

Parental Bereavement: Looking Beyond Grief - Challenges and Health

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Dissertation submitted in partial fulfillment of  
the requirements for the degree of Doctor  
of Philosophy in  
Nursing in the Graduate School  
of Duke University

2016

ABSTRACT

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## **Abstract**

There is no imaginable event more devastating for parents than the death of their child. Nevertheless, while bereaved parents grieve they are also expected to carry on with their life. For these parents in emotional turmoil after the loss of a child, the day-to-day activities that were once routine may now be challenging. Parental bereavement has been described as a life-long complex, intense, and individualized response, with grief responses interwoven in their daily activities, but the nature of these daily life challenges are not known.

In their daily routines, parents who have a deceased child, include known activities that remind them of the child. These behaviors have been described as “continuing bonds,” a concept, which will be analyzed in this dissertation in order to describe a clear conceptual definition and present a model for future research.

Using the Adaptive Leadership Framework as the theoretical lens and a mixed method, multiple case study design, the primary study in this dissertation aims to provide understanding about the challenges parents face in the first six months following the death of their child, the work they use to meet these challenges, and the co-occurrence of the challenges and work with their health status. Bereaved parents challenges are unique to their individual circumstances, complex, interrelated and adaptive, as they have no easy fix. Their challenges were pertaining to their everyday



life without their child and classified as challenges related to: a) grief, b) continuing bonds, c) life demands, d) health concerns, f) interactions, and g) gaps in the healthcare system. Parents intuitively responded to the challenges and attempted to care for themselves. However, the role of the healthcare system to assist bereaved parents during this stressful time so that their health is not negatively impacted was also recognized. This study provides a foundation about parental bereavement challenges and related work that can lead to the development and testing of interventions that are tailored to address the challenges with a goal of improving bereaved parents health outcomes.

## **Dedication**

This dissertation is dedicated to my niece Anneka Mascarenhas whose fond memories served as an inspiration for this dissertation and my sister who endured her loss by strengthening her faith in the divine power she believes in. I would also like to dedicate this dissertation to my own children who have been my constant and ongoing support throughout my PhD program.

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# 1. Chapter 1

## 1.1 *Problem and Introduction*

While the death of a child is unimaginable for parents, when it occurs (Hawthorne, 2016) there are significant consequences on parents' day to day functioning and health (Donovan, 2015). In 2003, the Institute of Medicine's (IOM, 2003) *"When Children Die"* report highlighted the paucity of research in pediatric bereavement care and called for the integration of bereavement care into pediatric palliative and end-of-life care, with a goal to improving services to bereaved parents. Despite, this initiative more than a decade ago, pediatric bereavement services are not standard practice nationwide and lack empirical and theoretical foundation (Donovan, 2015; Harvey, 2008). In the absence of empirical evidence, hospitals often rely on adopting programs with assumed effectiveness (Harvey, 2008), which targets the bereaved parents' emotional response of grief with little emphasis on global health outcomes.

Parental grief is complex, intense, life-long (Arnold, 2008), and likely has long lasting implications on parental well being. In addition, parental grief has been described as more intense than the grief due to loss of a spouse or parent (Rostila, 2011) and when compared to adults who lose a spouse or parent, parents who experience the loss of a child have higher morbidity and mortality rates (Rostila, 2011; Werthmann, 2010). Additionally, parents' bereavement occurs over a lifetime in part out of their desire to maintain a relationship with their deceased child.

To illuminate this idea that grief transcends time Klass' (1993) proposed a new concept of "continuing bonds." "Continuing bonds," posits that grieving individuals maintain bonds with the dead while building new relationships with the living. However, it is not clear whether continuing relations with the deceased is adaptive or mal adaptive for the individual who has lost a loved one (Klass, 2009). While some studies have demonstrated that continuing bonds is a normal response to bereavement, its consequences on bereavement outcomes including grief resolution and health is still debated (Field & Friedrichs, 2004; Field, Gal-Oz, & Bonanno, 2003; Ronen et al., 2009; Ronen, 2006). Yet, memory making activities that exemplify the activities of continuing bonds, like picture taking or offering parents the child's hair locks or foot prints as mementos are integrated into end-of-life care and palliative care services on the assumption that they are beneficial for parents (Kobler et al., 2007).

The lack of clarity in research findings on "continuing bonds" may be in part due to the absence of a clear understanding of what constitutes a continuing bonds relationship. Refinement of this important concept using a systematic concept analysis will help delineate its critical attributes, reduce ambiguity, and increase its relevance for clinical practice and research (Wilkins & Woodgate, 2006). Clarification of the concept can also contribute to the theoretical understandings of bereavement and with more research the impact of continuing bonds on parents' bereavement trajectories will become clearer.

Traditionally, parental bereavement is studied using theories or concepts that characterize the parental bereavement response such as grief, attachment, coping, adaptation, caring, life-transitions, and resilience (Barrera et al., 2007; Barrera et al., 2006; Davies, 2004; Dokken, 2013; Field, Gao, & Paderna, 2005; Foster, 2010; Harper, O'Connor, & O'Carroll, 2013; Hoekstra-Weebers, Littlewood, Boon, Postma, & Humphrey, 1991; Kachoyeanos & Selder, 1993; Kavanaugh & Moro, 2006; Klass, 1997; Rando, 1983, 1985; Wijngaards-de Meij et al., 2008). Thus, while these theories and concepts expand our understandings of parental grief, they do not help us to understand the complexities of parental bereavement related to challenges they experience in their life without their child (Dokken, 2013). We lack insight through study of how these challenges may influence bereaved parent's health outcomes.

A deeper understanding of parental bereavement and the work that parents do to try and address the challenges they face will help describe the complexities of the parental bereavement period. The Adaptive Leadership Framework (Adams, Bailey, Anderson, & Galanos, 2013; Thygeson et al., 2010) provides the theoretical lens, through which we examined the challenges and the related work that bereaved parents faced. Once the challenges are identified bereavement care interventions can be developed, tested, and integrated into our continuum of pediatric palliative, end-of-life, and bereavement care services with the goal to improve bereaved parents health outcomes.

## ***1.2 Background***

### ***1.2.1 Bereavement and Grief***

The studies that explore parents' responses to the death of their child encompass both bereavement and grief research often without distinction between the two terms. Additionally, since grief is recognized as the universal response to death, bereavement has often been studied from the lens of grief thus resulting in the ambiguity of the two phenomena. The phenomenon of grief was first described by Freud (1917), as an emotional state of sadness. Grief is recognized as a normal but complex response to the death of a significant person and is manifested in each individual through physical, psychological, spiritual, social, and intellectual responses (Dyer, 2005). Additionally, in some situations, the responses associated with bereavement can begin prior to the loss or in anticipation of the loss. This is a transitory phase of grief identified as anticipatory grief (Al-Gamal, 2010). Parents can experience grief even prior to the death of their child.

Bereavement however, is the "objective situation of having lost someone significant" (Stroebe, 1988) Bereavement is the "state" (Mariam Webster, 2014) of the loss of a loved one, while grief is the reaction to the loss of a loved one. Consequently, the "bereavement period" is the time when the individual is grieving as a response to the loss of a significant person. Thus the bereavement period is often studied through the lens of grief and grief theories.



**Table 1 Evolution of Grief**

Theorist	Attributes/ Focus	Type of Model	Stages/Phases
Freud (1915)	<ul style="list-style-type: none"> <li>Emotional response of sadness</li> <li>Experience of loss and the process of recovering from the loss</li> </ul>	No model	
Engel (1964)	<ul style="list-style-type: none"> <li>A linear process</li> <li>Does not include the recovery or grief resolution</li> </ul>	Time based	2 stages: <ul style="list-style-type: none"> <li>Shock</li> <li>Disbelief</li> </ul>
Kubler Ross (1969)	<ul style="list-style-type: none"> <li>A linear process</li> <li>Includes the grief resolution stage of acceptance</li> </ul>	Stage and time based	5 stages: <ul style="list-style-type: none"> <li>Denial</li> <li>Anger</li> <li>Bargaining</li> <li>Depression</li> <li>Acceptance</li> </ul>
Martocchio (1985)	<ul style="list-style-type: none"> <li>A linear process</li> <li>Includes the grief resolution stage of acceptance</li> </ul>	Stage and time based	5 stages: <ul style="list-style-type: none"> <li>Shock and Disbelief</li> <li>Yearning and protest</li> <li>Anguish, disorganization, and despair</li> <li>Identification in bereavement</li> <li>Reorganization and restitution</li> </ul>
Parkes and Brown (1972)	<ul style="list-style-type: none"> <li>A linear process</li> <li>Based on attachment theory</li> </ul>	Stage and time based	4 stages: <ul style="list-style-type: none"> <li>Shock and numbness</li> <li>Yearning and searching</li> <li>Despair and disorganization</li> <li>Reorganization and recovery</li> </ul>
Bowlby (1980)	<ul style="list-style-type: none"> <li>Non-linear</li> <li>Based on dual process model of loss and recovery</li> </ul>	Stage and time based	2 processes: <ul style="list-style-type: none"> <li>Loss oriented</li> <li>Restoration oriented</li> </ul>
Sanders (1989)	<ul style="list-style-type: none"> <li>An "Integrative Model"</li> <li>Combines loss and recovery termed as healing</li> </ul>	Stage and time based	5 stages: <ul style="list-style-type: none"> <li>Shock</li> <li>Awareness of loss</li> <li>Conservation</li> <li>Withdrawal</li> <li>Healing</li> </ul>
Worden (1991)	<ul style="list-style-type: none"> <li>Tasks of mourning model</li> <li>Includes grief resolution stage of acceptance</li> <li>Recognizes "grief work"</li> </ul>	Stage and time based	4 stages: <ul style="list-style-type: none"> <li>Accepting reality of loss</li> <li>Work through and experience the grief</li> <li>Adjustment to the environment</li> <li>Withdraw emotionally from the deceased and relocate self</li> </ul>
Cowles and Rodgers	<ul style="list-style-type: none"> <li>Delineated attributes, antecedents, and consequences of grief</li> </ul>	Concept analysis	

**Table 1 Evolution of Grief**

Cowles and Rodgers (1990)	<ul style="list-style-type: none"><li>▪ Delineated attributes, antecedents, and consequences of grief</li><li>▪ Grief: process, normal, dynamic, pervasive, and individualized</li></ul>	Concept analysis	
Cowles (1996)	<ul style="list-style-type: none"><li>▪ Added the cultural perspective</li><li>▪ Cultural influence in the outward expression (mourning)</li><li>▪ No other differences</li></ul>	An expanded concept analysis	
Klass (1997)	<ul style="list-style-type: none"><li>▪ Continuing bonds concept</li><li>▪ Continued relationship with deceased</li></ul>	Concept, not stage or time based	

Grief theorists have advanced our understanding of grief from recognizing the phenomenon of grief, to defining grief, examining it as a process, and identifying potential outcomes (see Table 1). In addition to grief theories, other related concepts or middle-range theories such as coping, caring, resilience, and life transitions (Barrera, 2007; Davies, 2004; Dokken, 2013; Field, 2005; Foster, 2010; Harper, 2013; Wijngaards-de Meij, 2008; Wijngaards-de Meij, 2008; Kachoyeanos, 1993; Kavanaugh, 2006) have also been used to describe parental bereavement trajectories including their coping, adaptation, and grief outcomes. However, these theories have not added to our understanding of the challenges individuals face during bereavement. This theoretical evolution of grief and other related theories has significantly facilitated our understanding of grief as a natural and complex response typically seen in bereavement.

### ***1.2.2 Parental Bereavement and Grief***

Parental bereavement is described as a “narcissistic wound” in which parents question their social roles, identities and existential beliefs (Caeymaex, 2013). Bereaved parents’ grief is considered most traumatic of all grief as it defies the natural order of things,

as for a child to die before their parent is seldom anticipated. Parental grief is profound and the bereavement period is life-long with significant consequences on the health and well-being of the bereaved parent.

### ***1.2.3 Parental Bereavement a Life-Long Process***

The view that grief somehow resolves when a parent begins life without their child is simplistic. The standard theory and process of grief resolution requires the parent to adapt to a life without the child: however, parents never really relinquish the bonds with the deceased child, the appropriate view is that parents maintain a relationship with their deceased child throughout their life (Klass, 1997) seems appropriate. Thus the bereavement period for parents is a life-long experience in which they continue their relationship with the deceased child and adapt to the challenges of the life-long nature of bereavement.

To maintain a relationship with their child, many parents hold on to tangible memories of their child such as a hair lock or foot/hand prints/molds (Romanoff, 1998; Ronen, 2009) alongside the intangible memories of their child's existence such as the special moments they had with the child, or the child's first smile or first word. Some parents continue to celebrate the child's birthday or engage in other rituals to commemorate the birth or death of their child (Brosig, 2007). Thus, bereaved parents create a new reality of their life, which involves memorializing the deceased child as their life progresses. However, the effect of continuing a relationship with the deceased child on bereavement outcomes has conflicted outcomes in study.

The use of continuing bonds during spousal bereavement was related to positive moods two years after the spouse's death (Field, 2004), but at five years, use of continuing bonds was associated with less grief resolution (Field, 2003). Thus, these contradictory findings pose a quandary regarding the conceptual relevance of continuing bonds. Additionally, continuing bonds literature has failed to highlight the challenges bereaved parents face as they integrate the memories of their child in their day-to-day living. The gap in this literature calls for an in-depth understanding of the concept of continuing bonds.

### ***1.3 Adaptive Leadership Framework***

Existing grief theories have not informed our understanding of parental bereavement in a way that interventions can be developed and individualized to address parental needs. In part we do not understand the challenges faced by bereaved parents and therefore the target for intervention development is not clear. Therefore a new theoretical approach to study parental bereavement can provide us with a way to understand the challenges bereaved parents face. Dr. Ronald Heifetz, who focused on leadership in organizations, first developed the Adaptive Leadership framework. In this framework two types of challenges are described: technical and adaptive (Anderson, 2015). Central to the framework is the role of an "adaptive leader" who accentuates the individuals' capacity to adapt to a situation, despite its complexities and challenges (Adams, 2013; Bailey, 2012). In technical challenges, both the problem and the solution are easily identified, and thus the "adaptive leader" similar to a healthcare provider, can provide the solution and fix the

problem through their expertise (Adams, 2013). However, in adaptive challenges, the problem is complex and not clearly defined, so there is no obvious solution (Adams, 2013). Hence the work has to be done by the individual with the guidance of the “adaptive leader.”

Healthcare is typically equipped to address the technical challenges bereaved parents face (Anderson, 2015), as an example, a bereaved parent may have a headache and pain medication is prescribed to address the headache. But if that headache is caused by lack of sleep due to constant memories of the dead child, the challenge and required work to address the problem, is more complex, and the same health provider may be inadequate or unaware of how to best assist the bereaved parent.

#### ***1.4 Bereaved Parent's Health Status***

The death of a child completely transforms the lives of the parents who experience it and can have a pronounced impact on individuals' health (Rostila, 2011; Van Ommeren, 2003; Werthmann, 2010). Bereavement engulfs all aspects of parental health negatively impacting physical, psychological, and social health outcomes. When compared to non-bereaved parents, bereaved parents have higher incidences of medical and psychological conditions such as cancer, cardiac illnesses, anxiety, depression, and post-traumatic stress symptoms (Barry, 2002; Lannen, 2008; Stroebe, 2007).

These negative health outcomes are associated with health risk indicators such as changes in eating or sleeping habits, changes in body weight, blood pressure, blood sugar,

and engagement in addictive behaviors like smoking or drinking alcohol. Additionally, many of these behaviors lead to a decrease in their social interactions and change their relationships with others including their spouse (Chan, Lee, & Chan, 2012; Najman et al., 1993; Prigerson et al., 1997; Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). Research findings from studies done in Denmark and Sweden have demonstrated that bereaved parents are not just sicker, but are also dying earlier (Rostila et al., 2011; Van Ommeren & Levav, 2003; Werthmann et al., 2010). Understanding potential risks of the health status of bereaved parents can inform interventions that are targeted to improve their health outcomes as they face the daily challenges of life beyond the loss.

### ***1.5 Palliative/End-of-Life/Bereavement Care a Continuum***

The National Hospice and Palliative Care Organization defines pediatric palliative care as “both a philosophy of care and an organized program for delivering care” that “focuses on enhancing quality of life for the child and family, minimizing suffering, optimizing function, and providing opportunities for personal growth” (2003, p. 3). Thus, palliative care is an “active” and “total” approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond (Liben, Papadatou, & Wolfe, 2008, p. 852). Palliative care embraces physical, emotional, social and spiritual elements focusing on the enhancement of quality of life for the child/young person and support for the family. Palliative care also includes the management of distressing symptoms, provision of short breaks, and care through death and bereavement (Hain, Devins, Hastings, & Noyes, 2013).

Since the trajectories of children with complex life-threatening conditions might include multiple critical and acute moments along with periods of stability or remission, children should receive palliative care from the time of diagnosis.

For, children with life-threatening conditions, palliative, end-of-life-care and bereavement care is seen as a continuum and should begin from diagnosis through the child's illness and after death in the form of bereavement care to the family of the child. The American Academy of Pediatrics Policy on Palliative Care for Children supports this model of palliative care. In addition, the Affordable Care Act (2010) mandates state Medicaid programs allow children with life-limiting conditions to receive both hospice care and curative care simultaneously (Tamburro, Shaffer, Hahnen, Felker, & Ceneviva, 2011). Additionally, unlike adult palliative care, pediatric palliative care is not limited to initiation within six-month of expected death and therefore can occur over long periods of time and can include both active curative and palliative supportive treatment measures depending on the child's illness trajectory.

### ***1.5.1 Existing Bereavement Services***

To assist parents with the stress of the child's death, acute care settings have developed bereavement care programs. Current hospital-based end of life and bereavement programs' usually begin when the child is diagnosed as terminally ill or just prior to the death of the child and may continue through 1 year post-death (deJong-Berg & deVlaming, 2005). Bereavement care includes end-of-life practices that allow parents to engage in rituals

associated with birth or death such as baptism or blessing of the sick and offer memory-making activities like hand or foot-prints (Harvey et al., 2008; Kobler et al., 2007). Post-death interventions may include: providing information about grief processes: support groups: bereavement counseling: sending bereavement cards: and contacting bereaved parents either via a telephone call or a home visit to offer condolences (Bucaro, Asher, & Curry, 2005; Cox, 2004).

Additionally, bereavement care programs usually incorporate a multidisciplinary approach by including physicians, nurses, chaplains, and social workers in their team. Bereavement programs experience shortage of trained personnel (Kusano, Kenworthy-Heinige, & Thomas, 2012) and although bereaved parents appreciate the support offered by hospital-based bereavement programs, they prefer the known healthcare team member to contact them post-death (Gibson, Finney, & Boilanger, 2011). Due to the work demands and priority of the healthcare team to care for patients, there can be limited time for care of bereaved parents.

The needs of bereaved parents can fall through the cracks of the healthcare system, as parents are not under the care of the pediatricians who cared for their sick child nor are they necessarily under the care of adult health practitioners. If we are to fulfill this gap, Donovan (2015) recommends transitional hospital based bereavement care in addition to community organizations that provide bereavement services. However, there is emphasis to first understand the needs and challenges of bereaved parents at different time-points in



order to contribute the much-needed empirical data to improve hospital based bereavement care (Donovan et al., 2015). By understanding the challenges bereaved parents face bereavement care models that hospital and community based can assist and grow the adaptive capacities of bereaved parents in order to positively influence their overall health.

## ***1.6 Purpose Statement and Aims***

The overall purpose of this dissertation was to explore and describe the adaptive challenges experienced by bereaved parents during the first 6 months after the death of their child and to examine how these challenges co-occur with parent health outcomes. This purpose will be accomplished by four overall aims, with each chapter representing one aim.

### ***1.6.1 Chapter 1 Aim***

Chapter 1 introduces the problem and significance of parental bereavement and the theoretical shortfalls in the understanding of parental bereavement trajectories and challenges. In addition, a new theoretical lens to explore parental bereavement is proposed.

### ***1.6.2 Chapter 2 Aim***

Chapter 2 aimed to expand our understanding of the concept of continuing bonds using Rodgers evolutionary concept analysis method. This analysis was conducted to help increase and refine existing knowledge of continuing bonds, thus reducing the ambiguity of the concept and increasing its relevance across the pediatric palliative, end-of-life, and bereavement care continuum.

### **1.6.3 Chapter 3 Aim**

Through a secondary data analysis, chapter 3 examined parental bereavement challenges following the death of their infant and provided evidence that the Adaptive Leadership Theoretical Framework could be applied to bereaved parents at 6 weeks and 6 months of bereavement.

### **1.6.4 Chapter 4 Aim**

#### **1.6.4.1 Aim 1**

In Chapter 4 parents were recruited following the death of their child to prospectively to identify and describe their challenges and the related work done to address their challenges.

#### **1.6.4.2 Aim 2**

Change in bereaved parents' physical, psychological, and social health [body mass index, physical and psychological health measures (PROMIS-global, BSI-18), sleep pattern disturbances (PROMIS-sleep), and ability to participate in social activities (PROMIS-social)] in the first six months following the death of their child are described.

#### **1.6.4.3 Aim 3**

Lastly I explored the co-occurrence of parents' challenges, related work, and health status.

### **1.6.5 Chapter 5 Aim**

Chapter 5 is a synthesis of the findings from the proposed dissertation. This dissertation will be the first concept analysis of continuing bonds and the first to examine the co-occurrence of parental health status, challenges and related work during the first six months of the bereavement. The long-term goal of my research is to develop and test interventions for parents and children that can be integrated into the child's illness trajectory and continue through the parental bereavement period.

