisms. For one parent, the search for professional supports started when she realized her coping mechanisms were not healthy, and that she needed more support than what she had in place.

> "First I didn't want…I didn't…I don't need help…I didn't need help. And then once I realized what was…like what was going on…like the cutting's not healthy, this is not healthy…it was like I need help…I want help. So I went and got it." (02A, 1369-1372)

For another parent, the search for professional support came when he realized he needed to support his family through their grief as well as coping with his own. Though he was able to cope and support his family in the beginning, there came a time when he realized he needed extra support in order to maintain that.

> "I would never even thought of going to a support group or anything like that or a counselor or a psychologist or anything like that prior to that…when that happened I realized very quickly that I needed to do that just to keep strong and to have some support, so I can keep it together right. So, so I probably took advantage of that more than anybody in the family." (03A, 2716-2724)

Most parents specifically sought out other parents who had experienced the loss of a child, both for support from someone who intimately understood what they were going through and to gain some insight into what their grieving process might look like in the future. Many attended local parent support groups which included parents that had lost children from many different causes, but one couple specifically sought out parents that had lost children to the exact same condition as their son. This group not only offered them the support of parents who could uniquely understand their loss, but it also educated them about the condition that had taken the life of their son. Overall these support groups helped parents to understand that they were not alone in their grief, connected them with people who could truly understand their loss, and gave them a place where they could talk openly about their children without fearing how others would react. However, in some cases, these support groups also opened parents' eyes to the possibility of complicated grief and poor coping mechanisms that could plague them for years.

> "Being part of [the support group] certainly was helpful because we saw everything, we saw parents from across the USA who some were coping… some who, who were house-ridden…others who became engrossed in doing volunteer work…but what I saw that was

> consistent was that there was a huge amount of missing their children and a huge amount of love and a huge amount of sadness." (03A, 4159-4170)

One mother recalled her fear of being dragged back into the depths of her grief by other parents that had failed to move forward after their loss.

> "It would be nice to know that there are other parents out there that had stuff similar to what happened to me and stuff like that. But I'm also…I think I'm grieving pretty good right now. And I don't know where they're at, and I wouldn't want to be pushed back to where they're at." (02A, 1326-1330)

Some parents actually stopped attending the support groups because they found it discouraging to see people month after month that were not able to move on with their lives. Parents could not face the possibility that their grief would be that raw and incapacitating for the rest of their lives. They needed to believe that things would get better with time and that they would learn to cope with their grief, incorporating it into their lives rather than letting it destroy them.

> "meeting people who'd been at the level they were at, the depth for like 18 years, 20 years, you know talking about how they sometimes can't get out of bed in the morning and, and that was almost harder for me to see other people like that 'cause I always had hopes that I would, it would gradually get better, maybe not go away completely but to that level…was so extreme that I just couldn't, I found that actually more daunting than the grief itself at times 'cause I would just think I don't, I can't have the pain in my heart this deep for that long." (04A, 2848-2858)

Several parents sought out more individualized supports, such as personal counsellors and individualized grief classes, so that they could access the specific supports they needed when they needed them. Having individualized supports allowed them to work through their grief in the way they needed to, and also ensured they were not held back by people that were not coping as effectively with their grief. For some parents, these supports were life-saving, as one mother described, "since 'G' passed away I've been in counselling, and that's saved my life. Because I'm not ashamed to say that there were days where I wanted to end my life" (01A, 344-346). For some, however, the cost of individual counselling services was prohibitive and led to them trying to manage their grief on their own, negatively impacting their grief process overall.

> "I couldn't afford therapy…and so I just tried to handle it on my own…but I just went crazy. You know, I locked everybody out, I didn't talk to anybody, I didn't leave my bedroom, I didn't eat…I didn't do anything." (02A, 1566-1569)

In addition to these professional supports, most parents had an overwhelming amount of support from family, friends, and even people in the community that were connected to their child. This was often described by parents as a "parade of people" through their home that they felt obliged but ill-equipped to deal with as many were still in a state of shock from their loss. For some, support came in terms of helping with funeral arrangements, contacting family, arranging meals, and just being there for parents to talk. One couple described the support that they received and continue to receive from their friends and family, "the people that were important to us were there…they're still there. Like it's been… years and even with friends we'll, we'll talk about "G" and nobody stops us" (01B, 4136-4142)

Many parents identified that, although there was strong support in the beginning, support quickly dropped off in the first few weeks as others moved on with their lives and assumed the parents had done the same. It was as if there was a pre-determined timeline for grieving, and parents were expected to follow the same timeline as those around them or risk being left behind.

> "There's a time where it's okay to grieve. People around you are sad, you're sad, everyone around is sad, everyone expects you to be sad…but then there comes a point where that person, your support group to some degree…move on. The person you lost they didn't…it's very different, no one has as much real contact as parents do with their children. So they kind of move on and you're still here, you're still in the depth." (04B, 2966-2980)

> "Everybody's very supportive over the first month or two or three…after that it just disappeared right and they don't even, you don't hear from most of ever again, you know it's just like, as if it's kind of like okay well you know it, you're fine now, you've had your six months to grieve." (03A, 2739-2746)

Some parents described that withdrawal of support as a feeling of invisibility. They felt alone in their grief, and described it as others being unable to see what they were going through or openly avoiding them altogether. For some, this avoidance seemed to stem from people not knowing what to say and so they would choose to say nothing at all. For others, the avoidance seemed to stem from people fearing that if losing a child could happen to someone they knew then it could possibly happen to them. Facing the idea that they could possibly lose a child was unimaginable to them, so instead they avoided parents ensuring they would not have to face that idea at all.

> "They can't even look us in the eye now right…they act like we don't even exist anymore 'cause they can't, it's painful, it's too pain...they just don't know what to say right, it's just too painful for them to even acknowledge us." (03A, 2876-2882)
>
> "I've lost a few friends this way, a few people think that if it can happen to, to us, it can happen to them, it's too painful a thought to think about and so they would rather just say, well it has nothing to do with me and it will never happen to me." (03A, 2892-2895)

For most parents, the strongest supports came from their spouse, surviving children, and close family members. These were the people that most closely understood the parents' loss because they too were grieving that loss. For those who did not have a spouse or strong family support, often friends filled this role. Though they may not have been experiencing the same level of grief as parents, their history as friends made them ideal in terms of being supportive and understanding what parents needed most at that time. One couple clearly identified that they leaned most on one another, and described how they felt they would always be each other's strongest source of support, "I know that we'll always be talking to each other 'cause we can always sense when one of us is up or down and, and we just talk" (01B, 2293-2295).

Some parents, however, identified struggling to find support within their own family, as either their family did not want to talk about the loss or they kept quiet for fear of upsetting surviving children. As one parent described, "we never talk about 'E' with 'J', even though they were very, very close, like that’s not even a subject that ever comes up ‘cause I know it, he’s just too uncomfortable talking about it” (03A, 2964-2967). Though parents were able to talk to one another, they were often limited to doing so only when both parents felt like talking and when surviving children were not around to hear the conversation. One parent identified feeling openly discouraged from talking about the loss of her daughter by both her spouse and her surviving children, “it did make me a little annoyed ‘cause I thought, so I have to walk around the whole time not talking about something that’s really upsetting to me ‘cause I don’t want to upset anybody” (06, 2755-2757). This lack of support from those closest to her intensified her feelings of loss and made her question the appropriateness of her own grief response.

> “They don’t act like they need to talk about it…it is kind of weird for me ‘cause my husband never talks about it either…so it’s like did we really have a little baby named “C” ‘cause no one talks about it.” (06, 1547-1558)

Support was not only crucial for the family, but it was also identified by one couple as a necessity for healthcare teams involved in the death of a child. Although healthcare teams are trained professionals, they are also human and therefore are not immune to grieving the loss of a child. They too face moral conflicts over the death, as children are not supposed to die and the team’s role is to save lives. The death of a child is often seen as a personal failure by the healthcare team, even if the situation deemed survival impossible. And, unlike most people experiencing the death of a child, the healthcare team is expected to control their emotions and return to work with a composed, professional demeanor despite their traumatic experience.

> “Those nurses that have to deal with that, that they do get the proper aftercare you know when its traumatic for them too…they needed to be debriefed afterwards… because they have to go home to their family and they’re the ones that get the brunt of it.” (01B, 4695-4719)

Moving Forward

At some point in the grieving process, most parents came to the decision that, in order to be the good parent, they needed to move forward. For some parents, surviving children or children soon to be born were a driving force to move forward, refocusing them on life and the living that still needed them so very much. As much as parents might have wanted the world to stop while they grieved, their children still needed them as parents and they acted as reminders that there was still joy to be had in life.

> "I moved on. It's time to move on, you know, especially if I want more kids…I can't be in the same state as if I still lost him. I'm putting them through that, and it's not even their fault…that's not fair to them either…but I'll always remember him…always. I will never forget him…I just learned to move on…and live without him." (02A, 1685-1692)
>
> "I want to be out of that corner, I don't want to rock myself to sleep anymore…I want all that to stop, and like I said, I'm not having this baby just to stop all of that, baby was a surprise, but baby's helping…baby will help me to move on…but I'll always have 'B' there." (02B, 2487-2501)
>
> "I've had a traumatic life experience, why am I okay, or am I just not processing it for whatever reason…my theory is just, you just, like I had two other kids and you just can't, you know that's my theory is that I was being tough and just pushing through it and trying to make sure that my girls don't have a negative experience." (06, 1593-1601)

One mother recalled how she just decided that she was not going to be crippled by her grief, but rather was going to move forward with her life. It was not an easy path, and she struggled to get to that point, but she felt it was what she needed to do to go on living.

> "And I thought you know screw that, that I'm going to be sitting around when I'm 90 crying about it, just get on with it, chop chop…I think that's where I just kind of turned a corner, so probably about, after about a year I was still sad but I started to think you know what I need to focus on, I have two beautiful children, amazingly I'm still married… we were having rocky issues before…and this definitely drove a wedge between us. But I thought you know what I got through a whole year of it, like so I'm probably going to be okay." (06, 1775-1792)

Knowing their children would have wanted them to be happy also encouraged many parents to go on living after the death of their child. Moving forward and finding happiness was a way of honoring their child's memory and giving them what they wanted one last time. One couple described how they knew their daughter would have wanted them to be happy, "if it was either one of us and 'G' was still here, she would have been devastated, but she would have known you can still laugh…we know for a fact that she would have wanted us to be happy" (01B, 1242-1249). For one mother, her son's happiness was a driving force for her to go on living at a time when she seriously considered ending her life to be with him.

> "[the police officer] got a phone call and I had to stay in the room, and that's when I did my whole I can kill myself now…'cause they put me in a medical room so I had everything in there, I could have just had my own little fun. But I kind of had like my little talk, and just…I will take 'B's happiness and I will walk out of this room and I will make something of it." (02A, 474-479)

As much as parents acknowledged that moving forward was a coping mechanism to help them through the grieving process, they were also quick to explain that moving forward did not mean forgetting. Grief would always be a part of their lives, but they were choosing to continue to live rather than letting their grief bring the world to a standstill. One mother described how her sadness had not stopped her from moving forward, "I'm still sad about it, but it's the same thing, you have to go on, right" (06, 2305-2306). While one father clarified how moving forward did not mean he was ignoring the loss of his son, "I think ultimately if I had to choose I would say moving on is the healthier thing to do. It's not always easy and it doesn't necessarily mean you're ignoring them or forgetting them" (04B, 3069-3071).