## 2. Chapter 2

### 2.1 *Problem and Introduction*

Early conceptualizations of grief, grief theories, and grief therapeutics were dominated by the idea that a bereaved person “lets go” of ties with a deceased loved one (Moules, 2004). This view of grief emphasized the perspective that a grieving person relinquishes a relationship with a deceased individual to attain grief resolution over a period of time. Klass (1993) and his colleagues offered a paradigm shift in the existing grief narrative when they introduced the phenomenon of continuing bonds. As an alternate perspective on grief, continuing bonds underscores the view that grief transcends time as bereaved individuals continue to maintain a bond with the deceased while building new relationships with the living (Klass, 1997). Since being introduced in 1993, continuing bonds has become an integral part of bereavement literature.

Continuing bonds was first described as an “inner representation of the dead” that offers, “solace” to the bereaved (Klass, 1993). Since then, continuing bonds has been widely studied across all age groups, with all types of losses and through the lens of existing grief theories. Bereavement literature has progressed from early descriptions of the existence of the phenomenon among the bereaved (Klass, 2009; Klass, 1997), to assessing different types of continuing bonds behaviors (Field, 2013), and to finally determining the consequences of continuing bonds on bereavement trajectories (Field, 2003). While, the presence of continuing bonds with the deceased is no longer debated, the empirical evidence of the

consequences of continuing bonds on the bereaved is still inconclusive. Yet, memory-making activities that exemplify continuing bonds with the deceased have become an integral part of routine clinical practice during palliative and end-of-life care (Harvey, 2008).

Continuing bonds is still widely studied and included in clinical practice, but a comprehensive examination of the concept is absent. Hence, the **purpose** of this paper is to expand and clarify the meaning of continuing bonds to advance the science related to this phenomenon through a concept analysis using Rogers evolutionary method to identify and define key attributes (Rodgers, 1989).

## **2.2 Methods**

This evolutionary concept analysis used an iterative process to: 1) identify the realm within which continuing bonds exists, 2) specify the attributes that comprise continuing bonds, and 3) provide contextual relevance by identifying the antecedents and consequences of continuing bonds.

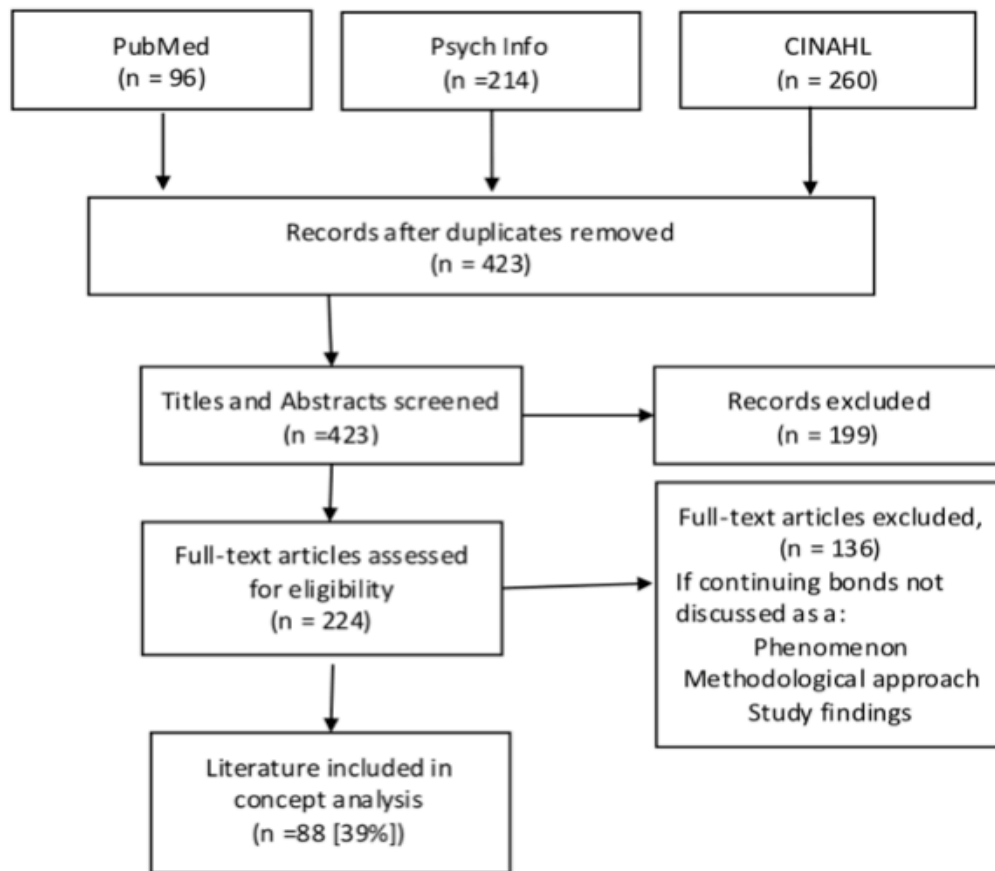
### **2.2.1 Sample**

The term *continuing bonds* is used widely in psychology and nursing literature and therefore literature from both disciplines were included. Three relevant databases PubMed, CINAHL, and PsychInfo, were searched using the key words or MeSH terms: "continuing bond", "continued bond/s", and "continuing relationship." In addition, as continuing bonds is associated with grief and grief was indexed as "bereavement" [MeSh], thus, the term "bereavement" was added to the "continuing bonds" key words.

Similarly, since continuing bonds is linked to attachment and death other terms "object attachment"[MeSh] or "attitude to death"[MeSh] or "death"[MeSh] were added to the primary search term "bereavement." Because the literature was predominantly published in English and the first author was fluent in this language, only literature in English language was included. A total of 570 articles were obtained from the three sources (see Figure 1.). After identifying, screening, and determining the eligibility of the literary work, 88 articles "relevant" to the concept were retained for full review. This sample represents more than the minimum 20% of literature recommended by Rodgers for a concept analysis. Atlas Ti software was used to code the journal articles, books, and individual chapters were read separately to identify the antecedents, attributes, and consequences of continuing bonds. In addition memos were maintained to note the evolution of the concept over time and also identify the quantitative and qualitative tools used to study continuing bonds.

### **2.3 Results**

Most literature used the term "continuing bonds" with only two variations identified: continuing connections (Boerner, 2003) and continuing attachment bond (Sirrione, 2014). Continuing bonds was studied extensively during bereavement following the death of a loved one. In addition, continuing bonds is described among immigrant population as a means of integrating and acculturating into a new culture (Henry, 2009).



**Figure 1 Sample Selection**

The bereavement literature includes examining the continuing bonds existence, behaviors, and consequences following death in different relationships including the death of a spouse (Field, 2003; Ho, 2013; Reisman, 2001), child (Riches, 1998; Rubin, 2012; Riches, 1998), sibling (Packman, 2006; Packman, 2006), and pet (Carmack, 2011). Continuing bonds was also studied in specific situations like bereavement in the adolescent period (Sirrine, 2014), traumatic deaths (Capitano, 2012; Wood, 2012), angered pre-death relationship (Root, 2012) and bereaved individuals with an intellectual disability (McRitchie, 2014). This

concept analysis focuses on the bereavement literature and presents: a) definitions, b) attributes, c) antecedents, and d) consequences. Finally a conceptual definition and continuing bonds model is presented.

### **2.3.1 Definition**

Merriam Webster defines continuing as, “to do something without stopping” and bonds as, “an idea, interest, experience, or feeling that is shared between individuals or groups and forms a connection between them.” Since the introduction of this concept, continuing bonds is defined as an “inner and ongoing relationship with the deceased by the bereaved” (Field, 2003; Root, 2012; Klass, 1996; Stroebe, 2005; Weiss, 2001). This inner connection is due to a “reconstructed social identity”(Klass, 2006) of the deceased by the bereaved and allows the bereaved to mentally represent the deceased individual’s identity beyond the physical existence (Boerner, 2003). Stroebe (2001) added that the inner relationship is the *mental representation* of the deceased by the bereaved due to the emotional connection with the deceased. The bereavement literature has remained consistent in the definition of continuing bonds and has highlighted the presence of an ongoing relationship of the bereaved with the deceased.

### **2.3.2 Attributes**

Five key attributes of continuing bonds were identified: a) ongoing relationship with the deceased, b) normal process, c) grief, d) demonstrated by acts, and e) evolving (See Table 2)



### 2.3.2.1 *Ongoing relationship with the deceased*

Maintaining a continued relationship with the deceased is the primary and most critical attribute of continuing bonds (Klass, 2001). This relationship is a continued inner connection of the bereaved with the deceased at a personal level (Stroebe, 2005). All of the literature highlights this continued relationship as central to continuing bonds.

**Table 2 Continuing Bonds Attributes**

#	Attribute	Definition
1.	Ongoing Relationship	A continued relationship by the bereaved with the deceased.
2.	Normal Process	A natural occurrence of transition in the relationship following the death of a loved one.
3.	Grief	The emotional response that coexists while maintaining the continued relationship by the bereaved with the deceased.
4.	Demonstrated by acts	Activities, behaviors, or expressions through which continuing bonds is manifested.
5.	Evolving	Includes the dynamic and transforming nature of continuing bonds.

Generally this relationship is maintained by the bereaved, but there are instances in which the bereaved perceives an interaction from the deceased through dreams, visions, or hallucinations, in which it appears that the deceased too communicates with the bereaved (Root, 2014). Nonetheless, the main premise of continuing bonds is an interaction between the deceased and the bereaved through the presence of an inner and ongoing relationship (Epstein, 2006).

### 2.3.2.2 *Normal process*

Continuing bonds was described as a natural occurrence following the loss of a loved one (Packman, 2006). Attachment theory underscores the strong bond between

individuals that is unlikely to be discontinued with death (Bonanno, 1999; Packman, 2006).

Based on the idea that relationships cannot be suddenly relinquished after death and therefore continue, the bond becomes a “normal” part of an individual’s bereavement trajectory (Klass, 1997; Stroebe, 2010). Similarly, continuing bonds cannot be “created” and is a natural transition from an earthly physical relationship to an inner personal mental representation and connection with the deceased (Packman, 2006).

### 2.3.2.3 *Grief*

Continuing bonds was introduced to expand our understanding of grief (Foster, 2008) and has its roots from the discipline of psychology. Since both grief and continuing bonds are a normal response to a loss, they coexist and occur as a consequence to the loss. The bereaved individual grieves as she/he maintains an ongoing relationship with the deceased. Without grief the bereaved would lack motivation for the continued relationship.

Continuing bonds contributes to the grief experience and therefore is examined as a manifestation of grief or an outcome of grief (Ronen, 2006). Thus, grief and continuing bonds share a complex and inter-related relationship (Boelen, 2006). Grief is an emotional response to the loss (Rodgers, 1991), while continuing bonds is an ongoing relationship that is shared by the bereaved with the deceased. Thus grief as a critical attribute of continuing bonds is essential to expand our understanding of continuing bonds.

#### 2.3.2.4 *Demonstrated by acts*

The inner relationship of the bereaved with the deceased can be symbolically represented through actions, behaviors, or expressions that maintain an ongoing relationship. The behaviors may be very concrete or physical, such as visiting the grave, holding on to the belongings, creating memorabilia to remember the deceased, memorializing the deceased through fundraisers or foundations (Field, 2003; Harper, 2011; Hoppes, 2010; Klass, 2003) or at an abstract level by feeling the presence of the deceased or seeking comfort or spiritual guidance from the deceased (Hoppes, 2010). These physical or abstract ways through which the bereaved individuals maintain an ongoing relationships with the deceased are referred to as continuing bonds acts. Acts can be defined as activities, behaviors, or expressions through which continuing bonds are manifested.

Several continuing bonds acts have been identified, described, and categorized since the introduction of the concept. Major categories of continuing bonds acts include: a) sensing and communicating with the deceased, b) holding on to the deceased's possessions, c) memorializing the deceased through creating memorabilia, d) performing rituals, e) imitating the deceased by continuing practices or routines done by the deceased, f) reminiscing or talking about the deceased to others, g) looking at photos or videos of the deceased, h) acquiring values and beliefs held by the deceased, i) performing activities to honor the deceased, and j) having dreams, visions, or hallucinations of the deceased (Epstein, 2006; Hoppes, 2010; Richardson, 2014; Root, 2014; Sirrine, 2014; Stroebe, 2008).

Field and Filanovsky (2010) performed a factor analysis of continuing bonds acts and classified the aforementioned continuing bonds acts into two broad categories: externalized and internalized. This categorization has been used to further examine the consequences of continuing bonds on bereaved individuals grief outcomes. Externalized acts exemplify the perception of a continued earthly presence of the deceased by the bereaved. These include acts in which the bereaved functions as though the person is still living, such as holding on to the deceased individual's possessions, hallucinating, or having illusions of the deceased (Field, 2010). Internalized acts are symbolic representations of the deceased by the bereaved. Abstract acts such as, using the deceased's belief system or life principles as a guide to emulate their behavior, or a belief that they are watched and protected by the deceased are described as internalized acts (Field, 2010).

#### 2.3.2.5 *Evolving*

The continued relationship of the bereaved with the deceased is dynamic as it can change over time (Foster, 2008) as the bereaved makes meaning of the reality of the physical absence of the deceased and integrates this physical absence in a new relationship with the deceased (Ronen, 2006). Additionally, the evolution of the relationship can be manifested through the transformation of specific acts of continuing bonds from a focus on externalized to internalized acts or vice versa (Boerner, 2003). For example bereaved parents who initially held onto their child's possessions or kept their room intact may later memorialize their child by engaging in altruistic acts like starting a foundation or organizing fund raisers.

This evolution can either occur due to individual's growth and development such as seen in a child that loses their parent or sibling (Packman, 2006) or a bereaved individual transitioning to accepting the death of a loved one through an adaptive integration of the deceased in to their current life (Foster, 2008). Thus, this evolution of continuing bonds depicts the dynamic and transformative nature of the concept. As such continuing bonds can be a positive attribute that symbolizes a healthy transition in the continued relationship of the bereaved with the deceased.

### **2.3.3 *Antecedents***

Just like grief, loss is the primary antecedent of continuing bonds. However, while grief includes losses in the form of illness, physical disability, body image, or self-identity (Rodgers, 1991) loss relative to the continuing bonds concept is primarily in the form of death or a loss due to separation as a result of immigration. Thus the antecedent for continuing bonds can be identified as a loss in the form of physical distancing, which is either temporary (immigration) or permanent (death). In addition, continuing bonds with the deceased is a manifestation of the grief experience (Epstein, 2006), and therefore grief can also be an antecedent of continuing bonds.

### **2.3.4 *Consequences***

Klass and his colleagues (Klass, 1993) introduced continuing bonds as a "healthy part of the grieving process," thus alluding to the adaptive nature of continuing bonds.

Initial research has focused on assessing whether continuing bonds is an adaptive or maladaptive response to the loss of a loved one with inconclusive findings.

Continuing bonds consequences are primarily described in terms of psychological outcomes including depression (Boelen, 2006), mood (Neimeyer, 2006), coping (Foster, 2008), and affect (Epstein, 2006). Studies with bereaved adults have also examined continuing bonds consequences on overall health outcomes (Epstein, 2006; Harper, 2014). Due to the conceptual overlap of grief and continuing bonds, outcome studies have also focused on elements of grief, including grief symptomology and complications (Harper, 2014; Ho, 2013; Barr, 2014; Field, 2013) and proposed that continuing bonds is an adaptive coping strategy that mediates grief and grief outcomes (Neimeyer, 2006). Thus grief can also be a consequence of continuing bonds.

In addition to examining the consequences on specific outcomes, some studies used types of continuing bonds acts to predict outcomes. As per Field's (2013) factor analysis classification, externalized acts are considered as maladaptive because they signify the inability to accept the physical absence of the deceased and are defined as lower order bonds (Reisman, 2001; Field, 2013). Internalized acts, which represent the abstract, and symbolic connections are presumed to depict an adaptive way of integrating the deceased into the bereaved individual's current life (Capitano, 2012) and are referred to as higher order bonds (Reisman, 2001).

Several factors influencing the consequences of continuing bonds have also been explored. These factors include: a) time since the loss, b) environmental context such as culture, religion, spirituality, and politics, c) individual characteristics such as pre-death relationship, coping, stress, and adaptation strategies, and d) deceased individuals characteristics such as, age at the time of death, cause of death, illness trajectory, relationship e.g. child, spouse, sibling (Klass, 1993; Root, 2012; Sirrine, 2013; Suhail, 2011). Table 3 lists the measures used to study various elements of the continuing bonds concept and the influencing factors.

**Table 3 Continuing Bonds Measures**

Domain	Variable	Empirical Referents
Continuing Bonds	<ul style="list-style-type: none"> <li>Continuing bonds attributes</li> </ul>	<ul style="list-style-type: none"> <li>Continuing Bonds Scale (quantitative)</li> <li>Continuing Bonds Interview (qualitative)</li> </ul>
Influencing Factors	<ul style="list-style-type: none"> <li>Social constraints</li> <li>Spirituality</li> <li>Relationship</li> </ul>	<ul style="list-style-type: none"> <li>Social constraints measure</li> <li>Spiritual transcendence scale</li> <li>Strength of relationship scale</li> </ul>
Consequences	<ul style="list-style-type: none"> <li>Grief</li> <li>Psychological</li> <li>Overall health</li> <li>Personal growth</li> </ul>	<ul style="list-style-type: none"> <li>Inventory of complicated grief: Inventory of traumatic grief</li> <li>Brief symptom inventory</li> <li>General health questionnaire</li> <li>Post-traumatic growth inventory</li> </ul>

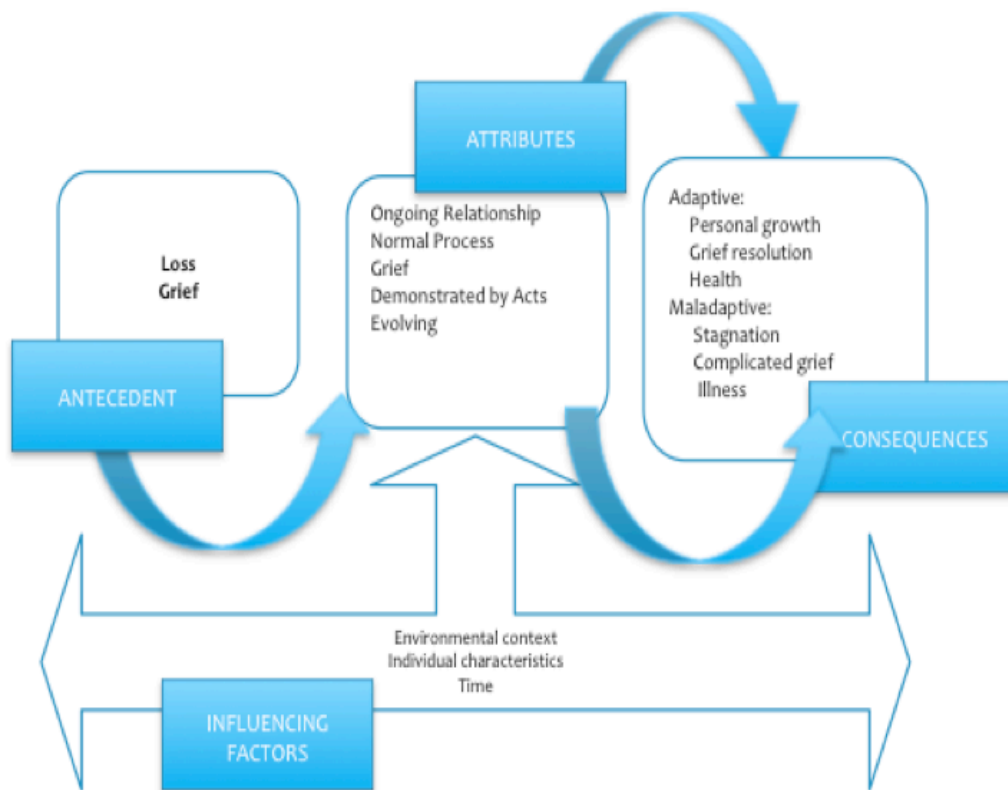
### **2.3.4 Operational definition**

Continuing bonds is a normal, ongoing, and evolving relationship of the bereaved consequent to the grief experienced upon the loss of a loved one and includes a symbolic representation of the relationship through acts that maintain a relationship with the deceased.

### 2.3.5 *Continuing bonds model*

The continuing bonds conceptual model (Fig 2.) represents the key elements of the concept, which are the antecedent, attributes and consequences. In addition, since factors such as: a) time, b) environmental context, and c) individual characteristics can influence continuing bonds trajectories: these elements are also added to this model. In addition, since continuing bonds consequences impact both grief outcomes and overall health outcomes, all elements of health and grief can provide a holistic approach towards determining continuing bonds outcomes. The model depicts continuing bonds consequences as either adaptive in terms of personal growth, grief resolution and health; or maladaptive indicated by personal growth stagnation, pathological grief, and illness. The tools identified in Table 3 can be used to measure and test the model presented.





**Figure 2 Continuing Bonds Model**

## **2.4 Implications**

Continuing bonds normalizes continuing a relationship with the deceased and offers an alternative approach to the view that relinquishing the relationship is required to attain grief resolution. Due to the inter-related nature of grief and continuing bonds some conceptual overlap cannot be ruled out, however the five attributes identified in this analysis can help guide further continuing bonds studies. Future research should also attempt to clarify the adaptive and maladaptive nature of specific continuing bonds act across the bereavement trajectory. Several factors might influence which act and at what

time-point the act could be predictive of adaptation. Additional empirical work is needed to clarify the evolution of continuing bonds and the relationship between an individual's continuing bonds and their bereavement trajectory. Therefore, future studies could use this proposed model to:

- Test the proposed framework.
- Include and develop existing measures that can test all aspects of the model.
- Further development of the scales that examine the attributes of continuing bonds.
- Examine the relationship between the attributes of continuing bonds and general health outcomes
- Identify adaptive continuing bonds acts that can be translated into testable interventions to improve bereaved individuals overall health outcomes.