Learning how to incorporate their grief into their lives was a major hurdle for many parents, but it was a crucial component to moving forward. One couple recalled feeling like they needed to accept their new reality before they could truly move forward, "the pain's still there, you learn to live with it…you have to be accepting of life because it's not fair to our other grandkids and our kids if we don't live" (01B, 310-315). Another mother described how she needed to learn to live without the physical presence of her son in order to move forward, "I wouldn't want to say like you forget about him, but you just kind of learn to live…finally learn to live with…without him here" (02A, 660-662). For one couple, the decision to move forward felt like an ultimatum between learning to cope with their grief and going crazy. They also recalled feeling pressured to move forward as everyone around them moved on with their lives.

> "when you go through something like this you make a choice, I'm going to cope and I'm going to try to live my life with dignity and do something to help other people and be loving or I'm going to go crazy. Those are your choices." (03A, 2774-2777)
>
> "you just sort of learn to live with it, I guess put it that way, you just, you just learn to cope because you realize that, that you know nobody else is going to really, at the end of the day nobody else is really going to care right…everybody else is just you know going to go on with their own lives, so you just, you just as a defensive mechanism you just, you just move on right, but yeah the pain is always there." (03A, 2814-2820)

The New Normal

Parents openly acknowledged that the moment they realized their child was dead was the moment they realized their life would never be the same. They were suddenly and completely thrust into a new state of "normal" in which their family structure and their own identity was permanently changed. One mother described how she felt the moment the healthcare team stopped CPR on her daughter, "so, they stopped CPR, and, um, I knew that right then and there our lives would never be the same" (01A, 115-117). Their children were the center of their worlds, and parents felt lost and disconnected without them. It's as if "the whole world is moving but you're in one spot…you're not going anywhere" (01A, 609-610).

The shock of losing their child hit parents almost immediately, but the understanding that they would never again be able to return to their previous "normal" took time to sink in. This new “normal” was forced upon them without their consent or their input, and it took time for parents to come to terms with that. For some parents, facing the reality of their “new normal” was something they knew they needed to do in order to stay healthy.

> “the professions that we’re in, you know, you know you have no, we know that to get better you have to move forward right, that if you stay in that one spot and just think about her day and night you’re going to get sick.” (01B, 351-354)
>
> “I’m not going to live my life thinking that my son is still walking on this earth because, guess what, it’s killing me more inside thinking that he’s still alive when you should be thinking he’s dead…his memories and the love and everything will still be here, but him physically, you can’t think that way.” (02A, 374-379)

But as the permanence of this new state of being sunk in, parents realized they needed to face their new reality and learn to live within it in order to move forward with their lives. Many parents described a critical shift in their worldview as part of their “new normal”, including a change in priorities and a renewed appreciation for the little things in life. Some parents also described experiencing a fear of subsequent loss, especially when they had no cause of death to pin their fears on. And all parents described struggling to balance living with remembering the child they lost, as many feared moving forward would somehow mean forgetting. The subthemes of critical shift in worldview, fear of subsequent loss, and balancing living with remembering will be discussed in the following section.

Shift in Worldview

Many parents described a critical shift in their worldview when discussing their “new normal”, partially attributing this to the fact that the worst thing that could possibly happen to them had suddenly became reality. Parents recalled having a sudden appreciation for how short life could be and how quickly the people you loved could be taken from you. Many parents identified a new appreciation for the little things in life, and a lessening of their tolerance for drama and pettiness in those around them. One dad described how his view of what was important in life changed after the death of his daughter, “don’t take life for granted…pick your battles…tomorrow’s not guaranteed, you have to live today” (01B, 3834-3859). He went on to explain how he had come to see that there was still joy to be had in the world, “I get the greatest joy out of the simple things in life now…’cause you know what, there’s so much joy in this world, you don’t have to look far” (01B, 3948-3955). Another father recalled how losing his son made him lose his own fear of death, “loss of fear of anything…nothing worse can happen…everything else pales in comparison…and I’m certainly not scared of dying anymore” (03A, 3578-3587). Many parents voiced similar changes in their worldview, with most describing a newfound appreciation for how precious life really was.

> “I hear people talking about these trivial little things in their lives…making a mountain out of a molehill and its irritating… I have just zero tolerance for it, it’s like, there’s so much other things to spend your time on.” (04A, 1819-1831)
>
> “I think it changes the way that you see life you know, you realize that it’s really precious, and something like that could happen at any moment, completely unexpectedly... you really need to enjoy absolutely every moment.” (06, 2179-2185)

For two mothers, this shift in worldview involved an understanding that, although the death of their child was traumatic for them, their situation was not necessarily the worst thing that could happen. One mother described how she did not want people to pity her because there were other people that had gone through even worse experiences than her, “people say to me, oh you poor thing you’ve gone through so much, there’s people out there who have gone through a lot more” (01B, 3909-3911). Another mother mirrored this opinion and cautioned people to always keep the perspective that it is possible someone else has been through something worse than you.

> “Someone’s always got a bad story behind them…never think yours is the worst. Mine may have been bad at times but I know there’s someone out there who’s had it worse than I have…than I’m having right now.” (02A, 1122-1127)

For many parents, the shift in worldview also involved how other people viewed them, and the fact that they were now forever labelled as “those parents that lost a child”. They struggled with how this label made people look at them and relate to them differently than they had before their child died. One father described this label as “collateral damage”, as he would forever have to live in the shadow of his son’s death.

> “it’s again collateral damage right, these are the kind of things that, that through no fault of our own that we now have this sort of label as that poor family, that poor family who lost that child…that’s what we’re known for now.” (03A, 4475-4481)

Fear of Subsequent Loss

Several parents also identified a fear of subsequent loss as part of their “new normal”, especially when there was no clear cause of death for their child. Losing a child was not something parents had previously considered, but once it happened they realized that if it could happen once then it could happen again. Parents admitted they would not survive losing another child, so they became hyper-vigilant and protective over their surviving children.

> “there was a time there where I’d really have to not look, not check, not put my hand under her nose, not put my hand on her back, but I really just had to make myself not, because like I said she doesn’t deserve to be, to live a life in fear too.” (04A, 2162-2165)

This fear not only applied to their surviving children, but also to children that had yet to be born. Two of the families were expecting children within months of their second interview, and they both specifically identified fearing the day this new child reached the same age as the child they lost. It was as if their risk increased as they approached that milestone, but then was reduced as they moved past that age.

> “I am, I’m nervous. I’m not, I guess I’m not so nervous now, but I know I’m going to be scared when she turns four…I don’t want to lose another child, but I mean it could happen. I don’t want to think that it’s not going to happen, I feel if I think that it’s not going to happen that’s when it is going to happen.” (02B, 2686-2694)

One father described how not having a cause of death made him fear everything in relation to his surviving daughter and his unborn child. He had nothing to pin his fears on, so instead he had to be wary of everything, a way of life that was physically and emotionally exhausting. He felt powerless to protect his children because he had no idea what exactly he was trying to protect them from.

> "I wish I like I said knew especially now that we're having another baby…what it was more so now than I think even then because every night I wake up because I don't know what happened before so I don't know how to prepare for it again." (04B, 2284-2291)
>
> "everything suddenly becomes unknown. I don't have a thing to put my fear into, I have everything to put my fear into…you could protect yourself against a certain thing in particular. Not to say you know that fear doesn't carry elsewhere but it's I think a little easier to deal with when you only have to be on the watch for one thing." (04B, 2501-2510)

Balancing Living with Remembering

The most challenging part of the "new normal" for parents was learning to strike a balance between remembering the child they lost and moving forward with their lives. One mother described how she tried to strike that balance, "I'm trying to live with his memory, not live with him being here…you got to move on…you got to live" (02B, 3513-3523). Many parents felt guilt over moving forward without their child, as if their lives should have stopped when their child's did.

> "even when you're into living you still feel kind of guilty that she's not here with you, even though you're enjoying yourself. You know you kind of have that guilt that you know we both carry that 'cause we're moving on to a new stage as well in our lives." (01B, 34-37)

One couple recalled the guilt they felt when they first realized they were expecting another child. They had struggled with the decision to have another child at all, as they did not want to feel like they were trying to replace their son. Once they found out they were expecting they felt a combination of joy over the new beginning and guilt over being happy at all. The new baby brought a renewed sense of hope to their family, and a feeling that maybe there were brighter days ahead. But, at the same time, this hope was tempered by a sense of guilt over betraying their son by replacing him and moving forward with their lives.

> “there are days where especially with another baby on the way it does feel like this is…replacement. And there’s other times where I feel that not moving on is a disservice to him. Well I didn’t understand it, he was a lot of joy…and to stop having joy simply because he’s gone feels like a betrayal. Sometimes moving on feels like a betrayal, sometimes not moving on feels like a betrayal.” (04B, 3041-3054)

Over time they realized that having another child was a positive thing, and that there was room in the family for both their son and the new baby. This realization did not mean that they would not struggle from time to time with this balancing act, but they focused on the positives and tried to just enjoy the new little life on the way. They wanted to ensure this baby knew about their brother without having to live under a shadow of sadness and grief from his death.

> “when I hit about five months I was starting to realize you know this is a good thing, this is, this is you know this is a blessing, this is something that we can definitely look forward to. But yeah for a while there it was a little hard and it wasn’t really, not that I wasn’t overly thrilled but I was very hesitant to be pregnant.” (04B, 55-59)

Chapter Summary

The first section of this chapter described the demographics of the participating parents and their children, including details of the timeframe since the loss. The second section summarized findings from this qualitative interpretive description study examining the parental experience of unexpectedly losing a child in the Pediatric Emergency Department. Parents described in their own words the challenges they faced, including staying afloat in the waves of grief, finding ways to cope with their loss, and learning to navigate their new normal. The next chapter will present the discussion, including a comparison of the findings to known literature, methodological limitations and strengths, and recommendations for practice and research.

Chapter VI: Discussion

Introduction

The first section of this chapter will present a discussion of the findings of this research study. The purpose of this qualitative interpretive description study was to not only enable a greater understanding of the parental experience of unexpectedly losing a child in the Pediatric ED, but also to filter that understanding through a disciplinary lens in order to inform healthcare practice. The central themes of grief as waves, being the good parent, coping through the waves of grief, and the new normal are discussed and compared to findings in the literature. In the second section of the chapter limitations and strengths of this research study are reviewed, along with recommendations for practice, education and future research opportunities.