### 3. Chapter 3

#### 3.1 *Problem and Introduction*

Parental bereavement research has focused on understanding parents' grief responses and has acknowledged that parental grief is complex, intense, highly individualized and *long lasting* (Arnold & Gemma, 2008), with the first 6 months of bereavement identified as the most stressful time (Meert et al., 2010). Parental bereavement is the "experience of the loss" of a child and parents whose child is deceased are referred to as bereaved parents (Zhang, El-Jawahri, & Prigerson, 2006, p. 1188; American Cancer Society, 2015). While bereaved parents grieve, they are also expected to carry on with their life. The day-to-day activities that were once routine for these parents may now be challenging due to the emotional turmoil they are experiencing (Arnold, Gemma, & Cushman, 2005). Consequently, parental bereavement trajectories include not only parental grief responses but all aspects of the parent's life that are affected by the death of their child.

While significant strides have been made to understand the grief responses of bereaved parents, little is known of the specific challenges they face as they return to their life without their child. Traditionally, parental bereavement research is often framed by theories or concepts that focus on the parent-child relationship (attachment and the continuing bonds) or characterize parental bereavement responses such as grief, coping, adaptation, life-transitions, caring, or resilience (Barrera et al., 2007; Barrera et al., 2006; Davies, 2004; Dokken, 2013; Field, Gao, & Paderna, 2005; Foster, 2010; Harper et al., 2013;

Hoekstra-Weebers, Littlewood, Boon, Postma, & Humphrey, 1991; Kachoyeanos & Selder, 1993; Kavanaugh, Moro, Savage, & Mehendale, 2006; Klass, 1997; Rando, 1983, 1985; Wijngaards-de Meij et al., 2008). These studies have contributed to our understanding of parental grief and highlight the unique circumstance brought by the unnatural situation of a child's death. However, these theories do not provide the structure needed to explore the full range of challenges bereaved parents face (Tan, Docherty, Barfield, & Brandon, 2012) that may be instrumental to the development of targeted interventions.

The Adaptive Leadership Framework is an organizational management theory recently found to be useful in healthcare (Adams, 2013; Anderson, 2015; Bailey, 2012) because of its focus on identifying challenges faced by individuals and categorizing them based upon who has the responsibility to do the work of adapting to the challenge. Challenges are viewed as either technical or adaptive (Anderson et al., 2015). In technical challenges, both the problem (technical challenge) and the solution (technical work) are more directly identified and often require an expert, such as a healthcare provider, to do the work (Anderson et al., 2015). However adaptive challenges are complex, not easily defined, and the individual experiencing the challenges must do the adaptive work (Anderson et al., 2015). Bereaved parents face both technical and adaptive challenges. Healthcare providers are typically equipped to address the technical challenges bereaved parents face. For example, a bereaved parent might experience the posttraumatic stress symptom of intrusive thoughts and have both a technical challenge (difficulty falling asleep) and adaptive

challenges such as concentrating at work or caring for other children. The varied nature of challenges, both technical and adaptive brings a level complexity to parental bereavement because they require the assistance of healthcare providers in addition to a substantial amount of work by parents. These challenges may also impact parental health when not identified and addressed early in the bereavement trajectory.

Bereaved parents have higher long term morbidity (Rosenberg, Baker, Syrjala, & Wolfe, 2012; Stroebe, Schut, & Stroebe, 2007) and mortality rates compared to adults who experience the death of a spouse or parent (Harper, O'Connor, & O'Carroll, 2011; Rostila, Saarela, & Kawachi, 2011; Werthmann, Smits, & Li, 2010). Higher incidences of cancer, cardiac events, anxiety and depression have also been reported among bereaved parents (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Li, Hansen, Mortensen, & Olsen, 2002; Li, Johansen, Hansen, & Olsen, 2002; Li, Johnsen, & Olsen, 2003; Stroebe et al., 2007). Parents exhibit a variety of health risk behaviors such as changes in eating habits, sleep disturbances, and engagement in addictive behaviors like smoking or drinking alcohol which impact their long-term health outcomes (Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013) which need the attention of healthcare services.

Some hospital-based, acute care settings have developed parent bereavement care programs (Morris & Block, 2015) that are typically initiated when a child is determined to be terminally ill and continue through 1-year post-death (deJong-Berg & deVlaming, 2005; Morris & Block, 2015). Bereavement services often include standard end-of-life practices that

allow parents to follow their personal or faith-based rituals (Leever, Deegan-Krause, Richard, Richter, & Nelson, 2004) in addition to memory-making activities like creating hand or footprints (Harvey, Snowdon, & Elbourne, 2008). Post-death services may include standardized practices such as: a) contacting bereaved parents by telephone call to offer condolences, b) sending bereavement cards, c) providing information about grief responses, support groups, bereavement counseling services, and other support services, and d) conducting 6-month or 1-year memorial services (Bucaro, Asher, & Curry, 2005; Cox, 2004; Woodroffe, 2013). The content and design of current pediatric bereavement care practices address parental grief responses and evaluation of these programs has primarily assessed parent satisfaction of the program (deJong-Berg & deVlaming, 2005; Harvey et al., 2008; Nagraj & Barclay, 2011; Steele et al., 2013).

While bereaved parents appreciate the support offered by hospital-based bereavement programs (Gibson, Finney, & Boilanger, 2011), these services are often not individualized to target particular challenges faced by bereaved parents when they reengage with daily life. The unmet needs of bereaved parents and potential for health risks highlight the need for the development of tailored parental bereavement care interventions that include a focus on overall health outcomes (Harvey et al., 2008; Zhang et al., 2006). However, prior to developing targeted interventions, more empirical knowledge is needed to understand the complex challenges bereaved parents encounter across the acute bereavement trajectory (6 months post death).

Due to the individualized nature of parental bereavement and its impact on parental health outcomes, parental bereavement trajectories are likely to be highly variable, complex, and need to be explored (Rosenberg et al., 2012). Therefore, the purpose of this study was to explore and describe the challenges bereaved parents face during the first 6 months following the death of their child.

## ***3.2 Methods***

### ***3.2.1 Study Design and Participants***

A qualitative descriptive study design was used to examine the challenges bereaved parents face across the acute bereavement trajectory (6 months post child's death). A secondary data analysis was conducted of narrative interviews with 10 parents whose children died of complex chronic conditions. The data was part of a larger study that used a case-based longitudinal mixed-method design to examine the trajectory of decision-making about life-sustaining treatment for children with complex, life-threatening conditions (1R01-NR010548) and who were cared for at a southeastern academic medical center. The secondary analysis reported on here was based upon data from a subset of parents from the larger study whose children had died. Ethical approval for the study was obtained from the institutional review board (IRB) for human subjects research.

Each case in the larger study was followed for up to 12 months from the initial diagnosis or until 6 months following the child's death and consisted of a child  $\leq 24$  months of age, the parent/parents, and a minimum of three healthcare team members. In the larger

study, parents were interviewed individually and completed self-report measures to capture their ongoing experiences with the decision-making, life-threatening events, and major changes in treatments. This data collection occurred at recruitment, monthly, or with any life-threatening event over one year. For parents whose infant died during this period data was collected at 1 week, 6 weeks and 6 months post death. The interviews conducted with parents at these 3 time-points after death were used for this secondary analysis. These interviews explored how parents were coping following the death of their infant. The first set of questions asked parents to talk about their emotions, challenges, and overall functioning following the death of their child. Probes and follow-up questions encouraged parents to provide details of their challenges and how they managed daily life.

### ***3.2.2 Sample and Setting***

The sample consisted of ten parents (five mothers and five fathers) of eight children who were interviewed individually at 6 weeks and 6 months after the child's death. One mother contacted the research team and requested an interview at 1 week after the child's death in addition to the other time-points. A total of nineteen interviews were analyzed (see Table 4). All children were diagnosed with complex life-threatening illnesses within the first year of life. Five children had a metabolic condition and were undergoing hematopoietic stem cell transplant, and three children had a complex cardiac condition. All parents identified Christianity as their religious preference.



**Table 4 Study Sample**

Case ID	No of interviews	Race	Married	Age	Living child
Case_1_Dad	3 (1 week, 6 weeks, and 6 months)	White	No	24	0
Case_2_Mom	2 (6 weeks and 6 months)	White	No	24	1
Case_3_Mom	1 (6 months)	White	Yes	29	1
Case_4_Mom	2 (6 weeks and 6 months)	White	Yes	30	2
Case_5_Dad	1 (6 months)	Hispanic	No	27	0
Case_6_Dad	2 (6 weeks and 6 months)	Black	Yes	41	2
Case_7_Dad	2 (6 weeks and 6 months)	White	Yes	33	1
Case_7_Mom	3 (1 week, 6 weeks, and 6 months)	White	Yes	30	1
Case_8_Dad	2 (6 weeks and 6 months)	White	Yes	37	0
Case_8_Mom	1 (6 months)	White	Yes	32	0
<b>Total</b>	<b>19 interviews</b>				

### **3.3 Data Analysis**

All participants were given pseudonyms to maintain their anonymity. A conventional content analysis technique followed by a directed content analysis as described by Hsieh & Shannon (2005) was used to analyze the transcribed interview data. For the conventional analysis, the transcripts were first reviewed to search for parents' talk about their challenges following the death of their child. To attain data immersion and to make sense of the data as a whole, the primary investigator (PI) read the interviews multiple times (Hsieh & Shannon, 2005). Next the PI conducted a directed content analysis by applying codes (Hsieh & Shannon, 2005) to any talk about challenges or issues they had encountered as well as their day-to-day functioning. After the initial code list was created, the PI reviewed and verified the codes, code definitions, and code applications with a second experienced content data analyst. After the interviews were coded, all authors

reviewed the final code list and categorized the codes as a technical or adaptive challenge based on the Adaptive Leadership framework. The categories were then further grouped into meaningful clusters (Hsieh & Shannon, 2005) of themes and sub themes. Atlas Ti 7 computer software was used to organize the transcripts and apply the codes during the analysis.

### **3.4 Results**

The themes highlight the complexities of parental bereavement challenges during the first 6 months following the death of their child. All of the challenges discussed by parents were categorized as adaptive challenges as they were complex and required the parents to use adaptive strategies to address the challenges. The challenges revolved around parents attempt to hold on to their memories of the child while trying to resume their life, their emotional response to the death, and the impact of this loss on their relationships with others. Three major themes and their subthemes were used to represent the data. The frequency of the sub-themes among participants is illustrated in Table 5.

1. Life without the presence of the child
  - a. The “void”
  - b. Getting back to life’s routines
  - c. Conflict between “not forgetting” and “moving on”
  - d. The question of “what if”
  - e. Role identity conflict

## 2. Emotional turmoil

### a. Emotional lability

### b. Emotional sensitivity

## 3. Transformed relationships

### a. Relationship with significant other

### b. Relationships with other family members, friends and community

**Table 5 Themes and Subthemes Frequency**

Parent	Time Point	Life Without the Presence of the child					Emotional Turmoil		Changed Relationships	
		Void	Life's Routines	Moving On Conflict	What If?	Role Identity	Labile	Sensitive	Spouse	Others
Father N=5	1-week		1							
	6-weeks		2	1	2		3		1	2
	6-months		1	2	1	1	1	1	1	
Mother N=5	1-week			1						
	6-weeks	1	3	2	1			2	1	
	6-months	2	4	3	4	1	5	2	5	4

### 3.4.1 Themes

#### 3.4.1.1 *Life Without the Presence of the Child*

This theme was used to represent parents' challenges with creating a life without the physical presence of their child. Life without the child, which parents often referred to as their "new normal," is explained through the subthemes described below.

#### 3.4.1.1.1      *The Void*

For most parents, the initial period following the death left them to face the stark reality of a life without their child. Most parents were distressed by the thought that they would never see their child again. At the 6 week interview a 27 year-old unmarried father with no other children stated "you come to the realization that you're never going to see him again....and that's just...constantly going through me." Another 24 year-old father who also had no other children said, "There's not a minute that goes by that I don't wish she was here."

#### 3.4.1.1.2      *Getting Back to Life's Routines*

While parents were troubled by thoughts of never being able to see their child again, they also had to face the necessity of getting back to their daily life. Parents referred to this life without the presence of their child as their "new reality," their "new normal" in which they described a period of "starting over." One parent described a fear of not wanting to be "set in the rut," where she did not want to get out of the bed to do her daily chores. Others acknowledged that "life has completely changed" and they had to get used to new routines and daily activities that did not include caring for their child. A 24 year-old mother who had one living child alluded to this in her 6-week interview:

It was really weird once I got home and you know everybody got back to their routine. Troy went back to work and Bill was going to school and you know the first day...I was home by myself and it was kind of weird you know, cause I was so used to being there taking care of Lily so it was different [tearful] not having that responsibility.

Parents also spoke about their need to stay busy. They filled their days by either going back to work or getting involved in new activities such as enrolling in school. Most of the parents sought to keep themselves occupied so they could avoid constantly thinking of their child. The 24 year-old dad with no other children described staying busy as:

I can't sit around and not do anything, I can't just sit there, and you know just not do anything. I haven't sat down and watched TV since I've been home, cause if I sit down I start thinking, I have to be doing something...

One mother kept herself busy by engaging in church activities. Another decided to enroll in school after 6 months:

And then I kind of got to a point where I felt like if I sat at home I wasn't going to get any better you know, I would just sit at home, cry every day and feel sorry for myself...So I signed up for school, and I started nursing school in October.

While most parents in their attempt to stay busy either went back to work or immersed themselves in another activity, one mother identified her unique challenge returning to work, "I haven't been able to go back to work yet just because with my job I'm a teacher, and I just have a hard time with the thought of walking into a room full of kids."

The need to immerse themselves in work in order to stay busy brought its own unique set of challenges for parents. The parent who enrolled in nursing school reflected on how this brought back memories of the care of her child:

.... and you know there are many times I've sat in class and had to hold back tears because it just reminds me of a time you know well. We might be talking about a procedure and I'm thinking 'oh I

remember when Lily went through that.' And my mind kind of drifts off into space, so you know, it's definitely been rough...

Similarly, the mother who became involved in church activities reflected on how the scriptures reminded her of the loss and pain she was enduring, "...so of course during the Bible study I like broke down crying and I like walked out and came back, and of course everyone who didn't know me was just sitting there staring at me." Despite efforts by parents to distract themselves and stay busy, parents acknowledged that staying busy was not always a successful approach to address their challenges as the grief would take them by surprise even if they were busy. One mother explained:

...I'm glad that I have something to focus on but then sometimes I feel like I try to fill in every minute so I push other feelings about Lily and stuff away but, then you know those feelings creep up along me. And then I have my bad moments but I think I'd have those times regardless if I were busy or not.

#### 3.4.1.1.3 Conflict Between "Not forgetting" and "Moving on"

Bereaved parents expressed their dilemma between wanting to "move on" in life and the desire to hold on to the memories of their child. Creating memorabilia and holding on to memories that were created when their child was alive became a significant part of the parent's life without their child. They showcased their child's life by putting up the child's pictures on the walls of their home and on websites. They created memorials like a garden or tombstone. They also held on to their child's belongings especially their toys, blankets, and crib. One mother said, "I have a little bear that was made out of one of his blankets like uh, kind of just cuddle with that, remember him wrapped up in it" They focused on

retaining the memorabilia so they would not forget their child: "I put pictures up all over the house of her. I guess I want to remember what I can actually see..." However, the memorabilia created by parents to fill the void of the physical absence of their child served as a constant reminder of the deceased child, but most parents keep memorabilia because they do not want to forget their child.

In addition, most parents also talked about wishing to move on with their lives, but they struggled with their desire to remember their child, while wanting to move on with life. A 24 year-old father who had no other children said this about his child's belongings, "if Natalie's stuff gets auctioned off I'm going to be highly aggravated because most of that stuff that's in storage is from the hospital and that's my memories." While, the 6-week interview found most parents identifying with moving on as a goal, the 6-month interview found few parents who acknowledged that they had "moved on." One father, a 37 year-old married soldier, explained, "moving on" by stating this, "...like it doesn't run our lives, it doesn't .....I guess the remorse over a loss isn't ruling anything. It's there but it's a secondary concern for most of the things that happen."

Another 33 year-old mother with a living child indicated that she had moved on at the 6-month interview. While, at 6 weeks she had acknowledged her desire to move on, "I guess like sometimes when I walk to her room and I'm just like, there's a crib still up, it makes me feel like, you need to move on," and was engaged in activities to create memories of her child by putting up pictures of her daughter in their new home and planting seeds to

create a memorial garden in her memory, at the 6-month interview she explicitly indicated that she had moved on and added that she had put the child's belongings away but has kept the crib as she planned for her next pregnancy, "Like I said it just feels like it just happened such a long time ago: I guess I've just moved on...and I don't even really talk about it that much anymore either."

However, this 33 year-old mother touched on a different set of challenges due to detaching from the child's memorabilia. She talked about neglecting to tend to the garden that was created in her child's memory and expressed discomfort when others continued to remind her of her child by sending seeds for the garden. She expressed uncertainty about how to respond to these gestures of remembrance from family and friends:

... the other day, a friend of mine sent me some note cards that have seeds in them and she's like "here you can put these in Mandy's garden" which I'm like "that's kind of strange, I guess I can send her a birthday card and bury it in the dirt." ... But yeah, people still when they like find a packet of seeds or something they'll mail it to me...

Similarly she expressed discord with her spouse related to visiting the child's grave, as she found visiting the grave as a "waste of time."

Yeah, I guess um, now it's just kind of, it seems kind of silly a little bit 'cause we're just going to look at a big rock sittin' on the ground...'cause it's not like visiting someone where you can sit and talk, I don't know... it feels like a waste of time to some extent.

Her spouse expressed his discomfort with his wife's coldness towards the deceased child's grave, ".... there's not one time she comes by and says, 'Hey, have they got the stone put up?', or drive by [the cemetery]." For this mother her desire to move on was a challenge



since her spouse didn't understand her behavior and her friend assumed that she still was engaging in activities to continue a relationship with her deceased child. Her bereavement response did not match her husband's bereavement response or her friend's expectations of how she should behave.

#### *3.4.1.1.4 The Question of "What If"*

This theme identifies parents' challenges related to thinking about the past, specifically the child's illness trajectory. Parents talked about recalling the period of their child's illness with questions like "what if." A 29 year-old mom who had one surviving child said, "I can't fall asleep at night because it's always the 'what ifs' in my mind, "what if this would have happened, or what if I would have stayed at the hospital longer like a lot of what ifs go through your head." The what if's were also related to the unanswered questions about the child's illness or death, specifically when there was no confirmed diagnosis prior to the child's death, or if the cause of the child's death was not specifically related to the initial diagnosed illness. These parents acknowledged their difficulty in coming to terms and tried to avoid thinking about the what if. A 33 year-old dad with one living child said:

I guess the struggle point for all of us probably, is it wasn't the thing that going into it that necessarily took her from us was the major heart condition it was a subset of problems that might have arrived because of the heart problem then also might have arrived because of the genetic problems that she had in the first place.

Similarly, parents expressed their challenge in addressing their what if in regards to “What if my child was still alive?” What would my child be doing now?” Parents dwell on the events that they will never experience with their deceased child and think of what could have been for their family if only. One dad said, “... Just thinking of ... what I would be doing if Natalie was still here, like the stuff that she’s missing out on.”

#### 3.4.1.1.5 *Role Identity Conflict*

Parents faced a role-identity conflict as they became aware that the absence of their child challenged their identity as a parent. They questioned if they could still be recognized as a “parent” after the child’s death, especially when there were no other children. One 37 year-old father who had no other children, stated, “I think it’s more the fact that I’m no longer a father... that’s the stuff you have to deal with.” While a 32 year-old mother with no other children, said:

You know there’s like a lot of things and it seems little but it really, is tough you know? If we had another kid it wouldn’t be a big deal but we don’t. So it kind of puts us in an awkward position like “well what do we say, do we have kids or do we not” I don’t know how to answer that question.

Similarly, parents with other children wondered if they should include the deceased child in their number count of children. Parents struggled with telling strangers about their deceased child because they did not want unsolicited sympathy from people they did not know well, “I’m in a new town and I meet new people and I don’t really want to be like ‘hi

my name's Ashley I had a baby that died' like I don't want that to be how people know me until later."

#### 3.4.1.2 *Emotional Turmoil*

Most parents indicated that they lived life one day at a time because they were uncertain as to how they would emotionally respond to the events of any one-day and how their response would influence their interactions with other people. Emotional lability and sensitivity were predominant features of the emotional turmoil bereaved parents experienced.

##### 3.4.1.2.1 *Emotional Lability*

On many days parents expressed they were uncertain about their ability to control their emotions. Each day's events or interactions could elicit grief responses. This unpredictability and emotional lability often resulted in parents identifying with the phrase "taking one day at a time." Parents labeled their emotional journey as a "roller coaster ride," with "some good days and some bad days." The days that parents were able to successfully engage in daily activities without crying were good days. All parents acknowledged that they had bad days in which their mood was labile, and other days in which they spent most of the day crying and constantly reminiscing about the child. A 24-year-old father said the following:

You know, you kind of get those, like you go through it real fast....you see good things, you see bad things, so it's just kind of like I can go from being [in] a jumpy mood to being just down in the

dumps. Ah, I don't know it's hard to explain it's just a rollercoaster: I have my good days and my bad days.

Bad days generally were on special occasions where parents remember and miss their child the most, such as birthdays, anniversaries, and holidays. Memorializing their child on these special days became an integral part of their celebrations of the occasion. One 23 year-old mother with no other children stated:

It's Christmas time you know [that] hits you a little bit and you know everybody's trying to, you know, we've got stuff set up for Natalie, we've got a stocking set up for her, we've got candles set up for her, it's just, it's just different...

Additionally, most parents identified bedtime as the hardest time of the day. Because of the slowing of the pace, parents' thoughts were drawn to the memories of their child. One 24 year-old mother with one living child stated:

I feel like a lot of times now I do okay throughout the day and then when it's time for bed is when I have my, my big breakdown so it's not like you know it doesn't keep me in bed the whole day I just have a rough night.