Grief as Waves

Grief has long been a source of inspiration for a multitude of artists, from musicians to sculptors and even poets. Many describe grief as waves that ebb and flow, with times when the waters are calm and times when the waves are overwhelming. The waves may change, but they never end, so those who are grieving are faced with the daunting task of learning to accommodate those waves into their life. This concept of grief as waves was also described by Eakes, Burke, and Hainsworth (1998) in their Theory of Chronic Sorrow, in which they defined chronic sorrow as “the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience” (p.180). Although the feelings of grief may fade over time, they felt chronic sorrow would still be experienced periodically as long as the disparity created by the loss existed. In the case of the loss of a child, the disparity includes both the gap between the ideal parent-child relationship and the actual one, and the lack of closure parents experience after the death of their child (Eakes, Burke, &

Hainsworth, 1998; Woodgate, 2006). The Theory of Chronic Sorrow also describes trigger events and how they can bring about a recurrence of grief, identifying the presence of the absence of the deceased as being one of the main triggers that bereaved people face (Eakes, Burke, & Hainsworth, 1998). And the concept of the waves of grief being never-ending is also identified in this theory, as Eakes, Burke, and Hainsworth (1998) describe:

> “although each episode of sadness abates over time, circumstances or situations in which the individual is confronted with the disparity created by the loss trigger recurrence of the grief-related feelings. Because of the cyclical nature of chronic sorrow, periods of happiness and satisfaction are interspersed with episodes of re-grief.” (p.180)

Parents in this study also described the grief over losing their child as coming waves, with many of their descriptions echoing the concepts in the Theory of Chronic Sorrow. They described how their grief would recur, often without warning, and how they struggled to overcome their triggers and learn to swim through the waves. Over time, parents identified coming to an understanding that those waves of grief were never-ending and would always be a part of their lives. Parents in this study, however, did identify three distinct subthemes within the waves of grief that described how their grief changed over time. These three subthemes included the first wave, ripples through the family, and waves are never-ending. Parents described the first wave of grief as overwhelming, crashing over them and leaving them in a state of shock where they were unable to face the reality of their loss. Over time, those waves rippled through the family, affecting each person in their own way and deteriorating the very fabric of the family structure. In the end, parents had to come to terms with the fact that the waves of grief would never end. Though the waves might become less extreme and further apart, they would always be present to a certain degree.

The First Wave

Parents described the first wave of grief as an overwhelming shock to their system, leaving them in a surreal state where they were unable to face the world or the reality of their loss. Truog, Meyer and Burns (2006A) had similar findings, and described early grief as a state of "disbelief, confusion, and a sense of unreality" (p.377). Denhup (2015) similarly described the grief over losing a child as a tsunami, a state of complete and utter devastation and destruction that parents are powerless to stop. Parents were left in a state of shock, surrounded by the destruction of the tsunami, and could not even comprehend the magnitude of their loss let alone devise a plan to rebuild. Part of the overwhelming nature of the first wave is the fact that child loss is unique, and is not something a parent ever expects to face. Several authors have identified child loss as a unique type of loss, and the worst kind of loss one can experience in their lifetime (Bogensperger & Lueger-Schuster, 2014; Denhup, 2015; Garstang, Griffiths, & Sidebotham, 2014; Rini & Loriz, 2007; Widger & Picot, 2008). Some authors hypothesized that the unique nature of child loss was due to the disruption of the parent-child bond, a primary bond that is central to parents' identity and life overall (Meert et al., 2009; Meert, Thurston, & Briller, 2005). Garstang, Griffiths, and Sidebotham (2014) describe child loss as "an upset to the natural order of events; most parents rightly expect their children to outlive them" (p.1). All of the parents in this study identified child loss as being a unique type of loss and the worst kind of loss one can experience, not only because parents never expect to outlive their children, but because the loss of a child included the loss of the future they would have had. Child loss in this study was also unique because the loss was unexpected, which has been identified by other authors as a factor that increases parents' risk of complicated grief (Davies, 2001; Wijngaards-de Meij et al., 2005). Unexpected loss leaves parents with no time for anticipatory grieving or preparation for the death, often leaving them with regrets over things left unsaid or undone.

Ripples through the Family

Though the first wave seemed to impact parents the most, it did not take long for the waves of grief to ripple through the entire family. And though each person within the family experienced grief over the same loss, they each experienced that grief in their own way. This not only made it difficult for family members to understand each other's grief, but also made supporting one another much more difficult. Even between parents that lost the same child, grief can be experienced in completely different ways due to a multitude of individual factors (Wijngaards-de Meij et al., 2005). Parents in this study identified many differences in the grief experienced by them and their spouse, with some identifying more physical symptoms while others were more emotional or completely shut down by shock. Coping mechanisms also varied greatly between parents, with some identifying a need to stay busy and avoid their grief by focusing on the tasks of life, while others were consumed by their grief and could not even manage to get out of bed. Several authors have attributed these differences in the grief experience to classic differences between the genders. As Davies (2001) describes:

> "men are socialized to be strong, controlling, self-sufficient, and the family protector, which may prevent the open expression of their grief…they feel it is their responsibility to manage and control the grief of family members, to keep the family's spirits uplifted." (p.6).

This concept was also identified by fathers in this study, who described feeling like it was their role to take over the "tasks" of life for the family while everyone else took time to grieve. Funeral arrangements had to be made, family had to be notified, and food still had to end up on the table despite their desire to simply sink beneath the waves of grief. One father described his regret over putting his grief "on the back burner" in order to support his family, as he felt this prolonged his grief and exhausted his coping resources.

Some authors attribute the individuality of parents' grief to differences in their attachments to their children. Mothers are believed to have a deeper attachment to their children because of the bonds created during pregnancy and the increased time and energy they invest in children during infancy. These deeper bonds are thought to cause mothers to experience more intense grief than fathers do, especially with the loss of infants (Davies, 2001; Wijngaards-de Meij et al., 2005). But some studies also show that fathers employ different coping mechanisms than mothers, which may lead to the impression that they are not experiencing as much grief. Mothers were identified as more likely to reach out and speak out about their grief, while fathers often employed more active coping methods like focusing on their work or speaking only to their spouse (Davies, 2001; Thompson et al., 2011). Most parents in this study felt that their spouse experienced the same intensity of grief as they did, but different coping mechanisms worked for different people. Only one mother described feeling like her spouse was not experiencing any grief over the loss of their child, and this caused her great distress and anger towards him. She could not talk to him about their loss and so felt even more isolated and unsupported in her grief.

For many couples, these differences in coping and the individual nature of grief caused great strain on their relationship, sometimes even to the point of divorce (Arnold & Gemma, 2008; Schonfeld, 2012). Whereas respecting the individuality of grief and allowing each other to grieve in their own way and their own time was protective to parents' relationship with their spouse. Much like the findings of Proulx et al. (2015) and Thompson et al. (2011), parents in this study cautioned people to not place expectations on how their spouse should grieve. Many of them had seen other couples separate over differences in grieving, and they were very careful to maintain open and honest communication with their spouse so they both felt supported and had their needs met. Despite the best of intentions, parents were not always able to offer one another support. Sometimes parents were overwhelmed by their own grief, and so had nothing left to offer their spouse in terms of support (Schonfeld, 2012). As Arnold and Gemma (2008) describe: “one parent can ‘abandon’ another when overwhelmed. ‘Marriage was held together mostly one day at a time, sometimes one hour, sometimes one minute” (p.669). Arnold and Gemma (2008) also described how those ripples of grief impacted parents’ relationships with surviving children:

> “ranging from difficulty loving their remaining children, being anxious, guarded, and overly cautious in their relationship, to experiencing a heightened sense of love and attachment with the need to protect from harm without impeding the surviving child’s growth.” (p.664-665)

Waves are Never-Ending

Part of the metaphor of grief as waves is the realization that the waves may change in size and frequency but they will never stop coming. This concept of grief as never-ending is consistent in the literature, with authors describing grief as an ongoing process with no end for many parents (Arnold, Gemma, & Cushman, 2005; Denhup, 2015; Thompson et al., 2011). Parents in this study described a similar realization early on in their grief, when they came to accept that grief would always be a part of their lives. The degree to which their grief impacted their everyday life, however, differed greatly between parents. Some parents described their grief as being just as fresh years after the death as it was on the day their child died, and they did not ever expect that to change. Most parents, however, found that their grief changed over time, with the waves becoming less extreme and longer periods of calm water between them. In a study by Denhup (2015), a mother described her parental bereavement as a “tsunami in her soul which will exist for the remainder of her life" (p.10). The tsunami is devastating and there is nothing you can do to stop it, but eventually the tsunami will end. What comes after the tsunami is a lifetime of recovering from the devastation and loss that it caused, which is the way parents describe their never-ending grief over the loss of their child.

Though parents accepted that grief would always be a part of their lives, some did experience a distinct moment when the weight of their grief suddenly lessened. Arnold and Gemma (2008) found parents had "a sudden lifting of spirits" three years after the death (p.668). Many parents in this study described a similar moment when the weight of their grief seemed to lift and they were able to take a full breath for the first time since their child had died. This did not mean their grief ended, but the intensity lessened and enabled them to go on living without grief over-shadowing every aspect of their lives. The time-frame for this event varied for each individual, even between spouses, but it seemed to happen randomly rather than being related to a specific event like the anniversary of the death. Most parents appreciated this easing of their grief symptoms, but they also clearly identified that they did not want their grief to end. As found in studies by Davies (2001) and Woodgate (2006), parents did not want their grief to end, as it was part of maintaining a relationship with their child and ensured they would never be forgotten. One father in this study clearly identified that he never wanted his grief to end, as he equated that with forgetting his child or not loving him enough to keep that memory alive.

Being the Good Parent

The theme of being the good parent was described by parents in this study as doing right by their child and ensuring their child would never be forgotten. Parents wanted and needed to maintain their role as the good parent for as long as possible, and they needed others to understand and acknowledge that they had been the good parent too. This theme of being the good parent has previously been identified in the literature in relation to parents caring for children with complex needs and parents of critically ill children who are facing end of life decisions. Woodgate et al. (2015), in their study of the experiences of parenting children with complex care needs, defined being the good parent as:

> "not only maintaining their child's health and safety, but also ensuring that their child had a good life. It was reflected in parents constantly striving to meet their duties and obligations toward their child. In some instances, this involved going that extra mile and making sacrifices." (p.5)

Similar definitions were identified by other authors in their research around parents' perspectives on being the good parent when they were faced making end of life decisions for their critically ill child. Parents in these studies defined being the good parent as the following: doing right by their child, being there for their child, ensuring their child felt loved, being an advocate for their child, focusing on their child's quality of life, and putting their child's needs before their own (Feudtner et al., 2015; Hinds et al., 2009; October, Fisher, Feudtner, & Hinds, 2014). All parents needed to fulfill this role for their child, but the individual variations in their definitions of being the good parent meant their priorities were not always the same when it came to care of their child. Parents also described how their role as the good parent changed after the death of their child by identifying the subthemes of the day their child died and after the death. The day their child died, parents prioritized doing right by their child. For some, this meant being physically present and advocating for their child, while others worried their presence would negatively impact their child's care so they put their own needs second and stayed out of the resuscitation room. After their child's death, some parents surrounded themselves with their child's things, needing that connection to physical items to reinforce their role as the good parent. Other parents prioritized forming new traditions that reinforced their child's continued role within the family, thereby maintaining their role as the good parent with the child they lost and those that remained within the family.

The Day their Child Died: Doing Right by their Child

The parent-child bond is at the core of a parent's identity and their entire world. The death of a child disrupts that bond by taking away a parent's physical connection to their child, but it does not end their role as parents. Rather, the death of a child forces parents to redefine their role as parents and to find new ways to maintain that bond. As in the study by Meert, Thurston, and Briller (2005), parents described a need to create an internal relationship with their child to replace the physical connection they had lost. This continued connection comforted them during their grief and helped them to cope with their loss (Foster et al., 2011; Thompson et al., 2011; Woodgate, 2006). Especially in the case of unexpected death, there was no time for parents to prepare for the loss of connection to their child and they struggled with things left unfinished, such as final goodbyes and last kisses.

Many authors found that parents' struggle to maintain their role as parents began even before their child's death, as the healthcare team took over their role as caregiver. Although studies have identified that parents should be allowed to assist in their child's care and participate in decision making with the healthcare team, many parents were not given the opportunity to do so (Lawrence, 2010; Meyer et al., 2006; Woodgate, 2006). Rini and Loriz (2007) reported that "active participation in their child's care allowed for a sense of control and facilitated preparation for the event of death" (p.277). Despite these findings, many parents were excluded from participation in their child's care and, in fact, were even denied physical presence at the time of death (Meert et al., 2008a; Rini & Loriz, 2007; Woodgate, 2006). Most of the parents in this study were not present at the time of their child’s resuscitation, as they were either completely denied access to the room or were quickly shuffled off to another room by themselves. One mother described how she had to argue with the healthcare team in order to be allowed in the room with her child, when all she wanted was to ensure her child would not be alone. As Woodgate (2006) described: “parents felt their role as a parent had been taken away from them during the time when their child needed them most, and that they had been cheated out of one last memory” (p.78).

Many authors found that lack of physical presence at or around the time of their child’s death left parents with regrets and questions that would never be answered (Garstang, Griffiths, & Sidebotham, 2014; Rini & Loriz, 2007). Parents in this study were left wondering what had actually happened during the resuscitation and if everything had really been done to try and save their child. One parent recalled reading details about the resuscitation in the autopsy report and how she was surprised that she had no idea what had really happened to her child. Parents also described regret over not being present for their child so that they were not alone in the final moments of their life. Even if the child was unconscious at the time, parents still believed their physical presence would have brought comfort and support to their child to ease their suffering. Physical presence around the time of death also gave parents an opportunity to say goodbye, words which were crucial to parents as they were the last words they would ever be able to say to their child (Meert et al., 2009; Meyer et al., 2006). Parents in this study who were not present at the time of their child’s death regretted not having that opportunity to say goodbye and regretted their child being alone at the time of their death. Despite this desire to be present with their child, Knapp et al. (2005) and Knazik et al. (2003) both found that many parents did not ask to be present in the resuscitation room. One couple in this study specifically recalled not wanting to be in the room with their child as they feared their presence would distract the healthcare team and negatively impact the care their child received.

The struggle to maintain their role as the good parent did not end with the healthcare team, but rather was further impacted at this time by the presence of the police and medical examiner. Police and medical examiner involvement is standard practice in all unexpected child deaths, but authors caution that their presence should not interfere with the family's ability to mourn (Garstang, Griffiths, & Sidebotham, 2014; Knapp et al., 2005; Knazik et al., 2003). There needed to be a balance between completing the investigation into the death and respecting the family's time and space with their child. Despite these recommendations, many parents in this study had their time with their child significantly shortened by being removed from the room to complete police interviews. One couple described being taken off-site to the police department for the interviews, believing that they would be able to see their child again when they returned to the hospital. However, on their return, they were informed that their child had already been taken to the morgue and they would no longer be able to see him. This not only took away their time to say goodbye, but it also left some parents feeling like they were being interrogated because they were somehow involved in causing their child's death. Garstang et al. (2014) described how police presence can imply that a crime has occurred and can be distressing for parents leading to a negative impact on their grief. One mother recalled being questioned by police about a life insurance policy for her child, and described how she felt like they were accusing her of killing her child for money. This added to the guilt she already felt over her child's death and led to her considering taking her own life in order to be with her child.

After the Death: Keeping the Memories Alive

After their child's death, many parents focused on keeping mementos of their child as these were the closest things they had to a physical connection. Parents in this study recalled clinging to their child's favorite things or keeping articles of clothing that still carried their child's scent in order to recreate that feeling of connection. One mother described carrying her child's favorite toy with her for months after his death, while another mother recalled putting her child's clothing in bags so she could take them out and have that olfactory reminder when she needed to reconnect to the memory of her child. Thompson et al. (2011) described keeping belongings as a way for parents to "maintain a sense of presence with the deceased in the absence of physical contact" (p.155-156). These mementos helped parents to cope by strengthening their memories of their child, thereby maintaining a connection between them despite the lack of physical connection (Knapp et al., 2005; Lawrence, 2010; Meert et al., 2009).

Another way that parents maintained their role as the good parent beyond death was to talk about them with other people. Sharing memories of their child not only renewed their connection to them, but also helped them to understand their grief experience (Meert, Thurston, & Briller, 2005; Woodgate, 2006). Arnold and Gemma (2008) described this as "the profound silence of grief meant not having anyone with whom to talk about the child's death" (p.669). Despite the importance placed on reminiscing and sharing about their child, not all parents found people willing to listen. Other people were often uncomfortable hearing about the deceased or did not want to talk about them for fear of the emotions that would be brought up in them and the bereaved parents (Thompson et al., 2011). One father in this study described how he had to "size people up" when they asked him about his family, as this required deciding if he should only talk about his surviving child or if he should "drop the bomb" about the child he lost. He recognized that talking about his deceased child was uncomfortable for many people, but he felt incredible guilt if he only talked about his surviving child and denied his other child's existence.

It was not only people outside the family that were uncomfortable reminiscing about the child, rather some parents found their own family unwilling to talk about them. The individual nature of grief means that people within the family may not be at the same stage in their grief as other family members, and so may not be prepared to talk about the deceased. This was identified by parents in this study, as they described how both parents had to be "in the mood" to talk about their child in order to truly share and have an in-depth discussion. One mother struggled with the need to talk about her child because no one else in the family was willing to talk about it. Her surviving children denied the existence of their sibling and her spouse denied a need to talk about their loss. She described intense feelings of loneliness and doubts that maybe she was not grieving the right way, as it seemed no one else needed to discuss the loss the way she did. Some authors have attributed these differences in coping styles to more fundamental differences between the genders. Davies (2001) theorized that men were pressured by society to not openly share their grief as it was their responsibility to be strong for their family. If they did try to share their grief with friends, it was often deflected or minimized as other men also did not feel comfortable talking about it. Wijngaards-de Meij et al. (2005) theorized that the difference between men and women could be due to differences in their attachments to their children. Women invested more time and resources into children, leading them to have deeper attachments and therefore more intense grief symptoms. Thompson et al. (2011) recognized that fathers might find talking to "outsiders" challenging, partially due to societal expectations of strength and independence, but found they did speak openly with their spouse and found comfort in being able to share memories of their child. These gender differences were found by participants in this study as well, as fathers described feeling like they needed to be strong for their family. They felt someone needed to "keep it together" and get tasks done, such as arranging the funeral, and they felt like it was their job to take on that role. Mothers in this study more often described being incapacitated by their grief initially, and they could not understand how their spouses were able to function with their grief.

As time went on, many parents found new and creative ways to maintain their role as parents and to reinforce their child's role within the family. Strategies included creating memorials, keeping personal belongings, visiting the gravesite, listening to favorite songs, creating special goodnight rituals, and having inner conversations with their child (Arnold & Gemma, 2008; Arnold, Gemma & Cushman, 2005; Foster et al., 2011). Many of the parents in this study also described celebrating birthdays and the anniversary of their child's death as ways to stay connected. One mother described how the anniversary of her child's death was the day they honored everything their child had loved, from food to music to favorite activities. Some parents described searching out ways to stay connected to their child for fear they would be forgotten, either by others or by the parents themselves (Proulx et al., 2015). One father described how his memories of his child had started to fade so that he had trouble remembering details about him. This led to an intense fear of forgetting his child and a lot of distress for the father, as he felt he was betraying hid child's memory by forgetting those details.

Despite the importance most parents placed on maintaining their role as the good parent, continuing that bond with their deceased child did not work for everyone. Some parents found it easier to cope and heal without having those reminders of their deceased child around them, so they chose to let those connections go after their child's death (Foster et al., 2011).

Coping through the Waves of Grief

Maintaining their role as the good parent was not an easy task, and parents described many different coping mechanisms that they employed to help them accomplish this. Some parents described drawing strength from their faith in God, and the knowledge that their child was protected by their faith and that they would be reunited with them after death. Others searched for answers around why their child had died, arming themselves with knowledge to protect their surviving children and to reassure themselves that their child's death had not been their fault. Some parents tried to find comfort in their loss by focusing on the positives, such as knowing that their child knew they were loved and that they were no longer suffering. Many tried to be the good parent by creating something positive from their loss, such as fundraising in their child's name or using their loss experience to help others. No matter what coping mechanism parents employed to help them maintain their role as the good parent, at some point they all needed the support of others to help them accomplish that goal. For some, this support began in the ED during their contact with the healthcare team, while others sought out personal counselling services or leaned on the support of friends and family. Over time, most parents found that to be the good parent they needed to move forward with their lives. Some did this because they knew their children would have wanted them to move forward and be happy, while others knew they needed to be good parents for the living as well.

Strength from Faith

Some parents turned to their faith in God for strength, taking solace in the idea that their children were safe in heaven because they'd been raised with faith. A study by Thompson et al. (2011) found similar results, with some parents describing how they turned to their faith in God and their belief that their child was now safe and free from suffering in the afterlife. Two mothers in this study described how the loss of their child had actually strengthened their faith, and they took comfort in the knowledge that someday they would be reunited with their child in the afterlife. This reunion with their child meant that their role as the good parent had not ended, but rather had evolved into a more internal bond. This concept of an eventual reunion between parents and their children is prominent in the literature, with many parents identifying this as giving them hope for the future (Arnold & Gemma, 2008; Davis, 2001; Meert et al., 2009; Thompson et al., 2011).

The Search for Answers

For some parents, faith was not enough and they needed a more concrete understanding of how and why their child died. In some cases, these answers enabled parents to maintain their role as the good parent by helping them to protect their surviving children. In other cases, this knowledge reassured parents that they had, in fact, been good parents and were in no way responsible for their child's death. One couple in this study actively sought out answers around their son's death by immersing themselves in learning everything they could about his condition. This not only armed them with the knowledge to protect their surviving children from a similar fate, but also helped them to understand that their child's death was not their fault. Other parents found answers in the autopsy results or when they were given a cause of death by members of the healthcare team. Knapp et al. (2005) and Garstang, Griffiths, & Sidebotham (2014) both described how autopsy results can be crucial for parents to gain this understanding and find meaning in their child's death. Having a cause of death helps parents to understand the "how" and "why" of their child's death and helps to relieve their own guilt over feeling somehow at fault for the death. Parents in this study described an incredible feeling of relief when they received a cause of death from the autopsy result, as this reassured them that they were not responsible for their child's death and that they had been the good parent.

Unfortunately, for most parents, there was a delay of several months before they received the autopsy results, during which time they imagined a multitude of possibilities for why their child had died. Garstang, Griffiths, & Sidebotham (2014) found similar results in their study, and described how autopsy results were only helpful if parents received them and understood them. Often there were significant delays in parents receiving results or parents received them in the mail so they had no one to ask questions of if there were things they did not understand. For some parents in this study there was no cause of death found despite an autopsy being completed. This lack of answers left parents with nothing to pin their anger or fears upon, creating even more uncertainty and unanswered questions than they had before. One couple's autopsy report that did not identify a cause of death did describe how their child appeared well cared for, and so they took comfort in knowing they had been good parents. Another mother recalled being frustrated by waiting so long for autopsy results only to be left with just as many unanswered questions as she had before the autopsy. She wanted a cause of death to blame and to point her anger at, but she was left with nothing but questions.