#### 3.4.1.2.2 Emotional Sensitivity

Parents acknowledged that they were emotionally sensitive to certain situations such as the birth or death of an individual. One 33 year-old mother with one living child referred to her emotional sensitivity when a family member became pregnant:

My brother had a baby 2 weeks ago and something my mom said to me about how hard it must be for me to see my brother have a baby and I think that [it] upset me more that she said that, and I, I got really upset about it.

Another 24 year-old mother with one living child recognized her emotional sensitivity to the news of anybody's death, as it brought back memories of the loss of her child:

I'm doing home health ... I'm taking care of like elderly in their homes and actually my first patient... She was a hospice patient and passed away recently so that kind of was hard on me.

Parents expressed distress over the unpredictability and highly sensitive emotional responses to people and situations. Life without their child and emotional sensitivity changed relationships with family, friends, and their community.

### *3.4.1.3 Transformed Relationships*

#### *3.4.1.3.1 Relationship with significant other*

Parents recognized that their individual responses were not always aligned with the responses of their spouse or family. One mother expressed distress related to a lack of emotional sharing with her spouse. At 6 months post child death, one 24 year-old mother with one living child and not married described it as: "It's kind of hard on me I wish he would, you know, feel like he could cry or whatever in front of me. Not that he hasn't, but I know a lot of times he does grieve in private." Fathers indicated that they try to hold on to their emotions as they felt the need to remain strong for their wives. The same 24 year-old mother also added,

He's there for me when I'm upset and you know and he talks if I want to talk about it or whatever, he listens and hugs me when I cry and you know, whatever. He stays busy, .....he does cry and I know that he does but it's just in private he'll look at pictures when I'm not there you know,

and think about Lily and cry or whatever but he doesn't do it as much when I *am* there- 'cause I, I don't know maybe he feels like he needs to be strong for me.

Thus, generally parents recognized that they and their spouses grieved differently, and acknowledged the individualized nature of their grief and were supportive of each other.

#### 3.4.1.3.2 Relationship with other family member, friends, and community

Bereaved parents also acknowledged that their relationships with family, friends, and their wider community had changed. Some parents acknowledged their sadness over the loss of a connection with individuals who were part of their child's life while ill, especially medical and nursing personnel. Maintenance of relationships with healthcare providers was not feasible after the death of their child, so they often continued their relationships with parents of other children with similar illnesses. They may have met these parents in the healthcare setting or through the websites they had created about their child. Similarly parents were appreciative of the support received from family and friends. However, parents also acknowledged their need to be alone at times. The 24 year-old father with no other children said, "So it's just once I've kind of shut off, and be quiet, people know, hey, give me my time and you know I like that time."

Some parents identified a change in relationships with friends or co-workers who appeared uncomfortable with talking to them after their child's death. A 29-year-old mother with one living child expressed this about her colleague's discomfort:

In my school, at least I think that, even some coworkers are just afraid to, to approach me and afraid to say anything you know, um... he's my son and

regardless of how long he's passed I mean he's always going to be my son and I'm always going to talk about him. I just feel like some people just find it uncomfortable and don't know what to say and, and I understand that completely I do because it's a very uncomfortable situation. You know I'm sure they don't want to upset me.

### **3.5 Discussion**

Since grief typically overshadows parental bereavement, our study aimed to understand how the unimaginable loss of a child influences a bereaved parent's life beyond the immense grief they experience. While this study reinforced existing knowledge of the individualized nature of parental bereavement, and their roller coaster emotional journey (Arnold & Gemma, 2008; Arnold, Gemma, & Cushman, 2005), it also sheds light on the nuances and complexities of bereaved parents' challenges in their life as they grieve.

Consistent with other studies, we found that bereaved parents described life after the death of their child as finding a "new normal" and they acknowledged their need to stay busy to avoid thinking of their child (Degroot, 2013). We identified challenges parents' encountered with new tasks they use to stay busy. Certain jobs like being a teacher or a nurse triggered reminders of the child for the bereaved parents. Parents who find their original job challenging might venture to seek new job or career choices, which might trigger additional challenges of the stress of a new environment with new colleagues who do not know of the parent's bereavement. In addition, in a couple, each parent needs to grieve the loss of their child and may not be able to emotionally support their partner. This finding is similar to other research that showed differences in grief response among couples with a potential for discord in relationships (Rogers, Floyd, Seltzer, Greenberg, & Hong,

2008). Challenges related to the difference in spousal response to the child's memorabilia was noteworthy; spouses may differ in how they want to remember their child, or how often they visit the burial site. When parents differ in how they want to keep continuing bonds with their deceased child, conflict in their relationship may develop. Thus, the cumulative nature of the challenges that arise from a parent's life changes following the death of their child were complex and highly individualized.

The paradox between wanting to continue the relationship with the child ("not forgetting") and wanting to move on posed its own set of challenges for bereaved parents. A parent's desire to not forget their deceased child seemed incongruent with their desire to move on with their life. These findings support the Dual Process Model of coping (Stroebe & Schut, 2010) with bereavement where bereaved individuals fluctuate between tasks such as wanting to continue the relationship with the deceased child, to tasks that help move the parent on in life (Stevenson, 2016; Stroebe, 2010). Parents in our study also wanted something tangible to associate with their child in order to enhance remembering such as photographs, plaster casts, clothing, blankets, hand or foot prints (Brosig, Pierucci, Kupst, & Leuthner, 2007). Not forgetting is also consistent with the bereavement concept of continuing bonds (Klass, 1993) where parents work to maintain a relationship with the deceased child. Hence moving on seemed like a goal bereaved parents wanted to achieve, but a bereaved parent can never really forget their child: highlighting the challenges bereaved parents face as they traverse through these tasks during the bereavement period.



The adaptive work identifies bereaved parents tools to help themselves, such as keeping busy and seeking support from friends and family. Parents' perception of support from their social system has been related to fewer physical and psychological symptoms (Christiansen, Elklit, & Olff, 2013). In addition, parents can engage in adaptive work such as tapping into resources available in their community, support groups, counseling, or psychotherapy (Snaman, 2016). The healthcare provider as an adaptive leader can help the bereaved parent to identify and direct them towards these resources. However, bereaved parents have shared their *sense of abandonment* (Tan et al., 2012) from the healthcare system specifically the pediatric team due to an abrupt end of relationship with the healthcare team after the death of their child.

The parent-/healthcare provider relationship is key in the parents' social network prior to the death of their child (Brosig et al., 2007). Yet, bereaved parents are overlooked by the healthcare system (Morris & Block, 2015), since the focus of family-centered care is geared towards care of the family while the child is alive, and healthcare providers consider interactions with bereaved parents as emotionally challenging time consuming, (Granek, Barrera, Scheinemann, & Bartels, 2015) and not reimbursable. Parents appreciate the contact made by the child's healthcare team following the death of their child (Brosig et al., 2007) but are also cognizant of the professional role and time commitment that is required to continue this relationship (Welch et al., 2012). While bereaved parents understand that their child's healthcare team may not be able to continue to support them during bereavement,

they may also fail to seek help from their primary healthcare providers when confronted by challenges that are adaptive in nature. Given the inter-related and complex nature of the adaptive challenges of bereaved parents,, healthcare leaders could help parents to understand their challenges and support opportunities (Anderson et al., 2015). Successful adaptive work could help address parents' health deficits previously described in the literature.

### **3.6 Conclusion**

We found parental bereavement challenges to be inter-related, complex, and adaptive in nature. The identified adaptive challenges focused on the absence of the child, the emotional response to that absence, and the changed relationships with family and friends. Parents attempted to engage in adaptive work to manage the challenges by reorganizing their lives, staying busy, and focusing on the surviving child/children while taking time to still hold on to the memories of their deceased child. Both the adaptive challenges and work were based on the specific situation of each parent underscoring the individualized nature of parental grief (Arnold et al., 2005). These adaptive challenges have the potential to change overtime. This study is limited by a 6-month time frame; therefore, future research is needed to identify the trajectories of the complexities of parent's bereavement challenges over a longer period of time.

Since this study examined responses of bereaved parents in an open ended interview that did not specifically ask about their challenges, future research designed to focus on

assessing bereaved parents challenges and the adaptive work they use would be important to substantiate our study findings. In addition, this study included bereaved parents of children with complex life-threatening illnesses. These parents have a close relationship with the healthcare team due to the illness trajectory and therefore the adaptive leadership framework seems like a good fit. However, instances of traumatic deaths of children like accidents, suicide or homicide, parental bereavement trajectories are different due to the nature of the death (Kovarsky, 1989; Wijngaards-de Meij, 2005). These bereaved parents need to transition from child-focused community bereavement services to their own primary care provider. Therefore the role of adult primary care providers (Snaman, 2016), (Donovan, 2015) as adaptive leaders for these bereaved parents needs to be examined using the Adaptive Leadership framework.

The Adaptive Leadership Framework provides focus on the range of challenges that bereaved parents face. The framework could also be used to develop bereavement care interventions that empower parents to develop their adaptive capacity and include adaptive leaders in the process in developing a shared understanding of the unique challenges that parents confront. Insight into bereaved parents' personal challenges can lay the foundation for future interventions that address bereaved parents' progress and overall health.

## 4. Chapter 4

### 4.1 *Introduction*

Bereaved parents face challenges that are unique to their individual circumstances (chapter 3). The findings from chapter 3 identified the challenges bereaved parents face are related to the physical absence of their child, their emotional turmoil, and the impact of the loss on their relationships. The desire to hold on to their child's memories, while attempting to move on in their life caused significant anguish for some parents (chapter 3). The individualized nature of parents' challenges is rooted in their unique life situation, such as the presence of other children, job status, spousal relationship, and relationships with friends and family (Arnold, Gemma, & Cushman, 2005; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008). These individual circumstances and the resulting challenges influence parental bereavement trajectories and have the potential to impact parental bereavement outcomes (Morris & Block, 2015; Morris et al., 2016).

Outcomes of bereaved parents have typically focused on their grief responses, yet bereaved parents also have higher morbidity and mortality rates when compared to non-bereaved parents (Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs, 2008; Meert et al., 2011; Rostila, Saarela, & Kawachi, 2011; Tabb et al., 2013; Van Ommeren & Levav, 2003; Werthmann, Smits, & Li, 2010). Bereaved parents morbidities include higher incidences of medical and psychological complications such as cardiac conditions, anxiety, depression, and presence of post-traumatic stress symptoms when compared to non-bereaved parents

(Barry, Kasl, & Prigerson, 2002; Davies, 2006; Dussel et al., 2011; Lannen et al., 2008; Wijngaards-de Meij et al., 2007). Poor eating and sleeping, changes in social relationships, and addictive behaviors such as smoking, alcoholism, or drug use during bereavement can also negatively influence health outcomes (Chan et al., 2012; Prigerson et al., 1997; Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). Thus, these factors can serve as indicators of parents' overall health status during the bereavement period.

Current bereavement care interventions are focused on reducing the psychological effect of grief through services such as support groups, counseling, psychotherapy, and crisis intervention (Endo, 2015) rather than evaluation of general health and well-being. The death of a child is the most stressful life event (Arnold, Gemma, & Cushman, 2005; Kreicbergs, Lannen, & Onelov, 2007) and bereaved parents' health outcomes are poorer than other individuals, including the physical, psychological, and social health status. Therefore parental bereavement challenges must be examined parents' challenges in concurrence with their health to highlight the co-occurrence of challenges and the potential subsequent effect on their health. This information can be foundational to develop and test bereavement care interventions that can assist parents to manage these challenges with the goal to improve their health outcomes.

#### ***4.1.1 Theoretical Framework***

The Adaptive Leadership Framework (Adams, Bailey, Anderson, & Galanos, 2013; Thygeson, Morrissey, & Ulstad, 2010) emphasizes the role of the individual person in

management of their own challenges and the importance of using their adaptive capacity to address the challenges they face. The Adaptive Leadership framework has been successfully applied to bereaved parents and highlights the role of the health care provider from prescriptive to that of an adaptive leader who enhances the adaptive capacity of the individual (Anderson, 2015).

This chapter uses this framework to expand our understanding of bereaved parents' challenges, the related work required to address these challenges, and their health status during the first six months after the death of their child. The purpose of this study was to examine parents' bereavement challenges, related adaptive work, the physical, psychological, and social health status during the 6 months after the death of their child diagnosed with a life-threatening illness. The specific aims of this study were as follows:

Aim 1: Examine the challenges and the related individual work done by parents.

Aim 2: Examine bereaved parents' overall physical, psychological, and social health.

Aim 3: Explore the co-occurrence of parents' challenges, related work, and health.

## **4.2 *Methods***

### **4.2.1 *Design***

A case-based, mixed methods study examined eight cases to assess the co-occurrences of bereaved parents' challenges, work, and health status during six-months after the death of their child (0 to <12 years) from a life-threatening illness. Ethical approval

for the study was obtained from the institutional review board for human subjects research.

#### ***4.2.2 Sample and Setting***

Convenience sampling (Onwuegbuzie & Teddlie, 2003) was used to recruit the cases. Each case consisted of both parents and the characteristics of the child who died (e.g. age, diagnosis, and length of illness). A total of 16 participants were recruited of which eight were mothers and eight were fathers (See Table 6 for case characteristics). All but one parent was in the 30's and that one parent was in the early 40's. Eligible participants were  $\geq 18$  years, spoke and read English, and had experienced the death of a child aged 0 to 12 years within the last two to three months. Most of the cases  $n=5$  were recruited through the palliative care program of an academic tertiary medical center. Three additional cases from other states were recruited through word of mouth. All participants remained in the study until study completion.

**Table 6 Case Characteristics**

Case	Parent	Child's characteristics	Race	Living children	Income	Education	Employment
1	Mother	Age: School age	White	2	30-60,000	Associate degree	Home maker
	Father	Length of Illness: 7 years	White	2	30-60,000	Bachelors	Employed
2	Mother	Age: Infant	Asian	1	60-100,000	Masters	Out of work
	Father	Length of Illness: 2 months	Asian	1	60-100,000	Masters	
3	Mother	Age: Infant	White	1	>100,000	Masters	Employed
	Father	Length of Illness: 9 months	White	1	>100,000	Masters	Employed
4	Mother	Age: Infant	Asian	0	>100,000	Masters	
	Father	Length of Illness: 6 months	Asian	0	>100,000	Masters	Employed
5	Mother	Age: School age	White	1	>100,000	Masters	Employed
	Father	Length of Illness: 2 years	White	1	>100,000	< 2 years of college degree	Employed
6	Mother	Age: Neonate	White	1	30-60,000	Professional degree	Home maker
	Father	Length of Illness: 1 week	White	1	30-60,000	Bachelors	Employed
7	Mother	Age: Toddler	White	1	60-100,000	Bachelors	Self-employed
	Father	Length of Illness: 2.6 years	White	2	>100,000	Bachelors	Employed
8	Mother	Age: School age	Black	1	60-100,000	< 2 years of college degree	Employed
	Father	Length of Illness: 3 months	Black	1	60-100,000	< 2 years of college degree	Employed

### 4.2.3 Measures

All parent data was collected at the two time-points 3 [T1] and 6 [T2] months after the child's death.

#### 4.2.3.1 Medical Records

For parents who were recruited through the palliative care program, their child's medical record was reviewed at T1 to obtain child demographic and illness specific data such as diagnoses, complications, and length of illness. For participants recruited through word of mouth, this information was obtained from the parents.



#### 4.2.3.2 *Body Mass Index (BMI)*

The BMI was calculated as part of the physical health assessment based on the parents' height and weight. Height was obtained by self-report at T1 and weight was obtained at both time-points either as self-report or by assessing the participant's weight with a calibrated scale during the home visit. BMI was calculated using the formula: weight (kg)/(height (m))<sup>2</sup>.

#### 4.2.3.3 *Demographic data (Appendix B)*

The demographic questionnaire assessed parent's age, gender, race/ethnicity, occupation, marital status, and number of children and a parent medical history inventory to describe case characteristics. In addition, a medical history inventory including parent's history of past illness (e.g. diabetes or hypertension), hospital or emergency department visits, smoking and alcohol intake history, utilization of bereavement services, and present health was also assessed. Data that remained constant at both time-points such as gender, race/ethnicity was eliminated from the T2 demographic data sheet.

#### 4.2.3.4 *Health Questionnaires*

Parents also completed health status questionnaires that assessed physical, psychological and social health (Patient-Reported Outcomes Measurement Information System [PROMIS]-global, sleep, and social: Brief Symptom Inventory-18 [BSI-18]). All PROMIS measures were completed using an online link. At the second time-point in the case study, the link was emailed a week prior to the scheduled interview to allow parents to

complete the questionnaires. If they did not complete it prior to the interview, time was given before their interview to complete the survey.

#### 4.2.3.4.1 PROMIS Measures

The PROMIS measures are the National Institutes of Health Roadmap initiative (Buysse et al., 2010) to build a pool of questionnaires to measure health outcomes. The Global scale (version: 1.0) is a 10-item measure that assesses overall physical and mental health, including pain and fatigue. The global sub scales scale has internal consistency reliability coefficients of 0.81(physical) and 0.86 (mental)(Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). The social scale (version: 8a) assesses the individuals perceived ability to participate in social activities. The sleep impairment scale (version-8a) includes 8 items that assess quality and ability to sleep. The Pearson correlation for the sleep scale with the Pittsburgh Sleep Quality Index (PSQI) was acceptable and between 0.66-0.85 (Buysse et al., 2010). The content and construct validity of the sleep scale (Buysse et al., 2010) and the social scale established content validity (Castel et al., 2008).

#### 4.2.3.4.2 BSI-18

The BSI-18 is the shorter version of the BSI- 53, a self-report scale derived from the Hopkins Symptom Checklist-90 (Derogatis & Melisaratos, 1983: Khalil, Hall, Moser, Lennie, & Frazier, 2011). This 18-item tool is a multidimensional measure of psychological distress (Asner-Self, Schreiber, & Marotta, 2006: Galdon et al., 2008) and takes 1-3 minutes to complete (Galdon et al., 2008). The BSI-18 is helpful in assessing for specific psychological

morbidities including anxiety and depression, which are prevalent psychological health concerns for this population. The Cronbach's  $\alpha$  is modest between 0.71-0.84 (Merport & Recklitis, 2012) and a modest predictive and discriminate validity (Meachen, Hanks, Millis, & Rapport, 2008).

#### 4.2.3.5 *Continuity Line (Appendix F)*

Participants at both time-points also indicated their perception of their own overall health on a visual scale from 0 to 10, with zero indicated as the worst health and 10 as the best health possible. This information was used to triangulate the health status survey data and the parents' perception of their health.

#### 4.2.3.6 *Interviews (Appendix C)*

Narrative style interviews assessed parental bereavement challenges and the individual work done by parents. Both parents were interviewed separately at both time-points after each one had completed all health questionnaires. The interviews began by requesting parents to tell the story of their child (e.g., "Tell me about ...(state child's name).". Probes assessed how parents were doing and what their challenges were (e.g., "What is the most difficult thing for you now? What things do you do to take care of the difficult thing?"). Probes were used to identify specific challenges related to child's personal belongings, memorabilia, celebrating special occasions such as holidays, anniversaries, or child's birthday would be used to assess challenges related to continuing bonds relationship with the deceased child. The second interview built on information obtained at the first

time-point and explored changes in earlier challenges or new challenges participants faced, and the needed changes in the individual related work required. Field notes (Appendix D) were maintained for each data point. The field notes included visual observations and a description of the context surrounding the interview.

#### ***4.2.4 Procedures***

Participants who met the eligibility criteria were contacted by a member of the child's health care team either through a phone call or mailing a study introductory letter (Appendix A). If the parents were willing to be contacted, further study details were provided, questions answered, and if the parent was in agreement, a verbal assent. For participants within 1-2 hours of driving distance and were willing for a home-visit, data was collected in person. For these parents the consent was reviewed and signatures obtained on the day of the first home visit. For parents who agreed for telephone interviews, the consent forms were sent via mail. Both parents had to consent to participate in the study. No data were collected before the consent process was completed. At first site visit, participant's height and weight was obtained, followed by either the health status questionnaires using an online link (demographic data and PROMIS scales) or the paper version of the BSI-18. The BSI questionnaire was read aloud to obtain the ratings on the scale for each item from parents who were interviewed over the phone. Parents then stated their self-perception of overall health using the continuity line, which was sent to them in their study packet. Finally the interview was conducted. Accommodations were made for completion of online

surveys after the interview, when interviews were conducted by phone if parents were located in other states and had not completed the online survey prior to the interview.

#### ***4.2.5 Data Preparation and Analysis***

The overall goal of the analysis was to describe parents' bereavement challenges, related work (**Aim 1**), health status (**Aim 2**), and examine the co-occurrence of challenges, work and health status (**Aim 3**). Data included quantitative survey data (four health status measures and one demographic data sheet) and qualitative data (interviews and field notes). In total there were a total of 32 interviews with each interview ranging from 30 to 90 minutes and field notes for each parent at each time-point. Total gathered quantitative data included 160 questionnaires, 32 body mass indices, and data from 16 continuity lines, each with two data points.

All interviews were digitally recorded and transcribed. A professional transcriptionist transcribed the digitally recorded interviews verbatim and the accuracy of transcripts was verified by comparing the transcription to the recorded interviews by the 1<sup>st</sup> author. All interview data was analyzed using the ATLAS.ti qualitative data analysis software system to code, organize, and manage the data.

All demographic and PROMIS data was downloaded from the REDCap database and converted in SAS files to perform the descriptive statistics. These BSI scores and the continuity line data was entered into excel files, which were then uploaded into the SAS v.7 statistical program for further analysis. The analysis was performed in three steps. Step one,

included analyzing both data types individually. Content analysis as described by (Miles, 2014) was done with the interview and descriptive statistics of the health questionnaires from participants. In step two, qualitative data was transformed to obtain a numerical count and merged with health status scores. Finally in step three, evaluation within and across case analyses were conducted (Stake et. al., 2014). All steps are described in detail

#### **4.2.5.1        *Step 1 Content Analysis and Descriptive Statistics***

In the initial phase of analysis both data types (interviews and health status data) were analyzed using procedures appropriate for the data type (interview data: content analysis, health status data: descriptive statistics).

Content analysis guided by the Adaptive Leadership Framework identified bereaved parents challenges and work from the interview data. Two elemental methods of coding, descriptive and in vivo, were used to identify and label bereaved parents challenges and work (Miles, 2014). Both deductive and inductive coding strategies were used to develop a code list. Challenge codes from chapter 3 were used as an initial start list and new codes were added as they emerged from the data. All codes were given an operational definition to ensure they were applied consistently across all interviews and cases (Miles et. al, 2014). Codes and code definition were revised and refined as needed throughout the analysis process. All coding decisions were recorded and. inter-coder reliability, with at 10% of the data coded by two people (first and last author). By using patterns, second level coding was identified from the data and grouped together to form themes and subthemes.

Each participant's health survey raw scores were first calculated. For the PROMIS scales, each question is value based on five possible responses from one to five. Questions that need to be reverse coded were given the value based on the reverse coding. Raw scores from the scale for each participant were calculated by deriving the sum of values of all the questions in a scale. The raw score/scale score table (See Appendix L) was used to obtain the T scores for the scale for each participant. For the BSI-18 the paper version answer sheet was used to record the value (0-4) for each question to the corresponding line. The lines were arranged in three columns to correspond to the three BSI subscales: (1) Somatization, (2) Depression, and (3) Anxiety. The total values of each column were added to obtain raw scores for each subscale, calculating the sum of all subscales to obtain the global (GSI) raw score. The raw scores of each participant were plotted on the profile for community norms based on their gender (father's = male profile, mother's= female) to obtain the T scores. BMI for each participant was computed by using the formula  $\text{weight (kilograms)} / (\text{height (meters)})^2$ . Finally, descriptive statistics were computed for all health status data were calculated using the SAS analytical software.

#### **4.2.5.2      *Step 2 Data transformation and data merging***

In this data analysis phase a matrix for each case was constructed. See Table 8 and 10 as examples. The challenges and work identified for each case were organized by parent and data collection time-point. The total number of challenges and work done by each parent was then transformed to a numeric total to enable data merging and to look for

patterns using the Tableau data visualization tools.

However, the total number of challenges by itself did not communicate the impact of the challenge on the parent's life. Therefore, challenge intensity was assessed for each interview. Challenge intensity is the measure of the impact of the challenge(s) on the parent in their overall life. I reviewed all the interviews again to identify a method to categorize challenge intensity. Challenge intensity was determined based on a) Textual language within the interview such as emphasis of the challenge in the interview and number of times the challenge was mentioned within an interview (challenge frequency), b) Total number of challenges, and c) Emotional state of the parent during the interview as documented within the interview transcript and field notes. Thus, the emotional context was combined with textual patterns (emphasis and frequency), and the total number of challenges to determine an overall challenge intensity for each parent at each time-point in the study. A higher number of challenges did not always correspond with higher challenge intensity, as each parent has a different approach or ability to their individual work in bereavement. There could be multiple challenges identified at a time-point but the interviewer observation of the emotions and textual patterns of the parent indicated that the challenges were not as bothersome, and the challenge intensity was mild. Conversely, a single challenge could have a considerable impact on the parent's life and therefore be categorized as moderate, or even severe. Therefore challenge intensity for each interview was based on a cumulative inference drawn during the entire interview and reflected how much the parent was



affected by their challenge/challenges at that time-point as described in the exemplar cases described in the results section. Three levels of challenge intensity were identified and defined as follows:

Mild: The challenges highlighted by parents are identified as not bothersome or having minor implications on life. The interview does not contain textual language, nor demonstrates emphasis of a particular challenge or repetitive discussion of a challenge (Low challenge frequency: 0-3). Total challenge numbers could vary, but generally ranged between 1 and 5. The parent was generally emotionally stable throughout the interview.

Moderate: The challenges highlighted by parents are identified as bothersome and having major implications on life. The interview contains textual language, which demonstrates emphasis of a challenge, “It’s like negative stimulus overload” or repetitive discussion of a challenge. Total challenge numbers ranged from 5 to 12. The parent was emotional and cried during the interview specifically while talking about the challenges.

Severe: The challenges highlighted by parents are identified as very distressing and having excessive implications on day-to-day functioning. For example, one parent said, “Every day is- is hard because you know there’s a piece missing from your puzzle.” The interview contains textual language, which demonstrates emphasis of the challenge(s) and/or repetitive discussion of a challenge. In addition, multiple challenges were identified with total challenge numbers 5 and above. The parent was emotional and cried at multiple occurrences or throughout the interview. See Table 7 for intensity quote examples.

**Table 7 Interview Challenge Intensity Examples**

<b>Challenge Intensity</b>	<b>Example Quotes</b>
Mild	<i>"But it'll, you know, it'll just you know kind of- it'll hurt my heart and you know I'll feel sad and- and cry or tear up a little bit."</i>
Moderate	<i>"Um, there were an unfortunate series of extenuating circumstances that have made our life that much more stressful and that much more difficult which has compounded the event."</i>
Severe	<i>"Um, the father/son moments that we had it's- it's really, really rough"</i>

After the challenge intensity for each interview was determined, a joint matrix that included health measure scores (T-scores for PROMIS and BSI-18), BMI, continuity line (parents health perception), the count and intensity of challenges, and the numeric count of work (see Appendix H) for each parent at both time-points was created. This joint matrix was used to conduct the next analytical phase.

#### **4.2.5.3 Step 3 Case Analysis**

This phase included analyzing the merged data both as a case (within case) and across all cases (across case). Each case was examined (within case analysis) to identify the specific challenge types, work done to address the challenges, total number of challenges, and challenge intensity by both time-points and both parents (Stake, 2006). The specific challenges, related work of the parent, and the overall health status were also examined for any changes between the two time-points and to assess for changes between both parents in the case, and at the two time-points. The Tableau data visualization system was used to combine data sets, create different visuals and look for similarities and differences across the cases (Stake, 2006).

### **4.3 Results**

These details present a rich description of the complexities of the first six-months of bereavement period for parents who have lost a child with life-threatening illnesses. All deceased children are given pseudonyms to identify the case. After presenting two cases, a synthesis of the challenges, work, and health status of all eight cases will be presented to address the study aims.

#### **4.3.1 Case of “Inadequate grief:” Connor**

This case includes a two-parent family comprised of married mother, father, and the 7-year-old male child (Connor) who died of a chronic illness diagnosed since birth. The family also included 2 other living children. Connor had multiple hospital admissions and long hospital stays between birth and death. Connor’s mother is a homemaker in her mid-thirties who self-identified as the primary care giver for the child, especially at home. Connor’s father was in his late thirties and had retired from his primary job about the same time as Connor’s death. He was currently under-employed and actively seeking a higher paying job.

#### 4.3.1.1 *Connor's Mother's Challenges and Work*

##### 4.3.1.1.1 Challenges

Connor's mother was generally emotionally stable during both the interviews, but had moments when she cried as she talked about her challenge related to her response to Connor's death.

At the 3-month interview she highlighted her cyclical emotional response to death and attributed it to Connor's lengthy hospital stays; "Since, he (Connor) spent so much time in the hospital a lot of time it just feels like he's at the hospital" (not really dead). She referred to her need to be constantly available for Connor while he was at the hospital as "used to being basically on call 24/7." Thus, after Connor's death she felt the need to stay occupied and "supposed to be doing something," just like she was before Connor's death. She kept herself busy doing household chores, especially when angry. Her feelings of anger was sometimes associated by her to the "why " related to Connor's illness and suffering. She also acknowledged times that were particularly emotionally difficult when she had her emotional outbursts; "At least once a month, it usually all just hits me...So then I'll just have a breakdown. And then the next day it's just... I'll be okay." She added that the days nearing her emotional breakdown also affected her daily functioning:

As the days progress again then it gets harder and harder. And usually leading up to the breakdown I know already- about a week before I don't feel like doing anything. I don't want to cook, I don't want to clean, I don't want to do- I just want to sit. (Mother crying).

Connor's room and belongings also contributed to his mother's challenges. "I couldn't go in his room for about the first month.... And now over time, I've been able to go in maybe for like fifteen minutes at the max." Most of his things in his room are intact, like his bed, pillow, and teddy bear. However, she stated that she enjoyed when her other living children played with Connor's toys and remembered Connor during their play. She acknowledged that Connor's death had made her "paranoid" as a parent because she feared that something might happen to the other children too and therefore was on the guard even if they had small bumps or a scratch. At the 3-month interview, Connor's mother's challenges were related to her cyclical emotional grief response, his belongings, and her paranoia about her living children's health.

At the 6-month interview, Connor's mother stated that she had not cried since the last interview and expressed her frustration about her lack of emotional response (crying). She was unable to fathom why she had not cried between 3 and 6 months and questioned herself, "I just haven't cried. I've been sad and I miss him every day and I think about him every day like normal. I just- I guess that emotional crying part just isn't there. Why? Why isn't it? I don't know." She indicated that since Connor had frequent hospitalizations, she was used to him not being at home with the family, which reflected her emotional state, "I think it's more of a denial phase where it doesn't feel like he's gone. I think a lot of it has to

do with him being at the hospital all the time... we're kind of used to not having him home."

At this time-point, she also acknowledged her general lethargy to do things and lack of interest in socializing or even just going outdoors:

We had family out and it was you know they wanted to do a lot of stuff and I was just kind of like, "But I don't want to. I don't want to do you know anything." Even just going to the store to get groceries was a big chore. You know I didn't- I didn't want to. You know friends- our neighbors or our friends that are here in town they want to hang out and I'll make excuses not to go, just- only because they have three kids. Three healthy kids. So it's like, 'I don't want to.' It's hard.

Thus, Connor's mother identified that she was socially isolating herself, which, consequentially affected some of her relationships with friends and family. In addition, she acknowledged a change in her personality after Connor's death:

Prior to having Connor, I was a very shy- keep to myself person. And then once we had Connor he kind of forced me to be opposite because I always had to be out at the hospital and everything and meet people. I feel like I'm reverting back to that way. So when people call I force myself to do it but as we're out doing stuff I'm just like, 'I'd rather be at home just sitting on the couch watching a movie than doing this I guess.'

She stated that she tried to reach out to Connor's health care team, "I think it would help if I was able to hang out with you guys at the hospital, knowing he's not there."

However, it was hard to schedule a meeting with any member of the team, as they were busy. She visited the hospital on Connor's birthday but many of the health care personnel involved in Connor's care were not working on that day but she was happy to see a few familiar health care providers. Thus, while she socially isolated herself from the rest of the

world, she felt comfort in memorializing Connor's birthday with the health care team members.

Commemorating Connor's birthday with the health care team was her way of continuing her relationship with the health care team and continuing bonds with Connor. During this interview, she also shared that Connor's room was rearranged and used now more as a storage room. She admitted that she could stay in the room a little longer but still felt some anxiety:

I can go in there a little more now but it- it's still- I've noticed especially when I'm touching his stuff specifically it- it takes- I can stay a little bit longer now- but I still get to that point where I'm like shaking. That I can feel it in my head and I'm like, 'Okay, let's put this down. Time to go.'

Celebrating holidays, birthdays, and anniversaries did not bring the same joy that she used to experience prior to Connor's death.

I mean I've been very excited about Halloween. (She starts to cry, sounds sad) But it's funny now that we're in October now I'm usually very excited about decorating and even now I'm like, 'Eh'. I'm like, 'Eh, I don't really want to.' Even though I know that's what I do. But that's how it's been ever since though, is- I get excited for something until it starts to come up (R laughs) to that point and then it's just like, 'Eh, I don't want to do it. I don't feel like doing it.' Um...just like my birthday was in August and I was like, "I don't even want to celebrate it."

At thitime-point Connor's mother's challenges were related to her continuing bonds response, even though she worried she was not adequately grieving the loss of her child. She continued to have difficulties with Connor's belongings and the fear of something happening to her living children. Connor's mother recognized a change in her personality,

which she said was reverting to herself prior to Connor. She highlighted her lethargy, and reluctance to socialize with friends and family, and avoiding and celebration of special occasions or holidays.

#### 4.3.1.1.2 Challenge Intensity

Challenge Intensity: At 3 months Connor's mother's challenge intensity was determined as moderate due to her intermittent emotional outbursts that affected her daily functioning and performing daily chores. At 6 months, although the number of challenges had increased, her main challenge was related to her social isolation. However, she was able to perform her household chores and also was involved in reaching out to other families through social media as described in the work she did. Therefore at 6 months her challenge intensity was determined as mild.

#### 4.3.1.1.3 Work

At 3-months Connor's mother responded to her emotional needs and cried or dealt with anger by keeping busy doing household chores. Her other surviving children were her source of joy and helped her continue her relationship with Connor through their play. Additionally, she had a friend who offered her the support system she needed during these tough times.

Similarly, at the 6-month interview, Connor's mother acknowledged the continued support from her friend and also mentioned an aunt she connected with once a month. While at this interview, she said she was socially more isolated, she shared that she was



seeking support through social media and using her Facebook to connect with other families with similar illness. She said, “My goal is that we’re gonna be the face of this disease.” Additionally at this time-point she indicated her desire to maintain a relationship with Connor’s healthcare team and reached out to team members. Thus, at this time, she had channeled her energy to giving back to the community and attempting to reconnect with the health care team.

#### 4.3.1.2 *Connor’s Father’s Challenges and Work*

##### 4.3.1.2.1 Challenges

At the 3-month interview, Connor’s father’s challenge focused mainly around his employment status. Throughout the interview Connor’s father communicated about his financial situation and his struggle to pay the bills as a “negative stimulus overload” during the first 3 months since Connor died. He described his situation as follows:

Um, there were an unfortunate series of extenuating circumstances that have made our life that much more stressful and that much more difficult which has compounded the event. Um, specifically since retiring from the military and regarding my employment. So I mean I get specific if you’d like specifics but basically my employment status has been a significant distraction and not a good one and a significant amount of stress and anxiety, at least for me. I’m not going to answer for wife but for me. So I haven’t really had the opportunity to- to grieve or think properly of him (Connor) because you know I’m consistently worried about how I’m going to pay the bills.

Consequently, Connor’s father feared he was forgetting Connor since he was not able to devote time to grieve his loss:

If I did not have to worry on a consistent basis about my employment status, the amount of income I'm generating, our ability to pay for our daily expenses... more proper thought could be spent on the grieving process. Instead it feels like we're going through certain motions... almost like we have forgotten about him to an extent. Because now there's this extreme and I do mean extreme with all capital letters followed by several amount of exclamation points, amount of stress on how are we going to you know, financially survive? And if we didn't have to worry about that you know then perhaps you know the appropriate time- whatever that is, I can't calculate that- but the appropriate time, the appropriate attention, the appropriate emotions could be spent remembering [our] son, grieving [our] son, dealing with the kids, whatever. Instead you know daily it's, 'What are we gonna do? What I am I gonna do? What am I gonna do?' And it's been a miserable situation and it's just- the sad reality is, it's just timing.

At the six-month interview, Connor's father acknowledged that he was at a better financial situation than at the 3-month time-point. However, he said that he got caught up in routine life distractions and therefore not really focused on grieving. He therefore experienced guilt, as according to him he was not spending enough time grieving. He attributed his immersion into his current life to the fact that Connor was often in the hospital and they visited Connor only during the weekends and therefore their weekday routine remained the same. He said, "Connor deserves more and should not be forgotten."

During this interview, Connor's father emphasized that a loss of a child is the type of grief that is always with you and even though you live life like a normal family, their situation is anything but normal. He briefly mentioned about the insecurities of his life situation with reference to his rental home and temporary job as a reflection of his lack of permanency and an unsettled life, which consequently affects his grieving for his child.

However, he stated that he wanted to reorganize Connor's room and dedicate it solely to him.

In addition, during this interview, Connor's father shared about his experiences with colleagues and shared how people's responses and interactions with them added to his life stressors:

You're gonna get a lot of same responses repetitive. "Oh, I'm so sorry for your loss. Is there anything I can do?" But do not invest in any of it. And be very, very wary of what you trust. And keep your eye on the ball. Because while so many people that worked for the company in the corporate realm that I had a lot of problems with- were empathetic and felt bad for me, even lost a child of their own to cancer-um, life goes on. So immediately when I was accused of misconduct by people who are trying to take the attention off themselves- I went from attempting to grieve and you know earn my pay check and you know conduct myself professionally to going on the defensive. Having to protect myself and then coming to terms with the reality of the business I was working for and how is irrefutable the right way to say it?

Additionally, Connor's father shared the gaps in health care services specifically with lack of sensitivity by hospital staff during end-of-life care.

What I remember was the unnecessary attempt to console me by the charge nurse, who I feel no ill-will towards. I know she's just trying to do the right thing. Where and in all actuality she overstayed. It's like, 'Okay, son has passed.', because that's...from that point forward that's me and my wife...The other thing that caught us off guard was how quickly they [hospital staff] wanted the room vacated. I had asked at least more than once how much time we have to clear out the room. 'Like do I have 24 hours? Can I come back tomorrow and collect his things? Me personally, or my wife, or my friends?' Cause I had friends from out of town. 'Can we personally collect the belongings? Don't touch them we will.' No, it wasn't until- I don't know how much time had passed that, 'Well you don't have to do anything. We'll take care of it for you.' And I was like, 'Wait, whoa, whoa, whoa, whoa. These are our things, these are his things. Nobody else needs to touch them.

What are you saying?' 'Well yeah we're gonna have to turn the room over as soon as possible.'

Here is what he said about decedent care:

The guy showed up with the slab cart and I'm looking at this thing like, 'What the hell is this?' And I asked him, 'Okay, how are we gonna do this?' You know because I was under the impression we're gonna make it look like you know he's asleep going for surgery or going somewhere else. You know so that it's not too insensitive when it passes by. And no, he's like, 'No, I got to do this. I gotta do that. I gotta zip him up in a bag. I got to put him on a slab.'" And I'm like, 'Dude it's my kid!' Um...hopefully I've kind of made my-my-my point clear.

One important recommendation Connor's father offered to improve bereavement care services through the health care system was to implement the "Observe, Orient, make a Decision and Act (OODA)" protocol, which caters to the individualized and unique circumstance of every family. He identified that each bereaved family's situation and needs are different and hence need to be approached accordingly.

Thus, at the 6- month time-point Connor's father underscored his challenges related to his remorse for not adequately grieving for his son, and also highlighted his changed relationships with people stemming from their insensitive response to Connor's death. He also was able to identify areas of improvement in bereavement care in the health care system.

#### 4.3.1.2.2 Challenge Intensity

At 3 months, although Connors' father's had a total of 3 challenges, he repeatedly emphasized the impact of his financial situation on his life and his ability to focus on his grief. Consequentially his challenge intensity was determined as moderate. At 6 months, with a change in his job situation, the challenges were related to his guilt feelings and the gaps in bereavement and end of life services provided by the hospital where Connor was treated, which put him at a mild challenge intensity category.

#### 4.3.1.2.3 Work

During both time-points, Connors father identified physical fitness as a big part of his daily routine, which he thought was helping him with his psychological well-being. In addition, although, throughout the first (3 months) interview, Connor's father described his current financial and life's situation as "toxic;" he wanted to reach out to Connor's health care team members and give them a teddy bear as his way to say 'Thank-you' to them;

There was a teddy bear that we got for Connor from the teddy bear factory. Everybody called him Connor bear. I don't know why, I don't know where that came from but everybody called him Connor bear. So I was gonna go to EBay and order enough of those bears and then we had his head shaved at the funeral home and I was going put a little piece of the hair behind the little patch where the heart would be and then I was gonna give them to the individual nurses so that they could all have their own little Connor bear.

Thus, weight management and giving back were the two work strategies Connor's father engaged in at both the time-points.

**Table 8 Connor's Parents Joint Matrix: Challenges and Work**

Time/ Parent	T1- Mother	T2- Mother	T1-Father	T2-Father
<b>Challenges at Each Interview</b>				
Theme	Challenge (Frequency)	Challenge (Frequency)	Challenge (Frequency)	Challenge (Frequency)
Grief	1. Emotions-anger & yearning (2) 2. Cyclical emotional response (1) 3. The why's- related to the child's illness trajectory	1. Emotions-anger, denial (2) 2. Inability to enjoy life (2) 3. Lack of crying (1)		1. Emotion-guilt (1)
Life's demands			1. Other stressors: Job and financial situation (10)	
Continuing Bonds	4. Child's room a reminder of loss (2)	4. Child's belongings a reminder (1) 5. Miss child on special days and holidays (2)	2. Fear of forgetting the deceased child (1)	
Interactions	5. Changed as a parent paranoid that something might happen to the living children (1)	6. Social isolation (2) 7. Changed as a parent-paranoid (1) 8. Changed relationships (2)		
Health Manifestations		9. Lethargy (3)		
Gaps in health care services			3. No hospice care (1)	2. Lack of sensitivity during end-of-life care (2)
<b>Number of Distinct Challenges at Each Interview</b>				
	5	9	3	2
<b>Challenge Intensity of the Interview</b>				
	Moderate	Mild	Moderate	Mild
<b>Work Strategies at Each Interview</b>				
Theme	Work	Work	Work	Work
Grief Work	1. Responds to emotional need to cry 2. Keeping busy			
Continuing bonds	3. Child's pictures and belongings give joy	1. Memorializing child's birthday		
Interactions	4. Support network 5. Living children	2. Support network 3. Social media as a platform to grieve		
Healthy Living	6. Weight management	4. Weight management	1. Weight Management	1. Weight Management
Health care services		5. Maintain contact with child's healthcare team		
Altruism		6. Giving back	2. Giving Back	2. Giving back
<b>Number of Distinct Work Strategies</b>				
	6	6	2	2

#### 4.3.1.3 *Connor's Mother's and Father's Health Status*

Both Connor's parents' had areas of concern in their mental and social health. At 3 months all of Connor's mother's health parameters were below the population means but at 6 months three (physical, mental, and sleep) of her four health parameters had improved (Table 9). However, her social health was worse at the 6-month time-point than at the 3 month, reflecting increased social isolation with time. Her BSI-18 scores, her depression subscale score and her global score were both higher than the cut off score 63, thus indicating the need for further evaluation psychiatric evaluation. However, her medical history data did not reveal any new diagnosis or any other significant findings.