The Search for Comfort

Another way for parents to maintain their role as the good parent was to focus on the positive aspects of their child's life, including how their child had positively impacted the lives of others (Meert et al., 2009). For many parents, this was evidenced by the volume of people that attended their child's funeral and the outpouring of positive memories those people had about their child. One mother in this study recalled how proud she felt that it was standing room only at her child's funeral because this showed her how many lives he had touched in the short amount of time he had lived. Another couple was overwhelmed by their child's classmates coming by and sharing stories about their child, an act which reaffirmed the positive impact of their child's life and reassured them that he would not be forgotten.

Some parents coped with the changes in their role as the good parent by focusing on the positives they still had in their lives. For some this involved focusing on their surviving children and appreciating the people they still had in their lives (Meert, Thurston, & Briller, 2005), while others focused on the blessing of the time they did have with their child (Meert et al., 2009). Some parents also focused on the positive that death meant their child was no longer suffering (Arnold, Gemma & Cushman, 2005; Proulx et al., 2015). Two mothers in this study felt that death was the preferred outcome for their child, as they would have suffered or been severely impaired if they would have survived the resuscitation.

Despite some parents' attempts to focus on the positives in their lives, not everyone was able or ready to find a "silver lining" in the death of their child. Some described getting caught up in anger and trying to find someone to blame for their loss (Meert et al., 2009; Meert, Thurston, & Briller, 2005). Parents needed an outlet for their pain and grief, and for many this meant striking out at others, including members of their own family. One couple described continued anger over the loss of their child years after the death, partly because they were unable to create anything positive from their loss and partly because they felt the healthcare system had failed them by failing to save their child. Another mother identified not being ready to find a "silver lining" in her loss, and was unsure if she ever would be. She had many regrets around her child's death, including not being present at the actual time of death, and felt she needed to resolve those feelings before she would be able to look for anything positive in her loss.

Creating Positive Memories

Many parents maintained their role as the good parent by trying to create something positive from their child's death, whether through organ donation, funding charities in their name, or using their grief experience to help others. Bogensperger and Lueger-Schuster (2014) described bereaved parents undertaking a "process of finding and integrating meaning of the loss and its consequences into one's worldview" (p.1). Arnold and Gemma (2008) further explained that for parents "finding some positive reason for the death means the child did not die in vain" (p.668). Parents in this study described a need to find something positive in their loss or to create a benefit from their tragedy, as they refused to believe their child's death was pointless.

Many authors have described ways in which parents have tried to create something positive from their child's death or their own grief experience. Some created meaning through organ donation, as this meant their child's death had given others another chance at life (Knazik et al., 2003; Meert, Thurston, & Briller, 2005). Some chose to use their experience to help others through volunteer work, raising funds for charities, or participating in support groups (Arnold & Gemma, 2008; Davies, 2001; Meert, Thurston, & Briller, 2005). One father in this study described how he shared his grief experience with others in order to help them understand the grief process and how to support their own loved ones through grief. Another couple set up scholarships and fundraising activities in their child's name to support activities and groups that she had been passionate about in her life. These activities not only served to create meaning around the loss of their child, but also reassured parents that their child would be remembered by others in a positive light. One couple in the study tried to create something positive in their son's name but they were unable to do so, and this not only intensified their grief but made them angry that their son's death seemed to be pointless.

The Need for Support

Regardless of the coping methods parents used to maintain their role as the good parent, at some point every parent identified a need for further support. For many parents, this need for support to maintain their role as the good parent started in the ED during their interactions with the healthcare team. The ED was an unfamiliar environment for most, and parents were often lost in a sea of strangers not knowing how to be involved in their child’s care or even be physically present to support them. Strong communication was one way the healthcare team could support parents in maintaining their role as the good parent, as this was crucial to them understanding, participating in, and making sense of their child’s death (October et al, 2014). Accurate and timely information provided by the healthcare team helped to reassure parents that everything possible was done for their child and that they did not suffer (Garstang et al., 2014; Knapp et al., 2005; Meyer et al., 2006). Having as much information as possible about their child’s death also helped to reassure parents that the death was not their fault, thereby reducing their feelings of guilt (Garstang et al., 2014). Despite the importance of this support through communication, many parents in this study identified feeling like they were left in the dark about the severity of their child’s condition. Many parents were left in a separate room while the healthcare team was attempting to resuscitate their child, and there was minimal if any communication about what was happening. One couple described how the lack of updates from the healthcare team led them to believe the resuscitation was going well, so it was a horrible shock to them when they were taken into the room with their child only to have him immediately declared dead.

Meert et al. (2009) and Meert, Thurston, and Briller (2005) described how parents wanted honest communication about their child and wanted to be updated regularly. They understood that this communication might not be easy for healthcare providers to give, but with-holding information only impaired their ability to maintain their role as the good parent. Garstang et al. (2014) and Meert et al. (2007) described similar findings with parents identifying distrust of the healthcare team when information was with-held. Being uninformed led to a loss of control and unnecessary suffering for both parents and their children due to false hope of recovery. One mother in this study who was present in the resuscitation room with her child recalled her distress over watching the healthcare team “break” her child. No one explained to her what was happening or what the healthcare team was doing, so by her interpretation they were breaking his bones and causing him to suffer even more.

A lack of information can be especially detrimental to parents facing the unexpected loss of a child, as they commonly feel guilt or blame themselves for the death because there is no “why” for their loss. Unanswered questions or misconceptions over medical care can be devastating, as it leaves parents feeling like they are to blame for the death or that not everything was done to save their child (Bucaro, Asher, & Curry, 2005). One parent in this study described how no one in the healthcare team explained what had happened with her child, so she went home believing that she had caused his death. It was not until she received the autopsy report months later that she found out the death was due to an undiagnosed medical condition and that nothing she could have done would have prevented her child’s death. Knazik et al. (2003) and Rini and Loriz (2007) describe the importance of healthcare providers keeping the family informed, especially when the family is not present in the room with their child. This communication allows parents to begin to process the severity of the situation and acknowledges the possibility that their child might not survive. This knowledge empowers parents to maintain their role as the good parent, greatly impacts their decisions around their child’s care, and gives them an opportunity to perform final tasks like saying goodbye.

Support by the healthcare team also involves informing parents about what comes next after the death of their child. Many parents were confused by the presence of police as no one had explained to them that the police and medical examiner are automatically involved in every unexpected child death (Garstang et al., 2014; Lawrence, 2010). Instead parents felt like criminals as they were taken away for interviews, some even separated from their spouse and taken to a police station for interviews to be recorded. One mother recalled how she thought the police were present because they had escorted the ambulance with her child to the hospital. It was only when they separated her and her spouse for video-recorded interviews that she realized they were there to ensure that she had nothing to do with causing her child’s death. Keeping parents informed helps them to feel prepared and in control, and helps to alleviate unnecessary guilt and trauma from what is already a very traumatic time in their lives.

For those parents that did receive support through communication with those involved in their child’s care, the communication was not always delivered in a compassionate way. Some parents felt physicians excluded them from conversations, “talked over them” by using technical jargon, made callous or judgemental remarks, or simply dismissed their feelings altogether (Bright, Huff, & Hollon, 2009; Garstang et al., 2014; Meert et al., 2008b; Meert et al., 2007). Rini and Loriz (2007) described parents having difficulty with how they were approached for consent for autopsy, as they felt the timing and presentation of the information was insensitive. Parents in this study described similar feelings when they were approached for organ donation and in communication with the medical examiner. One father clearly recalled getting the call about organ donation when they had just arrived home from the hospital and were still in their garage. The topic of organ donation was never brought up while they were in hospital, but in the phone call the father was informed that he had to make a decision on organ donation right then and there. His surviving son overheard the conversation and was distraught over the thought of his sibling being “cut up”, so the parents declined donation. Later, when they had time to process the event, they regretted not saying yes to organ donation as that could have created a positive from their loss. Both parents firmly believed that they would have said yes to organ donation if it would have been handled in a more respectful and compassionate manner.

Another way that the healthcare team supported parents in maintaining their role as the good parent was to be physically present and available in the ED. Parents wanted members of the healthcare team to be physically present, as this reassured them that they were important and that they were not alone in this experience (Meert et al., 2008a). Despite parents’ need for this support from the healthcare team, many parents found this support was not offered to them. Some parents found team members inaccessible as they were not physically present, others felt they were being avoided, and some felt “brushed off” as if the healthcare team had no time for them (Meert et al., 2008a; Meyer et al., 2006; Truog, Meyer, & Burns, 2006a). One father in this study recalled seeing the physician involved in his child’s care at the desk when they were leaving the hospital, but there was no eye contact and no offer of communication made so the father continued on his way out. He was surprised that someone who had shared such an intimate moment of his life could just go back to work and “forget” as if nothing unusual had happened that day. Meert et al. (2007) described how parents wanted “reassurance that the right decisions had been made and that no other plan of action would have altered the child’s outcome” (p.54). They reported a decreased intensity of grief in parents that had that emotional support at the time of their child’s death.

One of the other ways the healthcare team could offer support to parents was to advocate on their behalf, especially in terms of guarding their time with their child and their time to grieve. Meert et al. (2009) found parents appreciated when the healthcare team advocated on their behalf and delayed police interviews until they had a chance to say goodbye to their child. One of the fathers in this study strongly suggested parents be provided with an advocate to remain with them in hospital through the entire process of their child's death. He felt the advocate could liaison between the parents and the healthcare team to provide them with updates and information on their child's condition without disrupting the team working on their child. They could also prepare parents for what would come next, such as making decisions about the funeral home, notifying family, and the role of the police and medical examiner. They could provide emotional support to the parents both in the hospital and afterwards, as they would uniquely understand the parents' experience of loss. Most parents did not report feeling supported by the healthcare team, rather, similar to findings by Garstang et al. (2014) and Widger and Picot (2008), parents were left feeling abandoned, unimportant, and alone in the worst moment of their lives. Lawrence (2010) and O'Malley, Barata, and Snow (2014) both identified a number of barriers to ED staff being able to provide support to grieving parents, including lack of a previous relationship with parents, lack of time, and a multitude of competing demands. They do, however, acknowledge that the healthcare team needs to make time to offer parents this support because it positively impacts their ability to cope with their loss.

After leaving the ED, many parents continued to seek professional support to cope with their changing role as the good parent. Some sought out professional counsellors, individual therapies, or met with their own physician to ask questions and vent emotions about their experience (Arnold, Gemma, & Cushman, 2005; Meert et al., 2005). Many parents specifically sought out the support of other parents that had lost a child (Donovan et al., 2015; Meert et al., 2009; Meert et al., 2005; Thompson et al., 2011). Other parents that had lost a child were able to more fully understand and sympathize with parents' grief, their need to maintain a connection to their child, and their struggle to come to terms with their new reality. There were some parents in this study that found parental bereavement groups helpful, especially early on in their grief. However, differences in circumstances surrounding the death and differences in ability to cope often made it difficult for parents to relate to one another. Some parents in this study initially attended a support group for parents that had lost a child, but then stopped going when they realized the differences between them and the other parents were too great to overcome. They found many of the parents at the support group were consumed with guilt over their child's death and struggled with maladaptive coping techniques even if years had passed since the death. The thought of their grief being that raw for so many years scared some parents, and many ended up turning to more individual counseling services that allowed them to work through their grief at their own pace. One mother described how she feared she would be dragged back into the depths of her grief if she surrounded herself by people who were unable to cope with theirs, so she turned to individual counseling to protect herself from that potential negative influence. Donovan et al. (2015) and Thompson et al. (2011) both cite this individual nature of grief as a reason for grief interventions to be flexible and individualized so they maximize the positive impact they have on those who are grieving. Several parents in this study also described more positive support from individualized counseling services, as this allowed them to work through their grief in their own way and in their own time.

In the period immediately after their child's death, most parents had a lot of support from family and friends. Parents needed others around for emotional support and connection, but also to assist with tasks of daily living such as making funeral arrangements, making meals, or simply offering them a distraction from their grief (Meert et al., 2009). Parents in this study described a constant stream of people through their home for the first few weeks after their child died, but then slowly all those people faded away. Over time, other people moved on from the loss and expected parents to do the same. They no longer wanted to talk about the death and either avoided the topic or discouraged parents from bringing it up in the first place. Woodgate (2006) reported that "parents said the mere mentioning of their child's name would turn a room from one that was alive and noisy to one that was cold and silent" (p.80). Parents in this study described these challenges as well, and they struggled with the need to maintain their role as the good parent by remembering and talking about their child with the knowledge that doing so made others uncomfortable. Thompson et al. (2011) and Meert et al. (2009) had similar findings, describing how family and friends would "disconnect" from the parents because they were too uncomfortable talking about the deceased.

Denhup (2015) described this phenomenon as a state of invisibility, explaining that "bereaved parents dwell in invisibility, whereby their lived experience of parental bereavement…goes undetected by others. This contributes to the isolation many parents experience after a child's death" (p.10). Support from friends and family was crucial to parents' ability to cope their changing role as the good parent, as they provided strength, reassurance, assistance with daily tasks, and shared in the overall grief experience (Arnold, Gemma & Cushman, 2005; Meert et al; 2008a; Meert et al., 2005). It meant parents were not alone in their grief and provided them with those they could lean on for support when they needed it. One couple in this study described how their friends were there for them the day their child died and they were still there as support years later. Though they had a multitude of people around them offering support in the beginning, these were the core people that remained through everything and who would always be their greatest source of support.

Some parents preferred to seek support from their spouse rather than looking to people outside of their family. Proulx et al. (2015) found this to be the case with fathers as they identified their spouse as their most important source of support and the person with whom they could discuss the emotional aspects of their grief. Several parents in this study identified their spouse as their main source of support because they were the people that most clearly understood their loss. They could openly share emotions and reminisce about their child with their spouse in ways that they did not feel comfortable doing with strangers. One mother did not have this experience with her spouse, as her spouse refused to talk about their child's death. He did not feel the need to talk about his grief and preferred to just move on with life, even though she felt a strong need to talk about their loss.

As much as parents recognized their own need for support, one couple in this study also recognized that the healthcare team needed support after the death of a child because they too grieved the loss of life. Donovan et al. (2015), Lawrence (2010), and Schonfeld (2012) all supported this recommendation and urged healthcare providers to debrief after the death of a child and to seek out individual counseling services as needed. They recognized that the death of a child is hard on the healthcare team as well because they too believe children are not supposed to die and often take the death of a patient as a personal failure.

Moving Forward

Over time, most parents found that to maintain their role as the good parent they needed to move forward. But this move did not involve forgetting their child or leaving their grief behind, rather it involved striking a balance between focusing on the living and strengthening their internal relationship with the child they lost. As in a study by Meert et al. (2009), some parents in this study described moving forward and trying to find happiness because they knew that was what their child would have wanted for them. For other parents, surviving children were their driving force to go on living (Meert et al., 2005). One father in this study clearly identified his surviving daughter as his reason for getting out of bed in the morning. She had not stopped living despite grieving the loss of her sibling, and that inspired him to carry on despite his own grief. Some parents focused on trying to live the life their child would have wanted them to, as Thompson et al. (2011) reported parents looked forward and moved on with life because they knew their child would have wanted them to go on living. One mother in this study clearly recalled the moment when she decided to take her child's happiness and use it to inspire positive things in her own life, as she knew her child would have wanted her to be happy.

Although moving forward involved changes to their role as the good parent, it did not end that role and parents clearly identified that moving forward did not mean they were forgetting about their child (Truog, Meyer, & Burns, 2006a). For some, part of moving forward was accepting the fact that their child was gone and that they were never coming back. As Arnold and Gemma (2008) described:

> "acceptance is inevitable if one continues to function in life, to move on. Acceptance means resignation to the fact of death, to the fact the child is gone and death is an unalterable reality. Acceptance means gradually knowing the child cannot be brought back to life and focus must be on memories and the living children." (p.667).

Thompson et al. (2011) found similar descriptions by parents, with the idea that death had to be accepted because it had happened and could never be changed. Two parents in this study, who experienced a distinct point in time when their grief suddenly eased, described that change as involving acceptance of their child’s death. They suddenly understood in their heart and their mind that she was gone and was never coming back no matter what they did. Although this brought on a renewed sense of loss, it was also the point when they felt they could finally take a deep breath and move forward with their lives. Acceptance was not a universal part of moving forward, however, as some parents described living “next to” their grief rather than accepting it. They felt that by accepting the death they were saying it was okay their child had died, and that was a statement no parent was willing to make (Arnold & Gemma, 2008; Proulx et al., 2015).

The New Normal

The death of their child instantly propelled parents into a “new normal” where the entire fabric of their lives had been altered without their consent. Here parents struggled to redefine themselves, restructure their family, and completely rebuild their view of the world. For many, this “new normal” involved a critical shift in their worldview, as their belief in a just world was shattered by the untimely death of their child. Many experienced a renewed appreciation for the little things in life and a shift in overall priorities, including a greater focus on family and a lowered tolerance for things they felt were unimportant. One father described how losing a child caused a shift in his perspective because now the worst thing that could possibly happen to him had happened, which meant he was no longer afraid of anything including his own death. Many parents also experienced a fear of subsequent loss, especially when there was no cause of death on which to pin their fears. They struggled with the need to protect surviving children while not knowing exactly what they were trying to protect them from. And several parents described their “new normal” as a balancing act between focusing on the living and remembering the deceased. They did not want their child to be forgotten, but they also did not want their death to overshadow the lives of those who still lived.

Shift in Worldview

For many parents, the “new normal” included a shift in their view of the world, as the death of their child challenged their ideal of a benevolent world and went against the natural order of life (Meert et al., 2005). Proulx et al. (2015) and Thompson et al. (2011) found that parents often experienced a shift in priorities, as the death of their child reminded them of how precious and tenuous life really was. Many parents described a renewed focus on the present and chose to “live life to its fullest” because they now understood that time was never guaranteed. Several parents in this study identified having a lack of patience for things they considered petty or unimportant. They felt their child’s death shifted their perspective back to what was truly important, and that, for them, was family. One father described how he no longer focused on his work or worried about money, rather he understood that the most valuable thing in his life was his family and he wanted to focus his time and energy on them.

Fear of Subsequent Loss

For some parents, the “new normal” included a fear of subsequent loss, especially the fear of losing another child. This was especially true of parents with surviving children when there was no cause of death found for the child they lost. One couple in this study described how they checked on their surviving child constantly because they did not know why their child died and so had no idea how to protect their surviving child from having the same thing happen. The parents lived in a constant state of fear, leaving them exhausted and torn between trying to protect their surviving child and wanting her to live without that fear overshadowing her life. Wijngaards-de Meij et al. (2005) explain that “for the person who has experienced loss without forewarning, there is no situation that feels safe…loss can come again out of the blue” (p.621).

The unexpectedness of the death and the lack of a "why" left parents fearful of everything because they had nothing to pin their fear on, and they worried they would be unable to protect their surviving children from the same fate.

Balancing Living with Remembering

For many parents, the "new normal" also involved a balancing act between remembering their child and moving forward with their lives. Parents did not want to forget their child, but they needed to focus some time and energy on the living as well (Proulx et al., 2015; Woodgate, 2006). This was especially true for parents that were expecting another child, as they struggled with making room for the new baby while maintaining their deceased child's role within the family. One couple in this study described this struggle when they had to face changing their child's room into a nursery for the new baby. They suddenly had to face going through their child's things and changing the room that had always been his. This was not an easy task, as moving his things and dismantling his room felt like dishonoring his memory and taking away his role within the family. Although this was a very emotional process, they did find ways to balance making room for the new baby with maintaining a connection with their deceased child. They also made plans for the future and designed ways they could introduce the new baby to their sibling despite the fact that they would never meet in person.

Methodological Strengths and Limitations

This section focuses on the strengths and limitations of this study, with respect to the analytic framework chosen and the overall research design. It also outlines recommendations for future directions in practice, education and research.

Conceptual Framework

This qualitative study was guided by five major constructs including: parent(s), pediatric ED, unexpected death, coping, and meaning. These constructs helped in participant selection by framing inclusion and exclusion criteria, guiding the creation of interview questions around coping and meaning, and helping inform data analysis by framing the concepts of coping and meaning. Definitions of these major constructs were provided in Chapter I.

The analytic framework chosen for this interpretive description study was the Theory of Chronic Sorrow. Chronic sorrow was first used in the literature to describe the recurring waves of grief experienced by parents of children with mental disabilities due to their loss of a “perfect child” (Eakes, Burke, & Hainsworth, 1998). Subsequent research found the occurrence of chronic sorrow in many different types of loss, and identified it as a normal response to an abnormal situation. This theory offers an explanation of how people respond to single or ongoing losses, and includes a model of chronic sorrow as a framework for understanding those responses and the bereavement experience as a whole (Eakes et al., 1998). The defining characteristics of chronic sorrow include: a) a perception of sadness or sorrow over time in a situation with no predictable end, b) sadness or sorrow that is cyclical or recurrent, c) sadness or sorrow that is triggered internally or externally and brings to mind a person’s losses, disappointments, or fears, and d) sadness or sorrow that is progressive and can intensify (Eakes et al., 1998).

Parents in this study described similar characteristics in their experiences of unexpectedly losing their child in the pediatric ED. Several parents described their loss experience as recurring waves of grief with no identifiable end-point. They also described a variety of triggers that, when encountered, refreshed their grief symptoms and sometimes made them as raw as the day their child died. These triggers could be anything from an anniversary date, to hearing their child's favorite song, to seeing other children that resembled the child they lost. One couple did describe their sorrow as being progressive as they found no meaning in their son's death. Other parents found their sorrow lessened over time, not resolving completely but there were longer periods of calm water between the waves.

The Theory of Chronic Sorrow identified distinct management methods that were used by those experiencing grief, including internal coping strategies used by the individual and external interventions implemented by professionals (Eakes et al., 1998). Use of effective coping strategies and appropriate interventions helped those experiencing chronic sorrow to find emotional balance, increase comfort, decrease the number of trigger events, and reduce the degree of perceived disparity (Eakes et al., 1998). Effective internal coping methods included things like focusing on the positive aspects of life and talking to others that had experienced loss. Parents in this study identified a variety of coping methods, including turning to their faith in God, searching for answers, trying to find meaning in their child's death, creating positive memories, and maintaining a connection to their child even after death. Effective external coping methods were identified as follow-up with healthcare providers and receiving information about their child's death. Parents in this study identified support as the most important external coping method, including support from the healthcare team, family, friends, and other professionals such as the police and the medical examiner. This support included not only physical presence, but also the sharing of information and compassionate communication. These strong similarities between the findings of this study and the Theory of Chronic Sorrow reinforce the decision to utilize this framework to guide this study.