Connor's father's mental and social health scores were below population means at both time-points and just like the mother, his social health score was worse at 6 months than at 3 months. Additionally, his BSI-18 subscale and global scores were above the cut off (63) which indicated a need for further evaluation at the 3-month time-point, and were borderline at the 6-month time-point. In addition, his medical history data indicated that he had a referral to a physical therapist at the 3 months time-point and a psychiatrist at 6 months. No new diagnosis was identified in the medical history data review. Additionally, both parents identified self-perception of their overall health at above average with improvement at the 6 months time-point.

**Table 9 Connor's Parent health Scores**

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	54.1	50.8	42.3	50.8
	Mental	36.3	41.1	36.3	38.8
	Sleep	50.3	54.0	48.9	59.3
	Social	43.0	39.3	48.0	44.0
Brief Symptom Inventory (BSI) -18	Somatization	48	64	59	59
	Depression	66	65	63	67
	Anxiety	65	48	54	59
	Global	63	62	60	63
Continuity Line	Self-health Perception	Scale 0 to 10 0 = Worst health, 10 = best health			
		6	7	7	8
Height and Weight	BMI	30.4	30.4	28.6	29.2
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score $\leq$ 63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					

#### 4.3.1.4 Case Interpretation

This case highlights the competing demands of daily life and the parents' inability to focus on their grief response, causing feelings of "inadequate grief" and guilt. Thus, Connors parent's challenges were related to their grief response, and other life stressors, related to Connor's father's job and financial situation. In addition, since Connor had a long illness trajectory combined with long hospital stays; the parents struggled with their inability to grieve their child's loss because the absence of Connor was not atypical. The feeling of guilt as they immersed in their life's routines, also made them fear that they might forget Connor. Both parents' challenge intensity improved at the 6-month interview due to a



change in the emotional grief response for the mother and change in financial situation for the father.

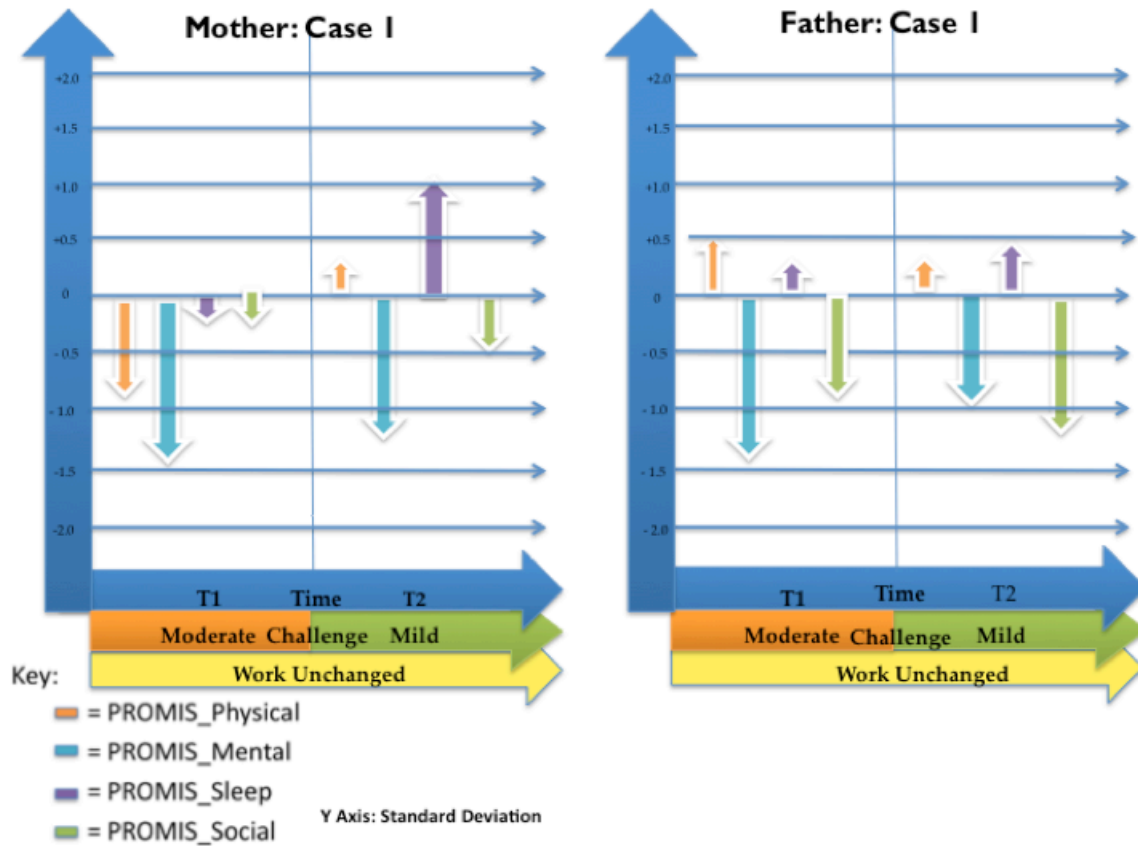
As for the work strategies used to address their challenges, both the parents wanted to reach out to Connor's health care team, and express their gratitude to them. Physical fitness was another strategy that both parents used to help themselves. Connor's mother also used social media to build a support network for herself and other parents who have children with similar diagnosis as Connor. The type of work strategies remained unchanged for both parents over the two time-points.

Overall, both parents showed improved health scores at the second time-point. Their social health scores however were worse and Connor's mother mentioned the social isolation in her interview. Though Connor's father did not overtly imply that he was socially isolating himself, his challenge related to changed relationships with people and his reference about people's comments affecting him were possible indicators that he too was isolating himself. The social isolation that both parents experienced could subsequently influence their mental health and overall well-being.

This co-occurrence model (Figure 3) depicts the changes in health scores at the two time-points. While their physical health and sleep improved, both parents demonstrated poor mental and social health at both time-points. The slight improvement in some health scores co-occurred with a lessening in their challenge intensity. The work related to

addressing grief emotions, connecting with Connor’s health care team members, and engaging in altruistic activities generally remained unchanged during the 6 months.

**Figure 3 Connors case: Co-occurrence Model**



#### 4.3.2 Case of “Grief Culture”: Maggie

This case includes a two-parent family comprised of married mother, father, and their 5 ½ year old female child (Maggie) who died of a chronic illness diagnosed 2 years prior to her death. Maggie’s mother was masters prepared employed white female in her

mid-thirties with European cultural ties. Maggie's father was a white male, employed, and in his late forties. This family had one other living child.

#### 4.3.2.1 *Maggie's Mother's Challenges and Work*

##### 4.3.2.1.1 Challenges

At the 3-month time-point, Maggie's mother's challenges were focused around her grief experience through her cultural lens. She said she felt "alone in grief" as the grief culture in the US was different than the culture she embodies. She shared how grieving publicly was socially acceptable in her home country:

"Yeah so in my culture...when someone dies there's a certain period of days and months....like some went up to a year, wear black. So that's kind of like a sign to others that, 'Hey this person is going through a loss and just a sign-outwardly sign to be more gentle and more nice, to help.'

Because of culture norms, she felt that people in the US were less accepting of any outward expression of grief, which was contrary to her own comfort,

I feel like in this culture your bereavement is only three days...So they feel like here you're expected to just you know, 'Get over it and move and go back to work.' And just say, 'Hey how are you doing?' You know and- and it's not it's just people are more at a loss of what to say or what to do.

She described how lonely she felt, "You feel on the outside, like no one understands you because they can't even imagine losing their child. It sucks; like you're part of this club that no one wants to be part of and no one can help you." She added that people do not know how to respond to a grieving individual, "people just freeze up and don't know want

to do or what to say," which resulted in her feeling alone. She also reported her difficulty in responding to peoples' general questions:

Honestly the hardest for me is when people ask me how I'm doing. And in this country there's just a hello and then they'll say, 'Hey, how are you doing?' And I have to answer ten times a day, 'Oh good. How are you doing?' In my mind I understand that's just a hello but my heart is hearing, "*'ow are you doing?*" And I'm not good right? I'm not always great. It's just sometimes... exhausting to go through the day and have to smile fakely and say, 'Oh I'm great. How are you doing?' Where you just want to scream and say, 'No I'm shitty! You know my daughter just died.' Which no one really want(s) to hear right?

She also frequently talked about her inability to be happy or enjoy life, "Just kind of blah, like uninterested in things. Even though I'm participating in ...work and a functioning member of the society, just nothing makes me excited or joyful, you know?" She felt drained from her emotional response, "It is just an emotional rollercoaster. You know it's just draining, up and down constantly." She shared her struggles to accept her child's death, "It's just-..it's hard to imagine that she's gone forever. ... I don't believe it; like it's real... it's actually happening to you...It's just an awful feeling that you're just maybe hoping is not real." There were many varied moments during the interview that triggered an emotional response:

Like (others) having all of their children healthy... birthday parties or- ... just doing regular things that you would do with your other child. I mean like going to the zoo, like today I just went to the zoo and I just like walked by all these- a picture of my girls with the flamingos you know I just took one a couple of years ago. It's just like any- anything that you've done with your child or seen others do with their children, it's hard. It just triggers the pain. And for me just being alone triggers a lot of emotions.

She shared about her changed relationships as “being around certain people is harder,” so she tried to surround herself with people who understand her. She also acknowledged that her relationship with her spouse too was affected:

I mean the grief-we understand, you know everyone is affected (by grief) differently, I mean (everyone) grieves differently but I think what affects our relationship is the lifestyle-our lifestyles are different... So we are trying to kind of not step on each other's toes .....it kind of came out in therapy that we would both like to spend more time with each other. But no one was willing to change their lifestyle for- for the other person.

She also recognized that she was a changed person who was less patient with people, complaining about trivial things in life and also paranoid as a parent, “It just makes you scared more, I feel like, with things that could go wrong. Like what if I lose my other daughter? You know, what if something happens to her?”

Thus at 3 months, Maggie's mother underscored her challenges due to the existing grief culture in the US, where she feels that grief is a “taboo subject” which people are not comfortable to talk about. She also felt that the societal discomfort about grief, which makes bereaved parents feel lonely, and like “outsiders.” This feeling of “being alone” despite having a network of friends and family can be linked to parents' social isolation, inability to find joy in life, and the consequent poor social health scores.

#### 4.3.2.1.2 Challenge Intensity

At 3 months, Maggie's mother's grief intensity was determined as severe, due to her social isolation related to cultural differences in her grief experience, emotional turmoil, changed relationship with others and her spouse, and her inability to find joy in life. Both the

number of challenges and its compound effect on her daily life contributed to her challenge intensity. At 6 months, Maggie's mother shared her emotional exhaustion related to the reality that she will not see her child any more, "I'm definitely more tired...now that the reality has settled in, you know, I'm realizing, 'Well this is my life ... it's not a dream.' And I have to figure out how to go on... grief takes a lot of- of your energy." She acknowledged that she continued to have emotional meltdowns, "I've cried at work ... working at my computer and something comes up and you know I can't hold it in."

During this interview, she shared how she had come to terms with people's casual question of "How are you doing?"

Well I actually wrote a blog post ... I actually made a full circle ... I went from answering the question fine and just faking it. And then I went into, you know, being angry and... frustrated with the question. And not wanting to say, 'I'm fine' and faking it. And then I made a full circle....choosing to be okay with that and choosing ...to say, "I am okay," because I am.

However, she continued to talk about her inability to be happy and enjoy life, "You are fighting to be okay and fighting to choose joy and you're fighting to go on." Even with her progress, She felt a lack of purpose in life. Nonetheless, she kept herself constantly occupied, which also compounded her feeling of exhaustion, "Just balancing family life and work and my grieving and my daughter's needs and just the house and everything, just cause it feels so overwhelming (exhaustion in the voice)."

At this time-point she once again acknowledged her changed relationship with her spouse, which also affected her decision making about future pregnancies. In addition, she

still had anxiety and fear of losing her living child, which further impacted her pregnancy decision.

She shared about how she was emotionally labile and sensitive to the circumstances around her, and how pictures of other complete families affected her, “Sometimes it hurts... when I see like on Facebook or somewhere... this complete family.” However, at this time-point she had connected with other parents who have lost children, which reminded her that she is not alone, “I now know so many families that lost a child that- it's kind of like we're a part of this sucky club and I don't feel as alone?”

There was also awareness that her other child was missing her sibling:

So yeah, the hardest time for me is when I see my other daughter you know missing her sister (starts to cry). It just breaks my heart... when I see her playing with her sister's picture... And just you know that she lost her best friend and playmate and role model; those are the hardest for me lately... you know she'll never have a sister. She lost her and just the impact on her little life.

Similarly, since the holiday season had just gone by, she talked about her anguish during the holidays and her anxiety about the anniversaries that were approaching.

New Years was actually pretty hard for me. I mean Christmas was awful but you know New Years was hard and I couldn't sleep at night. .. I just was feeling like, 'I want to let go of 2015' but then I didn't want to let go because that was my last time that I had memories [of my] daughter in my life... And we are coming up on February 11<sup>th</sup> [when] she was diagnosed... two years ago and her brain surgery was on Valentine's Day.

She was also fearful that as time passes the rest of the world would forget Maggie so the social media response to Maggie's Facebook page was also a source of anguish..

When I see, you know, she only has like not even 2,000 likes on her page. And I see sometimes all these other kids that passed and they have 17,000 ... And I'm like, 'She only has 2,000.' And you know people dislike her page every day and that bothers me. You know it's kind of like, 'People will forget her.' ... I think that's very... universal, across the board. Most /parents are terrified of their child being [forgotten]- you know and that's why they do a lot of fundraising and honoring and this and that.

#### 4.3.2.1.2 Challenge Intensity

This mother continued to have multiple challenges related to her grief response, and additional concerns like awareness of her other child's grief, and fears about the world forgetting Maggie, all of which contributed to her continued challenge intensity of severe at both time-points.

#### 4.3.2.1.3 Work

At 3 months Maggie's mother used resources such as information packet provided by the hospice, where Maggie was cared and a support network to help her express her grief as per her culture. She acknowledged changed relationships with her colleagues from which she had distanced herself, but surrounded herself with a few friends and family who understood and with whom she felt comfortable to express her emotions. She also highlighted that her other living daughter reminiscing of her sibling made her happy as that kept Maggie's memories alive. In addition, Maggie's hospital nurse, social worker, and chaplain reached out to her and sent resources, that she said she utilizes. Maggie's mom also immersed herself into self-care activities such as doing chiropractic adjustments; massage



therapy, yoga, exercises, journaling, and writing a blog. She added that exercise and healthy eating were always part of her routine even before Maggie's death.

At 6 months Maggie's mother continued to engage in self-care activities such as yoga, exercise, and even went out on a vacation. Similarly, at this time, her other living child and Maggie's memories captured through pictures and videos were a source of comfort for her. In addition, at this time she had developed an altruistic approach and was pondering starting a local support group for parents and also building a website to help other bereaved mothers. She wanted to educate people about being culturally accepting of grief and grieving individuals:

I feel like it's part of my mission to actually educate people about grief ... that's partially why I'm writing about grief and I want to get certified as a grief counselor and help people grieve because this culture is not equipped nor people know what to do when someone's grieving....I think part of my mission is ... tell people, "It's okay to grieve. You need to do that to heal. And it's okay to cry. And it's okay to you know not be okay. ... I feel like if we share and educate enough people or create enough resources... we can make the difference for people that are grieving and not maybe getting that support at their workplace or [in] their families, in their communities.

#### 4.3.2.2 *Maggie's Father's Challenges and Work*

##### 4.3.2.2.1 Challenges

Maggie's Father at 3 months shared a his emotional response to Maggie's death as an "internal battle" in which his "rational mind knows she's gone" but still unable to accept that reality, "... Part of you is still- it's still in disbelief that you'll- you'll never see your child

again." Just like Maggie's mother, he also shared his inability to be happy, "You know you're getting through your day but the struggle is... to be cheerful, you know? To try to find some happiness seems to be a challenge. Not that... I don't want to be happy..."

Similar to his wife, he too expressed discomfort to the casual greeting:

If anybody asks me you know, "How are you doing?" You're gonna hear that like how many times a day right? And it's- it's a bummer- I feel like shit but.. it's a constant struggle like really, it's tough you know? Some folks feel- it feels easier to talk to and that it stays there, they'll let you be and communicate. And other folks don't let you talk and start immediately with um trying to find something- some similar experience. .. You get a whole mixed bag of things.

He also shared his challenges related to Maggie's memorabilia, "We have videos that we play for our other daughter to see...and it's just hard -it's hard to watch. It brings up the loss and the pain like right away the wave of sadness..."

He also acknowledged his strained relationship with his wife, as he thought anger was "part of the grieving" that he was trying to work on, so it does not take a toll on their relationship, "It's been rough- I think the last two months we haven't- we haven't felt very close. We kind of like- we were kind of like the same charge repelling each other in opposite directions, and now it's- I think we've kind of come ...together slowly." Additionally, he expressed how peoples' comments can be thoughtless, 'You lost a child but now you have an angel watching over you.' He adds, "That's not a consolation prize that I need, that doesn't help me you know?"

In addition, he shared his anxiety about the upcoming anniversaries and holidays:

"And right now because it's fresh and we have all this- I guess there's anxiety for all the milestones that are coming up like her birthday you know? And the first round of holidays without her and-this whole year- the whole year until...- it's one year, it's all first's with everything."

However, even the present day to day activities seemed a struggle, "It's just hard... getting through each day... It's not gonna get any better or worse than it is right now. And I'm trying to accept the right now. But I don't like it."

His busy work schedule was not giving him enough time to focus on his grief:

"I really haven't had time to just go and unwind. I need like a good two to three weeks to just decompress, so I kind of like to do that instead of just, 'Oh my God I got to do this. Oh my God I got to do that.' You know what I mean? And I don't- I'm not constantly filling in my time with baseless stuff..."

Finally, he thought that society and the healthcare system was more supportive of grieving mothers, and ignored grieving fathers.

I guess part of me was kind of jealous like [my] wife's friends...paid for like yoga for like six months. And then they're sending [her] off to Costa Rica. And I'm like, 'Damn.' Like nobody is doing anything like that for me or offering anything like that to me... 'What about the dad?' And I read all these postings and blogs but it's mostly the mothers- the moms... I think the community is different for men versus women...you know the dads are always working and doing all these other things in the background all the time. But yet [dad] never get a lot of credit or acknowledgement. You know so you're just supposed to do it and be tough and strong.

He was unsure if there were any support systems available specifically for the fathers and would have been interested if services were provided.

At the 6-month interview Maggie's father reiterated his emotional struggles and his inability to be happy. This time he elaborated that his inability to be happy was related to the guilt he felt when he took time to have some fun:

I can't really rationalize it... I shouldn't have a problem with enjoying myself or doing something for myself. But um, then it's like you're- you're not giving attention to... the life of your daughter...it's kind of complicated like that, you know? You don't want to trivialize it, at the same time but then you don't want to wallow in it either. So it's a constant battle with how are you trying to cope with this from day to day?

He shared about his continued strained relationship with his wife;

Cause we're both grieving and you know it's- both parties can be fairly sensitive and it's hard to um try to help the other person cause you- you can't- I can't really take her grief on cause mine is enough, you know what I mean? I wish I could support her more but I really don't have the capacity to do that. It's just I think we're just both like so tired.

He expressed how grief had exhausted him both physically and mentally, "You feel kind of blah, you know, it's hard to get yourself motivated sometimes. I probably haven't done a lot cause I don't have energy..." He added that bereavement has changed him as a person and self-labeled himself as a "lost person."

You feel kind of lost. You know a big piece of you was taken away. And it's- you don't feel very grounded or rooted you know like it makes you question a lot of things. You know and then you start thinking about your own mortality and... other family members' mortality coming up... What's coming up next? That's- it kind of a weird place.... 'Who- who am I now? You know who am?' You ask yourself sometimes and you don't really know you don't have a clue...

When asked about his thoughts about grief culture, he shared that since he grew up in the US, he did not have any other culture for which to compare. He added that, "Nobody

educates you on death...at least not that I've seen anywhere." At this time-point he shared his challenge with Maggie's pictures and memorabilia:

It's hard, yeah it is hard, and you know talking about it makes it bubble up, and I just look at pictures... I wonder what she would look like in another five- ten years... I look at the last mark [on the wall] we have on her height that we took. You know I get sad thinking that we won't have any more marks for her. I mean it's- it's a struggle for you to walk around- look around the house and not have something trigger you."

However, he added that he did not want to be identified as a bereaved parent at all times, "I don't want to play the victim of, 'Oh my God I'm a grieving parent.'... I don't want that to be predominant over everything."

#### 4.3.2.3.2 Challenge Intensity

Maggie's father's challenges were identified as severe at the 3 month time-point, as he shared his challenges related to his emotional turmoil, strained relationship with his spouse, inability to be happy, and a lack of a support system, which resulted in his daily functioning becoming challenging. At 6 months, Maggie's father still acknowledged the same challenges with similar consequences on his daily living. His challenge intensity remained severe at this time-point as well.

#### 4.3.2.3.3 Work

Maggie's father at 3 months acknowledged addressing the grief emotions as one of his strategies to help himself, "You know there are times you just want to like go, but you can't go anywhere cause it's all inside of you...The process of grieving and then trying to let

it happen on its own and not... try to um fill it with busy work and things like that." He said he wanted to take time out to attend to his grief but was unable to do so due to life's demands:

I feel like I need space like I need to go, get away, get away from the city and go someplace in like the jungle or something you know? Being in touch with nature and in touch with- with the universe and God and everything. So um, it's kind of like- I feel like there's a spiritual journey that needs to happen now.