Research Design

As is the case with all research methodologies, interpretive description had certain limitations which must be acknowledged. Interpretive description is not a prescriptive series of steps to guide the production of new knowledge, and it's generalizability is tenuous due to the contextual nature of the data generated (Thorne, 2008). But it can reveal new knowledge about the subjective, experiential, tacit, and patterned aspects of the human health experience, which can then be used to guide practice decisions (Thorne, 2008; Thorne, Kirkham, & O'Flynn-Magee, 2004). The evidence-based context of healthcare requires critical evaluation of the knowledge on which healthcare decisions are based. Interpretive description recognizes that healthcare clinicians are not satisfied with research that purely creates a description of a clinical phenomenon. Rather, they want to identify associations, relationships, and patterns with the phenomenon which can then be used to inform clinical practice (Thorne, 2008). This coupled with a greater understanding of the human health experience will enable healthcare providers to improve the quality of care they provide to their patients.

Interpretive description was an appropriate methodology for this study because there was knowledge around the parental experience of losing a child, but it lacked contextual grounding within unexpected loss in the ED. Applying this methodology not only allowed for a critical review of the current knowledge, but also provided a greater understanding of the parental experience within that specific context. Interpretive description also allowed the researcher to contribute personal experience to current knowledge, and provided an opportunity to enhance that knowledge into a greater understanding of the parental experience.

Qualitative research overall, and interpretive description in particular, is meant to enable participants to describe their experiences in their own words within their own context. These are deeply personal and contextual findings, but they do allow for inferences to be made in the literature between bereaved parents and others experiencing similar types of losses. The findings from this research can improve understanding around the parental experience of unexpectedly losing a child in the pediatric ED, and can also inform future practice, education, and research in the healthcare field.

In this research study, there were also limitations related to the participant sample. First, there was limited ethnic and financial diversity, as most participants were Caucasian and working, middle class. Second, there was limited ability to clarify any differences in coping or meaning between fathers and mothers, as the majority of participants were mothers. Further research that includes a focus on fathers and diverse populations would potentially expand the themes and provide more insight into parents' experiences. Longitudinal research would also help us to understand how parents' perspectives change over time.

Future Directions

Results from this study have highlighted potential future directions for healthcare providers in terms of practice and education. Gaps in research were also identified, and so considerations for future research were considered. These future directions are outlined below in terms of practice and education and research opportunities. Parents also identified recommendations for other parents facing the unexpected loss of a child, both in terms of personal coping techniques and how to support others through their loss.

Practice and Education

As part of the interview process, parents were asked to provide recommendations to healthcare providers on how they could improve their care of parents experiencing the unexpected loss of a child in the Pediatric ED. Despite the individual nature of each parents' loss experience, their recommendations all focused on similar themes of communication, professional support, and helping them to maintain their role as the good parent.

The first recommendation focused on communication between the healthcare team and parents. Parents wanted the healthcare team to be present, both in terms of being physically present with the family and being available for them to ask questions. They wanted to be fully informed about their child’s condition, including frequent updates, full disclosure of medical treatments, and forewarning about death being a possible outcome for their child. And they wanted the healthcare team to explain to them “what comes next”, especially in regards to the role of police and the medical examiner. Strong communication allowed parents to fully participate in their child’s care, to maintain their role as the good parent, and to prepare themselves for the possibility of losing their child.

The second recommendation focused on support of parents by the healthcare team. Parents wanted physical support in terms of the healthcare team being present with them both before and after their child’s death. They suggested providing an advocate for parents, someone who could liaison between the healthcare team and the family to provide updates, information on what to expect, and guidance as to “the next steps”. They wanted the healthcare team to advocate for them, in terms of protecting their final moments with their child. The healthcare team could request police to hold off on interviews in order to allow parents time to say goodbye so as to not interfere in their mourning. And they wanted the healthcare team to ensure supports were in place for parents before they left. This meant providing written material on how to access counseling services and ensuring parents had some sort of follow-up from the hospital in the next few weeks. This follow-up would ensure parents had been able to access any needed supports and would reassure parents that they were not alone or forgotten in this experience.

The third recommendation focused on the healthcare team helping parents to maintain their role as the good parent. Parents wanted the healthcare team to respect their role as parents and to allow them to fulfill that role by being present, being involved in decision making, and being able to support their child. Parents also encouraged the collection of mementos, as those physical objects were crucial in reinforcing their connection to their child, especially early on in their grief. The collection of mementos showed parents that the healthcare team understood how important their child was to them and valued their continued role as the good parent.

Research

There is very little research on the parental experience of losing a child, and even less research on that experience in the context of the ED. Multiple authors have identified child loss and loss in the ED as risk factors for complicated bereavement, so further research needs to be done to identify how these contextual elements affect parents' grieving process. There is also very little research examining the differences between mothers, fathers, and siblings, in terms of their coping mechanisms and the meanings they attribute to their loss experiences. Research in this area could help to individualize supports for these family members and help educate healthcare providers on how to best support the family as a whole. For parents specifically, research into ways that healthcare providers could support them in maintaining their role as the good parent would be beneficial. This would not only allow for the individualization and improvement of parental supports, but would also provide healthcare professionals with knowledge on how best to support parents and how to help them achieve their goals around being the good parent. Examining the loss experience from the perspective of close family supports could also add another layer to understanding the parental experience of loss, thereby enriching knowledge of the grief experience overall. And a longitudinal study with parents that have experienced the unexpected loss of a child would also help to inform healthcare providers, as it would enable understanding of how coping and needed supports change throughout the loss experience. This knowledge could guide the creation and implementation of a variety of support sources for families that are tailored to the different stages of the grieving process.

Recommendations for Other Parents

Parents also offered some recommendations to other parents facing the unexpected loss of a child. The first recommendation was to respect the individuality of grief, both in terms of letting themselves grief in their own way and respecting their spouse's need to grieve in their own way. Parents cautioned that placing expectations on how someone should grieve only led to strain on the relationship and a breakdown of the family's support system. The second recommendation was related to supports, both in terms of being supportive to their spouse and ensuring that they sought out the support they needed. Most parents identified their spouse as their strongest source of support even years after the death, and they encouraged parents to foster that support system because it would be there long after other supports had dropped off. They also encouraged parents to seek out the supports they needed rather than trying to manage their grief all alone. Parents explained that there was no shame in seeking out professional supports as everyone gets overwhelmed by grief at times, and it's better to get the support you need rather than suffering in silence.

Chapter Summary

This chapter presented a discussion of the findings of this research study. The central themes of grief as waves, being the good parent, and the new normal were discussed and compared to findings in the literature. In the second section of the chapter limitations and strengths of this research study were reviewed, along with recommendations for practice, education and future research opportunities. Parents also provided recommendations for other parents facing the loss of a child, both in terms of personal coping mechanisms and supporting others through the loss experience.

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Appendices Listing

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Appendix A: Letter of Invitation

Dear Parent,

My name is Holly Bekkering, and I am a pediatric nurse and student in the Master of Nursing program at the University of Manitoba. This letter is being sent to you on my behalf by the Clinical Resource Nurse at the Health Sciences Center Children's Emergency Department. I do not know your name or have any information about you or your family.

To complete my Master of Nursing program, I am doing a thesis about the parental experience of unexpectedly losing a child in the pediatric Emergency Department. I would like to explore this experience from the parents' perspective in order to discover how they cope with their loss, the meanings they attribute to that loss, and how those things change within five years of their child's death. I would also like to uncover parents' recommendations for health care providers in the pediatric Emergency Department in order to best support them and meet their needs. Dr. Roberta Woodgate of the College of Nursing at the University of Manitoba is my advisor for this study. My thesis has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and the research board at the Health Sciences Center.

In order to complete my thesis, I would like to interview yourself and other parents who have unexpectedly lost a child in the pediatric Emergency Department. The interview should take approximately one to two hours to complete. A second interview will be offered in order to validate any information provided and to give you an opportunity to clarify or expand on information from the initial interview. The second interview should take approximately 30 minutes to one hour to complete and may be done by phone. If you wish, you may decline to participate in the second interview.

Once all the interviews are completed, I will gather all the information from your interview and the interviews of other parents and compose my thesis detailing the themes that arise. The identity of parents that participate in the study will remain confidential throughout the study and will never be revealed or discussed with anyone. The findings from the thesis will be shared with other healthcare professionals in order to improve their understanding of the parents' experience of unexpectedly losing a child in the pediatric Emergency Department. If you wish, you will have the opportunity to receive a summary of the study findings.

If you are interested in learning more about this study, please contact myself directly or return the enclosed form in the envelope provided. I will then explain the study in further detail and answer any questions you may have. If you decide to participate, I will set up an interview at a time and location that is convenient for you. If you decide not to participate, you can say no without any consequences. Participation in this study is voluntary and you may withdraw from the study at any point in time.

Thank you for your time and consideration of this matter.

Sincerely,

Holly Bekkering, RN, BN, MN Student

Appendix B: Phone Script

Hello ___________

My name is Holly Bekkering and I am a master of nursing student at the University of Manitoba. I have received your invitation to participate in my study and I am now calling to provide you with further information and answer any questions you may have in hopes of confirming your participation.

I am interested in learning more about families' experiences with unexpectedly losing a child in the Pediatric Emergency Department. The research will provide insight into how parents characterize their experience, the coping mechanisms they used, and any advice they have for healthcare providers caring for families during times of loss. There is very little written information on the unexpected loss of a child in the Emergency Department, and nothing published on the parental experience of such a loss. As a paediatric nurse, I feel that nurses and other health care professionals that care for families in these situations would benefit tremendously from learning all we can about this experience from the parents' perspective. Although every parent's experience is unique, it is hoped that your shared experiences will help health care professionals understand how best to care for parents and families during their time of loss. This knowledge may also help other families understand that they are not alone in their loss, potentially gaining insight from the coping mechanisms of other parents. Overall, this study will result in new insights into the parental perspective of unexpectedly losing a child in the Pediatric Emergency Department. Findings from this study may be used to guide program development and resource allocation in order to optimize the support that parents receive while in the Pediatric Emergency Department.

In the process of this study, I will be conducting interviews with parents that have unexpectedly lost a child in the Pediatric Emergency Department. The interview should take approximately one to two hours to complete and will be digitally recorded so as to not miss out on any important information. If you are willing, a second interview (which may be done by phone) will be completed in order to validate the collected information and for you to have the chance to add any other information you feel beneficial.

All interviews will be typed out and read. Common thoughts, feelings and themes will be extracted and compiled. Although I will be the only person knowing the identity of each interviewee, Dr. Roberta Woodgate, my advisor for this study, will also read and have access to the typed out interviews. All names will be given code numbers in order to maintain confidentiality. All material, including tapes and written data will be stored in a secured place and one year after completion of the study, all material will be destroyed.

This research project is being done in order to fulfill the requirements of my thesis. It is my intention to take the information that I collect from this study and publish an article in a professional journal. Confidentiality will be maintained throughout the entire process and your name or identity will never be released. Upon request, you will have the opportunity to receive a summary of this study.