His other daughter helps him to express his emotions," There are times where, yeah I know she's feeling it, and I just try to hug her and hold her and love her and-of course then it makes me sad. So we'll both cry." In addition, he mentioned that he visits the chiropractor as one of his friends had offered him some free passes, and he was more focused on healing himself from within, "So I'm just learning how to be me. A new me, another me. A redefined me. We're still- I- I guess I'm still a piece of coal and I'm still transforming into the diamond

At 6 months, Maggie's father once again shared that having another living child helped with healing, "Ah, you know I- it's- it's therapeutic to have your other daughter around and feel the love from her." At this time too he said he let his emotions flow when needed, "No, I'm- I'm not bothered by it, I know- I know it has to come out and I can't just bottle it up. Um, usually I just wind up having a pretty good cry for about ten- fifteen- twenty minutes or so." He also tried to focus on the good memories of Maggie, "I allow myself time to look at her [pictures] and you know reminisce and sometimes I'll just grab

her ashes and sit down and hold the urn, think about her and try to remember the positive things. You can do that but it still- it still hurts.”

He also acknowledged that he was seeing a therapist and was planning a trip so he could take time to focus on himself and unwind:

“I’m trying to re- reconnect with that person that- that side of me. The whole thing with setting up this trip was to get myself in a new routine and start working out, taking care of my physical-self more and getting ready so I can jump off the couch to go do what I want to do without being in shape and you know being able to enjoy it and having enough stamina and the strength to do it. And not exhaust myself.”

However, Maggie’s father emphasized the role of time in bereavement could transform grief and eventually be healing, “Wake up” and ah, know that there’s something bigger and better out there. But during this time it’s hard to see it. And you know- we’re- we’re gonna get through the dark phase. We’ll come out of it.”

Table 10 Maggie’s Parents Joint Matrix: Challenges and Work

Time/ Parent	T1- Mother	T2- Mother	T1-Father	T2-Father
Challenges at Each Interview				
Theme	Challenge (Frequency)	Challenge (Frequency)	Challenge (Frequency)	Challenge (Frequency)
Grief	1. Emotions- crying, and yearning (4) 2. Being alone in grief (2) 3. Inability to enjoy life (3) 4. Cultural difference in grieving (2) 5. Difficulty accepting the child’s death (2)	1. Emotions- crying, and yearning (5) 2. Inability to enjoy life (1) 3. Grief nature: cyclical (1) 4. Difficulty accepting the child’s death (1) 5. Changed person: Impatient (1)	1. Emotions-heavy feeling, and yearning (12) 2. Inability to enjoy life (1) 3. Grief nature: cyclical (2) 4. Being alone in grief (1) 5. Difficulty accepting the death (1) 6. Grief and self identity (1)	1. Emotions- disbelief sorrow, yearning (8) 2. Inability to enjoy life –guilt (3) 3. Grief nature: cyclical- “peaks and troughs”(3) 4. Grief Identity: grieving parent (1) 5. Changed person- “lost person” (1)

Life's demands	6. Life is difficult (1)	6. Life stressors: busy life (Difficulty balancing busy life and grief) (1)	7. Life stressors: busy life (1) 8. Life is difficult (5)	6. Life is difficult: Hard to do routines (3)
Continuing Bonds	7. Miss child on special days and holidays (1) 8. Moving on (question the life's purpose) (1)	7. Miss child on special days and holidays (2)	9. Child's belongings a reminder (1) 10. Miss child on special days and holidays, anxiety and sadness (1) 11. Child's memorabilia (ash urn) as a frequent reminder (1) 12. Moving On (1)	7. Miss child on special days and holidays, anxiety and sadness (2) 8. Child's memorabilia as a frequent reminder (1)
Interactions	9. Changed as a parent- Fearful (1) 10. People's responses and comments (2) 11. Changed spousal relationship (2) 12. Changed relationships (2)	8. Changed spousal relationships (1) 9. Living child's response: missing sibling (1) 10. Social media: decreased responses, fear of others forgetting child (4) 11. Pregnancy decisions (1)	13. Spousal relationships (2) 14. People's responses and comments (1) 15. Child's illness: difficult time (1) 16. Living child's response: missing sibling (1)	9. Spousal relationships (2) 10. People's responses and comments (1) 11. Grief culture: grief as a "taboo" (2)
Health Manifestations	13. Lethargy (1)	12. Lethargy (4)	17. Lethargy: Lack of motivation (2)	12. Lethargy: Lack of motivation (3)
Gaps in health care services		13. Gaps in healthcare services: disconnect with the healthcare team (1)	18. Gaps in healthcare services: No services for fathers (2)	13. Gaps in healthcare services: No contact with team (1)
<b>Number of Distinct Challenges at Each Interview</b>				
	13	13	18	13
<b>Challenge Intensity of the Interview</b>				
	Severe	Severe	Severe	Severe
<b>Work Strategies at Each Interview</b>				
Theme	Work	Work	Work	Work
Grief Work		1. Emotional response: crying	1. Emotional response: crying 2. Keeping busy	1. Emotional response: crying 2. Grief as evolving: Time heals
Continuing bonds		2. Family rituals 3. Memorabilia as helpful		3. Memorabilia as helpful



Interac tions	1. Support network 2. Living children	4. Support network 5. Changed relationships: closer with sibling	3. Living children as helpful	4. Support network
Health y Living	3. Weight management 4. Self care: chiropractor, massage, trip	6. Weight management 7. Self Care	4. Self Care: chiropractor	5. Self Care: chiropractor
Health care service s	5. Hospital services: sent resources	8. Grief counseling and support group	5. Hospice care: bereavement services: provided resources	6. Grief counseling
Altruis m		9. Changed person: Positive approach to life, less judgmental 10. Giving back: Website and support group to educate others about grief	6. Changed person: Positive approach to life, time heals	7. Changed person: Positive approach to life
<b>Number of Distinct Work Strategies</b>				
	5	10	6	7

#### 4.3.2.3 *Maggie's Mother's and Father's Health Status*

Just like Connor's parents, Maggie's parents also identified areas of concern based on their health status scores (See Table 11). While Maggie's mother had sleep and social T scores below the population mean at both the time-points, Maggie's father had all four areas of health physical, mental, sleep, and social health T scores below population means at both the time-points. However, both parents chose a fairly high rating about self-perception of their overall health, which remained constant at both the time-points (See Table 11). Both parents' BSI-18 scores did not reveal any concerns. Similarly, according to their medical history data, no new diagnoses were identified during the 6-month time frame.

**Table 11 Maggie's Parents Health Scores**

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	47.7	44.9	50.8	50.8
	Mental	45.8	41.1	50.8	53.3
	Sleep	45.5	47.3	35.1	30.0
	Social	25.9	40.2	43	40.2
Brief Symptom Inventory (BSI)-18	Somatization	61	50	55	50
	Depression	61	65	70	62
	Anxiety	48	48	53	54
	Global	59	58	62	58
Continuity Line	Self-health Perception	Scale 0 to 10 0 = worst health, 10 = best health			
		8	8	7	7
Height and Weight	BMI	29.3	29.8	29.7	30.2
PROMIS: Population mean T scores = 50 BSI-18: If any 2 subscale scores or Global score $\geq 63$ , indicates need for further evaluation Red Scores: Below population mean T scores Green Scores: At or above population mean T scores					

#### 4.3.2.4 Case Interpretation

This case highlights the challenges bereaved parents face due to the existing grief culture where there is an unspoken message to bereaved parents that they should mask their emotions and get back to life's routines despite their emotional turmoil from the grief of their child's death. Maggie's mother in her bereavement compared the European cultural response to the American culture, and felt socially isolated from members of the community, as people around her unable to empathize with her. At the second time-point, she indicated there was a need for people to be educated about grief, as people are not comfortable talking about loss. Although Maggie's father did not have any experience of how other cultures respond to death, he too indicated that he felt social pressure to get back

to work immediately, with no time to respond to his emotional need to grieve his child's death. Additionally, both parents were also challenged by their strained relationship, which they were working on, however did complicate Maggie's mother's decision about future pregnancies. She recognized that she had become very paranoid as a parent and feared that something might happen to her living child, but feared getting pregnant again could further burden and strain her relationship with her spouse. Both parents challenge intensity remained the same during the 6-month timeframe.

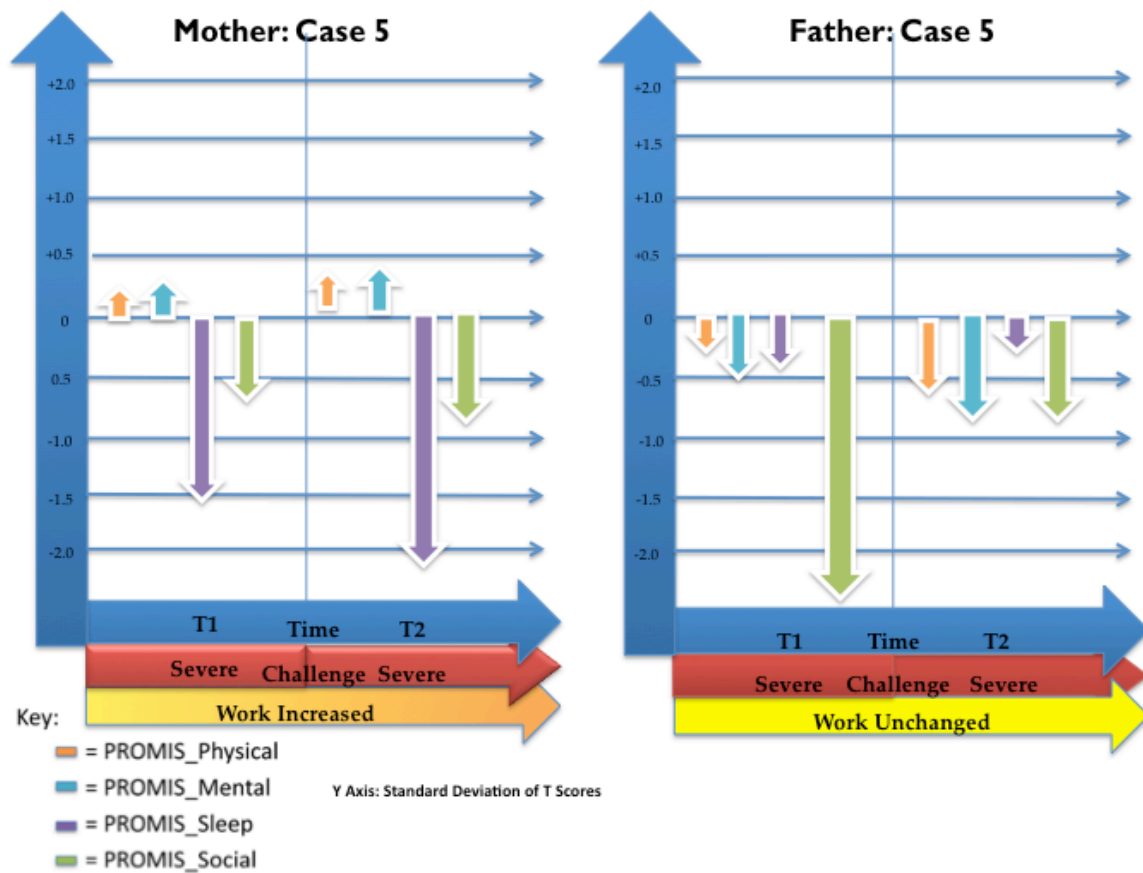
As for the work to address their challenges, Maggie's mother was trying to keep herself busy and engaged in several self-care activities. At the second time-point she indicated that keeping herself busy was draining and making her emotionally and physically exhausted. Since she was not comfortable with masking her emotions, she sought a network of family and friends with whom she could share her feelings. Maggie's father on the contrary, indicated that he preferred his "solitude" and wanted to take some time out by himself. Both the parents acknowledged that having a living child was healing. They engaged in activities that resemble continuing bonds such as having the family ritual of lighting a candle daily for Maggie, so that they do not forget her. Maggie's mother also used social media as a platform to grieve and wrote blogs about her bereavement journey. She wanted to create a website to help other bereaved parents too. These work strategies remained unchanged for the father over the 2 time-points. However, the mother at six

months had increased her work strategies. But in her pursuit to give back and reach out to other grieving parents, her staying busy was exhausting and emotionally draining her.

As for their health, Maggie's mother's social health reflected her isolation, although her physical and mental health T scores were at the population T score means. Maggie's father health scores indicated poor overall health, and although his social health score improved at the second time-point, it was still below population means at both the time - points. At the second time-point, Maggie's father had indicated that he did meet up with friends, but sometimes had to deal with subsequent guilt from allowing himself to have fun. Thus, a different perspective of social isolation was revealed, in which parents felt guilty to socialize and have fun, in addition to the social isolation related to distancing from people who parents perceive as not empathetic towards you.

The co-occurrence model (Figure 4) for this case depicts the changes in health scores at the two time-points. While some aspects of their health improved, both parents demonstrated areas of poor health, specifically social health. Maggie's father had all 4 areas of health below population means, which could be an indicator of his severe challenge intensity affecting his health. Although Maggie's mother physical and social health were above population means, her social and sleep health were worse at the second time-point. Thus, despite the engaging in various self-care activities to help herself, she still struggled emotionally and socially with her relationships. Both parents number of challenge and

intensity remained high despite the self-work they did. The mother specifically indicated the need for additional professional individualized and family bereavement care.



**Figure 4 Maggie's Case: Co-occurrence Model**

Thus these exemplar cases provide specific examples of parents' challenges during the first 6 months of bereavement and work strategies they engage in to help themselves. The two exemplar cases depict challenges, related to their grief and continuing bonds experience; life's demands such as financial constraints or care of family, health concerns

such as exhaustion and lethargy, strained relationships due to interactions with people around, and healthcare gaps. Similarly, work strategies such as responding to the emotions such as crying or channeling anger through household chores, surrounding self with support network of friends or family, engaging in self-care activities such as healthy eating and exercise, and also staying in touch with the healthcare team were some of the work strategies that parents engaged in, which corresponded to the challenges identified.

#### **4. 3. 4        *Across Case Findings:***

Challenges and work exemplified in the above cases were also identified across all remaining cases. Based on the across-case analysis, the challenge codes that depicted a common thread or meaning were grouped together as themes (See table 8 and 9) and presented below.

Thus, bereaved parents' challenges after their child's death, related to their emotional and everyday aspects of their life, were categorized as challenges related to a) grief, b) continuing bonds, c) life demands, d) health concerns, f) interactions and g) gaps in the health care system (Table 12). Similarly, bereaved parents engaged in work that was congruent with the challenges. The work done to address the challenges were categorized as a) grief work, b) continuing bonds, c) altruism, d) interactions e) healthy living, and f) health care services (Table 13). In addition, it was observed that any one strategy could be a challenge for one parent and work to address the challenge for another parent, but under different circumstances. For example, some parents reported that to distract themselves

from their child's memories they kept themselves busy, while other parents indicated that their busy lifestyle, did not allow them time to do the necessary grief work. Similarly, while continuing bonds acts such as memory making and following rituals could be healing and help to keep the deceased child's legacy, these behaviors can also cause anguish and distress and thus be a challenge for some parents in some situations. Below is a description of the challenge themes and codes followed by work themes and codes.

#### 4.3.4.1 *Challenges*

Challenges parents faced were related to leading their life without their child. Parents acknowledged that their emotional struggles from their *grief* response to their child's death were episodic and referred to as grief coming in "waves" or being "cyclical." Parents also expressed that they were "alone" in their grief and that people who have not experienced a child's death cannot understand their emotional turmoil. A mom whose 11year-old son died said: "I don't even tell anybody how I'm feeling because - I don't think they understand. I just don't." Some parents shared feelings isolated in grief, as people around them were not comfortable to talk to them about their child's death. One parent referred to it as the "white elephant in the room" that no one wants to talk about or discuss. While generally parents talked about their sadness, they also commented that they performed their daily activities even though it is not with the same joy as before, as expressed by this mom whose 5 and half years old child died of cancer: "Even though I'm participating in... my work and [am] a functioning member of the society just nothing

makes me excited or joyful..." Bereaved parents struggled with getting back to their routines:

It's hard to explain. So um, we were working on going back to our normal routines and it felt weird to be doing the things that we were doing before (child's name) was born. Because so much had happened in nine months that I shouldn't be doing the same things I was doing nine months ago. (Mother of 9 month-old child who died of cancer)

As parents attempted to focus on their present life without their child, they also wanted to hold on to their memories of their deceased child. The *continuing bonds challenges* refer to the challenges that bereaved parents face related to their emotional connections with their child's belongings and their quandary about what to do with these things. In addition, while the memorabilia created during and after their child's death helped them to keep their child's memories alive, they were also painful reminders of their loss. Parents often held on to the child's belongings, memories, and memorabilia because they either never wanted to forget their child or were afraid that they would forget their child as they moved on in their lives. This 38 year-old mother who lost her two and a half year-old child who was diagnosed with pulmonary hypertension since birth stated,

Her bed is still set up and her sheets are still on and you know not in any way because I have these feeling she may come back. It's just I am not ready to take it down and take it away. Cause I guess I'm afraid I'll forget you know I'm afraid that- that's- that's an end in itself is kind of moving beyond that. I'm just not ready.



**Table 12 Challenge Themes and Codes**

Challenge Themes	Codes
Grief	<ol style="list-style-type: none"> <li>1. Being alone in grief</li> <li>2. Changed person</li> <li>3. Difficulty accepting the child's death</li> <li>4. Different "why" (denial/avoidance)</li> <li>5. Emotional response to the death: sadness, anger, guilt, denial, yearning, emotional sensitivity</li> <li>6. Grief and culture</li> <li>7. Grief and self-identity</li> <li>8. Grief nature (grief comes in waves/grief is cyclical)</li> <li>9. Inability to enjoy life</li> <li>10. Moving On</li> <li>11. New normal</li> <li>12. No closure</li> <li>13. Past experiences with death</li> <li>14. The why's and what if's</li> </ol>
Continuing Bonds	<ol style="list-style-type: none"> <li>1. Celebrate or memorialize the child on special days/occasions</li> <li>2. Child's belongings</li> <li>3. Fear of forgetting the child</li> <li>4. Memorabilia</li> <li>5. Moving on</li> </ol>
Life demands	<ol style="list-style-type: none"> <li>1. Getting back to routines</li> <li>2. Other children</li> <li>3. Other stressors: Financial responsibility, Unemployment, illness, busy life</li> <li>4. Resuming work</li> <li>5. Life is difficult (codes: It is hard or everything is hard)</li> </ol>
Health manifestations	<ol style="list-style-type: none"> <li>1. Anxiety</li> <li>2. Exhaustion</li> <li>3. Lethargy</li> <li>4. Panic attacks</li> <li>5. Vertigo</li> </ol>
Interactions	<ol style="list-style-type: none"> <li>1. Child's characteristics: illness trajectory, death acuity, age, diagnosis, length of illness,</li> <li>2. Changed relationships with other (family, friends, community)</li> <li>3. Changed as a parent (fearful, paranoid)</li> <li>4. Grief culture (others)</li> <li>5. Living child's response to the death</li> <li>6. Peoples reminders, responses and comments</li> <li>7. Pregnancy decisions</li> <li>8. Social media as a platform to grieve</li> <li>9. Spousal relationships</li> <li>10. Unanswered questions related to illness or death</li> </ol>
Health care gaps	<ol style="list-style-type: none"> <li>1. Healthcare services: lack of sensitivity during end-of-life care, algorithm approach to care, billing issues, limited or no contact with pediatric team.</li> <li>2. No hospice care</li> <li>3. No bereavement care</li> </ol>

However, the need to move on often was related to *life's demands* to care for self, their surviving children, spouse, and the unspoken pressure or their perception of the grief culture around them: At the 6 month interview a mom whose child died of anencephaly at 48 hours after birth said:

It's a hard thing to realize that people are starting to- and you're getting to that point where people are like, "Are you pregnant? Are you gonna try soon?" So yes, society, friends, world is telling you like, 'Alright it's been long enough. Like chop, chop.'

Further parents' *life's demands* such as meeting their financial needs, resuming work, caring for other children posed additional challenges for them. A father expressed how his need to work full time, did not give him time to "unwind."

You know I'm the guy and I'm supposed to go back to work. And just because you know I've got family responsibilities and we have bills to pay and food that we've got to be able to eat and- and what not. So I don't know specifically which direction that pressure came from. Um when I say moving I'm referring to just getting back into the daily grind of life.

Additionally, parents shared their challenges about pregnancy decisions after losing one child. This 35 year-old mom who had one surviving child said:

The thought of getting pregnant again, it's almost been six months...I'm half/half you know? I'm going through the, 'Wow that would be wonderful. Like I would love that.' And then... the other side creeps up like, "Oh my goodness, like it's really scary too.

Parents also acknowledged specific *health concerns* that developed during these six months including, anxiety, exhaustion, lethargy, panic attacks, and vertigo.

All of these life's demands interplayed with the bereaved parents *interactions* and relationships with others around them. Their child's death affected not just the parents but the people around them as well. Parents' felt people around them were uncomfortable to address their loss. Bereaved parents experienced challenges related to their existing relationships in which people distanced themselves due to their discomfort or parents socially isolate themselves because they experienced a lack of empathy in their relationships or felt guilty to socialize and have fun after their child's death. Thus, some parents shared that their relationships with immediate family members, including spouse, parents, family, and friends had changed. Spousal relationships seemed to be strained as both parents either grieved differently or were not available for each other due to their own grief or because they were busy with their jobs. This mom who was a homemaker stated the following about her relationship with her spouse:

... because you feel that you've gone through something together but  
because the way people grieve is so different- between a husband and  
a wife that's been one of the hardest and also just the working a lot. ...I think  
it makes me feel alone. We've lost someone together but the fact that we  
grieve so differently makes me feel like I'm just alone in this.