Once you agree to participate, you are free to withdraw from the study at any point of time without any consequence. You may also choose not to answer questions or stop the interview whenever you wish. Do you have any questions regarding this study? Would you be willing to participate?

If “No”: Thank you very much for your time and consideration of this study.
If “I would like to think about it”: Thank-you for your consideration. When should I call you back to find out about your decision?
If “Yes”: Thank you for your participation. When would be a good day and time for you to schedule the first interview? Would you like for it to take place in your home?
If “No”: Where would you like to conduct the interview?

At the first interview, I will be asking you to sign a consent form saying that you will participate based on the information that has been provided to you. The consent form can also be mailed out to you ahead of time if you would prefer to look over it and ask any questions you have before the interview. You will also be asked to fill out a short demographic form so I may get to know your family better. In order to prepare for the interview, it may be beneficial to think about your thoughts, feelings and experiences and any events or decisions that stand out in your mind. My goal is to find out all about parenting a child with autism while living in a rural area.

Thank you for your time. I look forward to seeing you on __________ at __________.

Appendix C: Consent Form

Research Study Title: The Parental Experience of Unexpectedly Losing a Child in the Pediatric Emergency Department.

Study's Investigators:

1. Holly Bekkering, RN, Graduate Student, College of Nursing, University of Manitoba.
2. Dr. Roberta Woodgate, College of Nursing, University of Manitoba, Advisor.
3. Dr. Susan McClement, College of Nursing, University of Manitoba, Internal Committee Member.
4. Dr. Bryan Magwood, Faculty of Medicine, University of Manitoba, External Committee Member.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. This research is one of the requirements for completion of the Masters of Nursing program at the University of Manitoba. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, ______________________, agree to participate in the above study. I understand that the purpose of this study is to explore the parental experience of unexpectedly losing a child in the pediatric Emergency Department. My characterization of my loss, the meanings I attribute to my loss, and the coping methods I have used will all be discussed. My recommendations for healthcare providers on how to best support parents through their loss will be determined. And I understand that knowledge gained from this study will be used by healthcare providers to improve their care and support of parents experiencing unexpected loss in the pediatric Emergency Department. I have read the written information provided about the study and any questions I had have been answered.

I understand that if I agree to participate in this study, I will be asked to participate in two open-ended, digitally recorded interviews. I understand that the Master of Nursing student, Holly Bekkering, under the supervision of Dr. Roberta Woodgate, will be doing the interviewing for the interviews. I understand that I will be asked questions related to my experience of unexpectedly losing my child in the pediatric Emergency Department. I understand that the first interview will take approximately one to two hours and will be digitally recorded for further analysis and interpretation. I understand that the second interview will take approximately 30 minutes to one hour and will also be digitally recorded. I also understand that I may decline the second interview if I do not wish to be interviewed again. I understand that I will be asked to complete a Demographic Form prior to being interviewed. This form should take approximately

10-15 minutes to complete. I understand that the interviewer will be taking field notes during the interview to describe her observations, reflections, and potential arising themes. These notes will be kept confidential except to be shared with her advisor to aid in analysis of the data.

I understand that my participation in this study is completely voluntary. I understand that even if I decided to participate, I may withdraw at any time and refrain from answering any questions without prejudice or consequences. As well, the information that I have provided will not be included within the study if I choose to withdraw from participation.

I understand that there are no direct benefits for me to participating in the study. However, I understand that this study will result in knowledge that may help healthcare providers to better support parents that unexpectedly lose a child in the pediatric Emergency Department. I understand that there are no undue risks to me by taking part in the study. I understand that talking about the loss of my child may bring up strong emotions, and that if I become upset the interview can be paused or rescheduled at a better time. And I understand that if I need someone to talk to about my feelings, a list of community resources for bereaved parents will be provided by the researcher.

I understand that findings from this study may be presented at a health or education conference or published in a professional journal. In all instances, my or my family's identity would not be discussed or revealed to anyone. Only Holly Bekkering, the study's researcher, will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that my name will be replaced with a code number so that no one will be able to identify me. I understand that only Dr. Roberta Woodgate and Holly Bekkering will have access to the interviews. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e. abuse situations). I understand that all the data including the digital recordings, interview transcripts, field notes, and demographic information will be stored in a locked cabinet within the researcher's home and on a computer protected by a password known only to the researcher. I understand that all data will be destroyed following completion of the study. I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification of new information throughout my participation. I understand this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and by the ethics board at the Health Sciences Center. If I have any concerns about this project I may contact Dr.

Roberta Woodgate at (204) 474-8338 or the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to me to keep for my records and reference.

I agree to take part in the first interview. Yes _________ No _________

I agree to take part in the second interview. Yes _________ No _________

Signature of Parent/Guardian ________________________________ Date ______________

Print Name of Parent/Guardian ______________________________

Signature and Title of Witness _______________________________ Date ______________

Print Name of Witness _____________________________________

I would like a summary report of the findings. Yes _________ No _________

Please mail a summary of the report findings to:

Name: ______________________________________

Address: ____________________________________

City/Province: _______________________________

Postal Code: _________________________________

Appendix D: Demographic Questionnaire

ID#:

Date:

Information on this form will help me to get to know you and your family better. All information collected will remain confidential.

1. How old are you?
    Yourself: Sex ___ Age __ (years)
    Partner: Sex __ Age ___ (years)

2. Are you:
    Single ______Married_____Separated____
    Divorced_____Widowed_____Common-law______

3. How many children do you have in your family:

Age	Sex	Grade Level/Daycare

4. Where do you live: Rural ____ Urban _____

5. How much time has passed since the death of your child:

6. How old was your child when they died:

7. Is there anything else you would like to tell me about yourself or your family?

Thank you for your assistance in helping me understand and learn more about the needs and experiences of parents who have unexpectedly lost a child in the pediatric Emergency Department.

Appendix E: Interview Guide

Introduction to the Interview

I would like to learn more about what it is like to unexpectedly lose a child in the pediatric Emergency Department. I would like for you to share your experiences from the time prior to your child's death to the present period. To help tell your story, I will be asking you a series of questions. I would like you to talk about your experience of losing your child, the needs that you had, the available support or the support that was unavailable, how your life has changed, your coping methods, and any other thoughts or feelings that come to mind.

Note: Probes will be used only as necessary to encourage further discussion.

1. Tell me about life when your child was alive.
    a. Who was in your family at that time?
    b. What was the day-to-day like for your family?
    c. What was the day-to-day life like for you as a parent?
    d. Tell me about some good memories that you had with your child from that time.
    e. Were there any challenges that you faced being a parent at that time?
    f. What types of things did you and your family do to cope with problems at this time?

2. Tell me about what brought you to the Emergency Department with your child.
    a. What were the circumstances?
    b. Were you present with your child before they went to the pediatric Emergency Department?
    c. If not, how did you find out they were in the pediatric Emergency Department?
    d. How did you get to the hospital?

3. Walk me through what transpired in the pediatric Emergency Department.
    a. Describe the communication between you and the healthcare team.
    b. Describe the support provided to you by the pediatric Emergency Department.
    c. At what point did you realize that your child's medical situation was not going well?
    d. Describe what was happening around the time of death.
    e. How were you told that your child had died?
    f. Who told you that your child had died?

4. Tell me about what happened after your child's death while you were still in the pediatric Emergency Department.
    a. Were you able to be with your child?
    b. Did a member of the healthcare team stay with you?

   c. Were you provided with bereavement information or resources?
   d. How did you get home from the hospital?

5. Tell me what life was like for you and your family after your child's death.
   a. Describe your family's life in the first few weeks.
   b. Describe your family's life from the first month to the first year.
   c. Describe your family's life from the first year until now.
   d. What types of things did you and your family do to cope through this time?
   e. Did your methods of coping change over time?

6. Tell me what life is like for you and your family now.
   a. Who is in your family at this time?
   b. What is day-to-day life like for your family?
      i. How is your relationship with your partner?
      ii. Has your relationship with your partner changed?
   c. What is day-to-day life like for you as a parent?
      i. Has your parenting changed from previous?
      ii. How has your parenting changed?
   d. Tell me about some good experiences or joys that you have at this time in your life.
   e. Tell me about some difficult times or challenges that you have at this time in your life.
   f. What types of needs do you have at this time?
      i. Do you have supports to meet those needs?
      ii. Are there supports that could better meet your needs that are presently unavailable to you?
   g. What types of things do you do to cope?
   h. How do you see things for the future?
      i. Do you have concerns for the future?
      ii. Do you have fears about the future?
      iii. Do you have plans for the future?
   i. How has the loss of your child changed your worldview?
      i. Has it changed your priorities in life?
      ii. Has it changed your relationships?
      iii. Has it changed your view of the world and your role in it?

7. Based on your experiences, what advice would you give to other parents that unexpectedly lose a child in the pediatric Emergency Department?

8. What suggestions would you have for healthcare professionals about how they can best support parents who unexpectedly lose a child in the pediatric Emergency Department?

9. Is there anything else you would like to talk about that you feel is important for me to know?

Appendix F: Community Resource Listing

THE COMPASSIONATE FRIENDS

Winnipeg Chapter – 685 William Avenue, Winnipeg, MB

Phone: (204) 787-4896

Email: smtaylor@hsc.mb.ca

Website: www.tcfwinnipeg.org

ABORIGINAL SERVICES

Phone: (204) 787-3427

Available: Monday-Friday: 8:30-4:45

Please leave a message during evenings and weekends and your call will be returned.

CHILD LIFE (sibling support)

Phone: (204) 787-2650

Available: Monday-Friday: 8:30-4:30

Please leave a message during evenings and weekends and your call will be returned.

SPIRITUAL CARE

Phone: (204) 787-3884

Available: in hospital 24 hours a day

KLINIC CRISIS LINE

Phone: (204) 786-8686

Available: 24 hours a day

Appendix G: Invitation for Meeting with Medical Director

Faculty of
Health Sciences

College of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-8338
Fax: (204) 474-7682

June 8, 2016

Dear Parent,

My name is Dr. Scott Sawyer, and I am the medical director of the Children's Emergency Department at the Health Sciences Center. This letter is being sent to you on my behalf by Holly Bekkering, the principal researcher for the study in which you recently took part. I do not know your name or have any information about you or your family.

I understand that being interviewed for this study may have raised questions regarding the care you received while in the pediatric Emergency Department. To address your questions, I would like to offer you an opportunity to meet with me to discuss the care you received. If you would like to set up a meeting, I can be contacted by phone or email, and then we can arrange a time that is convenient for you. With your consent, I will review your child's medical chart prior to our meeting in order to familiarize myself with your case and better enable me to answer any questions that you might have.

I appreciate your participation in Holly Bekkering's study, as it will improve our knowledge and help us to better support parents during times of loss in the future. Also, I encourage you to bring forward any questions and concerns you may have, as discussion around patient care only works to improve the care we provide to patients and their families.

Thank you for your time and feel free to contact me with any questions or concerns.

Sincerely,

Dr. Scott Sawyer

Section Head, Pediatric Emergency Medicine

HSC Winnipeg Children's Hospital

840 Sherbrook Street, Winnipeg, MB. R3A 1S1

Phone: 204-787-2433

Email: ssawyer@exchange.hsc.mb.ca