While some fathers, indicate that they wanted to stay strong for their spouse and therefore would not show their emotions and even avoided talking about their deceased child with their wives. This father who lost his 11-year-old son said:

I can listen to her (wife) talk but as far as me expressing the way I feel  
because I mean I can see her getting upset... just thinking about memories.  
And me trying to be the strong one, I try to- I try to be strong...

In addition, social media and their interactions with others on social media made bereaved parents feel forgotten and lonely. Parents shared how as time passed their blogs about their child did not receive as many “likes” as before. They interpreted this as people were forgetting their child. This mom whose child died within 48 hours after birth said:

I'd say probably around the first-ish- second-ish month right around there- the numbers went from you know 7,000 down to like you 2,000 or 1,000 and then it was like 400. So no, I knew it was gonna happen and I even told my husband right away like, 'Here it comes. Like I need to be ready for it.' You know without freaking out.

Thus, the bereaved parents' community played a role in the challenges bereaved parents experienced including the health care system. Bereaved parents identified *gaps in the health care system*, such as lack of sensitivity during end-of-life care, billing issues, lack of bereavement support for fathers, and lack of continuity of relationship with the pediatric care team. Some parents noted that there was no hospice care for children and bereavement care services from the hospitals they were affiliated with during their child's illness.

To address the gaps in health care a parent suggested a 6-month reach out to the parents via a phone call or email. Another parent recommended that the healthcare team help parents connect with other parents who have experienced loss or have a child with similar illness. Yet another parent commented that doctors and nurses need to be educated on how to help parents specifically during end-of-life:

I think that the doctors and the nurses should be more educated on like, “Okay these are- these are the steps.” Like just like the- the logistical details, it would be helpful if they also had a directory of you know resources in the

community or national resources....like packet of information that when you're ready you can look back through and say, 'Okay maybe I need this. '

Thus all these challenges affected the parents' bereavement period and how they engaged in adaptive work to help themselves.

#### 4.3.4.2 *Work*

Parents intuitively engaged in adaptive work that was often congruent to the challenges they faced. Parents engaged in *grief work* such as taking the time to tend to their emotional needs such as cry, anger, denial, and guilt. Most parents shared that they either cried when they were alone or somebody with whom they could share their grief. This mother said, "You know you've got to just go through it. You've got to try not to suppress... the grief. You need to just try and you know not walk around it or over it but just when it hits you- just to try and go through it."

Typically parents distracted themselves by focusing on their "new normal," kept busy and relied on time to come to terms with their child's death. Parents also discussed how they wanted to "move on" in life but held on to their child's memories, memorabilia, and started family rituals to *continue bonds* with their child so that their child remained a part of their current life. This mother whose child died within 48 hours said, "I realize that there's this kind of thread of me wanting to ... eternalize her memory somehow within my world. You know not just in our personal world but also in everyone else's world."

**Table 13 Work Themes and Codes**

Themes	Codes
Grief work	<ol style="list-style-type: none"> <li>1. Emotional response to the death: crying, accepting the death</li> <li>2. Grief as transforming or evolving</li> <li>3. Keeping busy</li> <li>4. New normal</li> <li>5. Positive response to why's and what if</li> </ol>
Continuing Bonds	<ol style="list-style-type: none"> <li>1. Celebrating or memorializing special days</li> <li>2. Moving On</li> <li>3. Rituals, memorials, and memorabilia</li> </ol>
Altruism	<ol style="list-style-type: none"> <li>1. Changed person/attitude to life, focus on the positive</li> <li>2. Giving back</li> </ol>
Interactions	<ol style="list-style-type: none"> <li>1. Changed relationships</li> <li>2. Child's illness trajectory</li> <li>3. Grief culture</li> <li>4. Other children</li> <li>5. Spirituality</li> <li>6. Support network</li> <li>7. Spousal relationships</li> <li>8. Social media as a platform to grieve</li> </ol>
Healthy living	<ol style="list-style-type: none"> <li>1. Changed habit</li> <li>2. Getting back to routines</li> <li>3. Resuming work</li> <li>4. Support network: family, friends, and community</li> <li>5. Self care: massage, chiropractor, vacations, yoga</li> <li>6. Weight management: healthy diet and exercise</li> </ol>
Healthcare services	<ol style="list-style-type: none"> <li>1. Counseling</li> <li>2. Others: condolence cards, resource pamphlets</li> <li>3. Remembrance services</li> <li>4. Staying connected with health care team members</li> <li>5. Support groups</li> </ol>

Most parents also acknowledged their personal transformation after their child's death. They admitted to an altruistic and a positive approach to life and engaged in "random acts of kindness" to give back to the community that served as their support network during this stressful period. Thus parents *interactions* with their spouse, family,

friends and community provided a support network for these parents. Most parents also used the social media as a platform to share their story or to help other parents.

In addition, parents' spirituality and the presence of another child were often cherished. A mother who had one surviving child after the loss of her 2 month-old expressed how the presence of another child was her motivation to care for herself too, "I mean with another child I don't think it will be fillable, but God has blessed me with one more child to take care of so I need to take care of myself too."

Thus, parents took deliberate steps to help themselves and incorporated a *healthy living* into their lifestyle to have a sense of well-being. Almost all parents focused on weight management strategies such as eating a healthy diet and exercising. Some parents took a family vacation and even included self-care practices such as massage therapy or a visit to the chiropractor. Other parents stayed in touch with their child's healthcare team. Parents appreciated information pamphlets about resources sent by the hospitals and participated in Remembrance Day events conducted by hospitals. Like this father whose two and a half year-old child died of cancer stated:

We had a wonderful group of nurses um who have been super supportive. They did give us actually the grief support group that we do attend-all three of us attend it- both myself and wife and then also other daughter.

Finally, parents also acknowledged using the help of professional counselors and support groups, sharing meetings with grief counselors or support groups offered them

opportunities to share their experience. This father who participated in support groups stated the following:

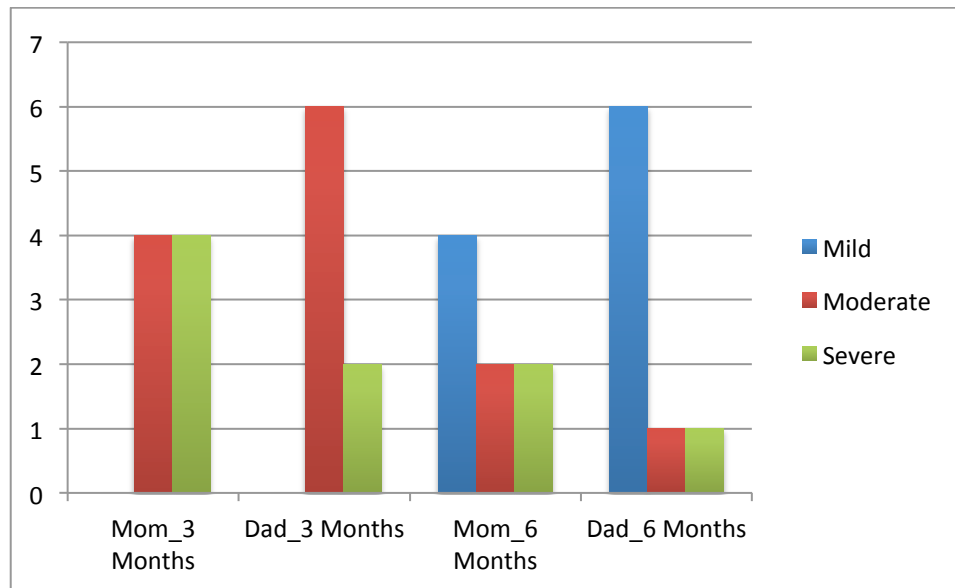
I would say I'm pretty encouraged following those sessions. It's just that you know I'm not alone and everybody grieves different. And even though I don't get the opportunities to grieve frequently there are other people that grieve similar to me and they are going through the um the same feelings as I am.

Thus parents engaged in various tasks to help themselves, but also reached out to the community and the health care system as part of their adaptive work to address their challenges during the first six months after their child's death.

#### 4.3.4.3 *Challenge Intensity*

Across all cases at 3 months (T1), parents challenge intensity was moderate or severe and most parents' challenge intensity had improved from 3 to 6 months with fathers having the most improvement (See Figure 4).





**Figure 5 Challenge Intensity Across Time**

#### **4.3.5 Aim 2: Describe the Health Status**

Health status of the parents on physical, mental and sleep measures was typically within one standard deviation of the population mean (See Table 14). Except for the PROMIS social measure. Some parents scored 2 standard deviations below the population mean scores. In addition, based on data from the continuity line, most parents indicated that their overall health improved at 6 months and rated their overall health at a 7 or 8, with 10 indicating best health (See Appendix H Joint matrix with all scores). In addition, while most of the parents did not clinically manifest any psychological symptoms of somatization, anxiety or depression, 37.5% of parents scored below the population mean on the PROMIS

health measures and on the PROMIS social health scores, all parents were below the population mean (Table 15).

**Table 14 Health Scores Descriptive Statistics**

Instrument/Variable	Mean Scores	Mother		Father	
		T1	T2	T1	T2
PROMIS: Physical	Median	52.5	50.8	50.9	49.3
	25 <sup>th</sup> ,	49.3	46.3	47.7	44.9
	75 <sup>th</sup>	44.1	54.1	54.1	55.9
	Min,	42.3	42.3	39.8	42.3
	Max	54.1	57.7	57.7	61.9
PROMIS: Mental	Median	47.1	49.6	45.8	44.7
	25 <sup>th</sup> ,	42.3	41.2	39.9	41.1
	75 <sup>th</sup>	52.1	50.8	47.1	47.1
	Min,	36.3	38.8	33.8	38.8
	Max	53.3	53.3	53.3	59.0
PROMIS: Sleep	Median	48.9	47.2	50.3	50.1
	25 <sup>th</sup> ,	43.5	39.4	46.4	41.4
	75 <sup>th</sup>	54.5	55.1	54.6	57.2
	Min,	35.1	30.6	41.4	41.4
	Max	56.1	60.3	66.3	60.3
PROMIS: Social	Median	37.8	38.5	37.3	38.9
	25 <sup>th</sup> ,	32.5	35.7	31.3	34.9
	75 <sup>th</sup>	43.5	41.1	41.6	40.7
	Min,	29.7	25.9	25.9	25.9
	Max	48.0	44.0	46.0	44.0
BSI: Global	Median	53.0	51.0	56.0	48.5
	25 <sup>th</sup> ,	48.0	48.0	50.0	39.0
	75 <sup>th</sup>	61.0	56.5	62.5	59.5
	Min,	47.0	39.0	48.0	36.0
	Max	62.0	63.0	67.0	62.0

**Table 15 Percentages of Parents Below Population Means**

Instrument	T1			T2		
	Mother	Father	Total	Mother	Father	Total
N /%	8(100%)	8(100%)	16 (100%)	8(100%)	8(100%)	16 (100%)
PROMIS_Physical	2 (25%)	4 (50%)	6 (37.5%)	3 (37.5%)	4 (50%)	7 (43.75%)
PROMIS_Mental	5 (62.5)	7 (87.5%)	12 (75%)	4 (50%)	7 (87.5%)	11 (68.75)
PROMIS_Social	8 (100%)	8 (100%)	16 (100%)	8 (100%)	8 (100%)	16 (100%)
PROMIS_Sleep	6 (75%)	3 (37.5%)	9 (56.25%)	4 (50%)	3 (37.5%)	7 (43.75%)
BSI_Somatization	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (12.5)	1 (6.25%)
BSI_Depression	2 (25%)	2 (25%)	4 (25%)	1 (12.5)	3 (37.5%)	4 (25%)
BSI_Anxiety	1 (12.5)	2 (25%)	3 (18.75%)	0 (0%)	0 (0%)	0 (0%)
BSI_GSI	0 (0%)	2 (25%)	2 (12.5%)	1 (12.5)	0 (0%)	1 (6.25%)
Clinical manifestation: PROMIS - Population mean score = 50; BSI-18 - Either any 2 subscales or the GSI score $\geq$ 63, indicate need for further assessment						

#### 4.3.5.1 *Medical History Data*

The medical history data collected via self-report revealed that 4 of the 16 parents had new diagnosis within the 6-month period (See Table 16) after their child's death. Two mothers were diagnosed with anxiety and another with sleep disorder. One father was diagnosed as pre-diabetic and another father was referred to a psychiatrist for further evaluation but was not medically diagnosed with any condition. Self-reported smoking was unchanged but two parents reported a change in alcohol consumption after their child's death. The mother who was diagnosed with sleep disorder reported she was taking medications to aid her to sleep.

**Table 16 Health History: New Medical Diagnosis**

Parent	Illness Diagnosis	
	T1- 3 Months	T2- 6 Months
Mother	1	2
Father	1	0

#### ***4.3.6 Aim 3: Co-occurrence of Challenges, Work, and Health Status***

Data visualization tools and joint matrices were used to examine the number of different challenges, challenge intensity, and number of work strategies for parents (See Appendix H) across all cases. As can be seen in Figure 6 the number of challenges corresponded with the challenge intensity, such that the higher the number of challenges, the higher the intensity of those challenges. Yet, the amount of work done was highest when the challenge intensity was moderate and about the same amount of work was completed for mild and severe challenge intensity. In addition, co-occurrence models were created for each case to examine the patterns of change in challenges, work, and health over time (Appendix K includes co-occurrence models of the six remaining cases). No specific pattern types emerged as each case varied in their challenges, work and health status.

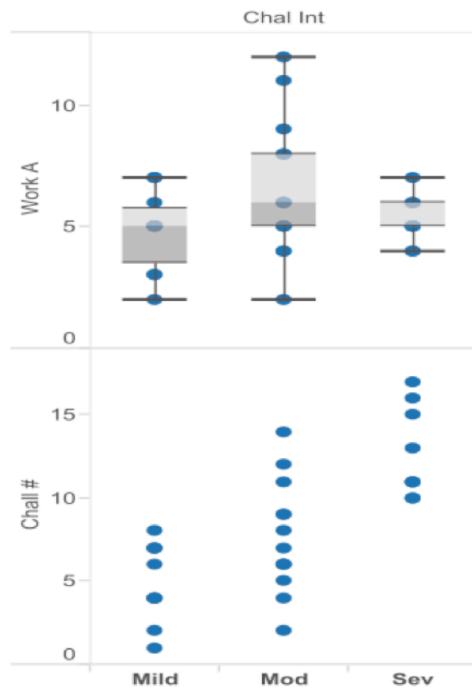


Figure 6 Visual Model: Challenges, Intensity and Work

Generally, most parents had less challenge intensity at six months, but no patterns in health scores were seen as the cases varied in their health status at the two time-points. Few parents showed improvement on some health status measures, others while some showed a decline. Specific health status did not relate to specific challenge types or intensity.

#### 4.4 Discussion

This study is the first to examine the co-occurrence of challenges, work done to address the challenges and health status of bereaved parents during the first 6 months after the loss of their child. As expected, most of the challenges these parents faced did not have a

quick and easy fix and therefore fell into the adaptive category which required parents to engage in adaptive self-work to help themselves.

We found that bereaved parents performed adaptive work similar to tasks identified as “grief work” (Davies, 2004; Bonanno, 1999; Stroebe, 2005) in existing bereavement literature. Similar to findings in Chapter 3, parents wanted to help themselves to not “be in the rut” and also in order to move on in life. Consistent with existing literature, bereaved parents in this study resorted to tasks to help themselves by staying busy, leaning on support from family, friends, community and even professional help including counselors and support groups (Snaman, 2016; Snaman, 2016). However, unique to this study we identified that most of the bereaved parents engaged in weight management strategies such as healthy eating and exercise, not just with the intention to reduce weight, but also to experience a sense of well-being. This is an important finding, as bereavement care does not typically include health-related interventions in their programs. Thus, bereavement care interventions should include strategies such as weight management to promote bereaved parents’ health and consequently improve their health status.

While in this study, bereaved parents health did not significantly differ from the health of the general population as suggested by other recent studies (Hawthorne, 2016) this study highlights bereaved parents’ health do need the attention of the healthcare system (Snaman, 2016; Morris, 2016). The social health of all bereaved parents in this study was below the population means throughout the 6-month period, which co-occurred with

parents highlighting their social isolation as a challenge in the interviews. Most parents' overall mental health scores were at least one standard deviation below the population mean highlighting the need to examine the role of social isolation on mental health needs to be examined. Social isolation with poor social health scores could contribute to poor mental health scores and merit further investigation. Additionally, 4 of the 16 parents had new diagnosis during the 6-month period, which is 25% of the parents. Furthermore, since this data is for only the first six months following their child's death, poor health outcomes may have not had time to manifest. Therefore, signifying the importance of further research to study parental bereavement trajectories with health outcome focus over longer time frames.

In addition, when bereaved parents challenge intensity was compared to work done by parents, it was interesting to note that parents with severe challenge intensity did less work when compared to parents with moderate challenge intensity. This either implies that bereaved parents who do not engage in adaptive work develop severe challenge intensity, or bereaved parents who have severe challenge intensity are unable to gather the resources to do the adaptive work required to take care of themselves. Thus this finding underscores the significance of the role of an adaptive leader within the healthcare system.

This study identified challenges bereaved parents face and the work strategies employed to address the challenges with a goal of informing the development of bereavement care interventions to improve bereaved parents' health outcomes. The adaptive leadership framework highlighted the importance of targeted bereavement care

interventions to facilitate bereaved parents' adaptive capacity to help themselves. Thus, interventions that enhance the bereaved parents' adaptive capacity through self-care and healthy living, such as mindfulness based stress reduction, yoga, and meditation techniques, should be tested and integrated into pediatric palliative and end-of-life programs that can be continued into the bereavement period (Morris, 2016). In addition, interventions such as the *Take A Breath* (Rayner, 2016) care model, which teaches parents acceptance and problem-solving strategies to reduce distress during the child's illness and telephone support interventions (Darbyshire, 2013) offered by health care team members can be integrated into palliative, end-of-life and bereavement care program.

However, existing bereavement care programs face financial and manpower constraints within the current health care system (Corden, 2004; Zhang, 2006). Thus, while, pediatric care providers might want to continue to stay in touch with the bereaved families, time constraints, work demands, and budgetary issues pose challenges for them (Donovan, 2015; Zhang, 2006). Bereaved parents have appreciated the continued relationship with their child's health care team (Snaman, 2016). Therefore, interventions that address the health care system challenges while meeting the bereaved parents needs is crucial.

Strategies that expand bereavement care services by including transition care services (Donovan, Wakefield, Russell, & Cohn, 2015) through community support groups and primary care adult services should be considered. Community programs such as compassionate care or local support groups including hospice care can partner with



hospital-based services to support bereaved parents (Donovan, 2015). Hospitals can assist community programs by providing clinical expertise of a health care team member such as a physician, nurse, or a counselor to help parents continue their relationship with the team and alleviate the sense of abandonment (Tan, 2012) shared by bereaved parents. Pediatric and adult care providers can be trained to take some responsibility to ensure that bereaved parents are referred for appropriate community based programs after their child's death.

The community-based programs can combine health promotion and illness prevention strategies that improve parents' adaptive capacity such as weight management, stress reduction meditation, and health assessment can be integrated into these community programs. These services can be part of an ongoing palliative, end-of-life program and continue after the death of the child. Therefore members of the family, community, and the health care team like social workers or counselors, nurse practitioners can play a significant role during the bereavement period (Carter, Edwards, & Hunt, 2014) and serve as adaptive leaders to help bereaved parents. Through these interventions bereaved parents can work to develop their abilities to manage their challenges they face during the bereavement period with a goal to reduce their negative health outcomes.

#### **4.5    *Limitations***

By the nature of the study only parents who were willing to participate were included and therefore I may have missed bereavement challenges and work from individuals unwilling to participate in research. Bereaved parents often participate in

bereavement studies for altruistic reasons, so that other parents can benefit from their experience (Stroebe, 2003). Since sharing their experience may be healing, these parents who agreed to participate in this study might represent the parents who are sharing their experience and therefore doing the required grief work. Thus, missing data from parents who might have an intense grief experience and not ready to share their story. The sample included sets of parents who had at least one year of college and whose economic status, except for one family, was average or better and therefore did not capture challenges from individuals with limited resources, which could be different. In addition, the six-month time frame studied is shorter than the 1-year time frame described in the grief literature as the anniversary time and therefore very challenging for parents. Therefore emerging challenges after six months were not captured. Similarly, negative health outcomes too might take more than the six-month timeframe to manifest and were missed. Future studies must explore bereavement trajectories that include this critical time-point.

#### **4.6    *Conclusions***

This chapter emphasized the complexities and the cumulative nature of the challenges that arise from a parent's life changes following the death of their child. In addition, it highlights that bereaved parents have challenges not just related to their grief experience, but other aspects of their life that influence their bereavement period. While parents engage in work to help themselves, the adaptive leadership role of the health care providers along with community resources are important to help bereaved parents improve

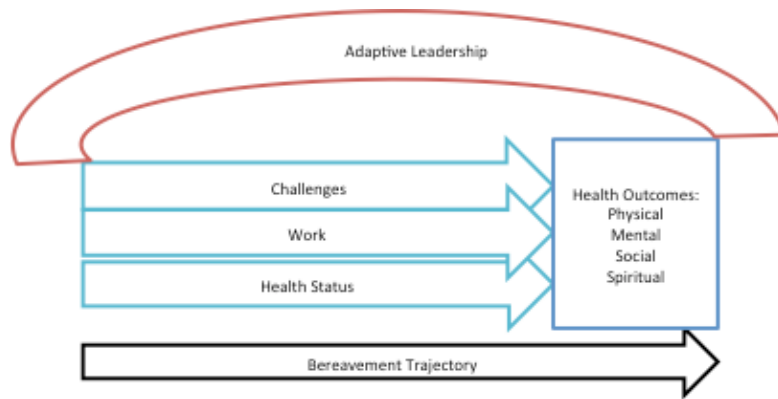
their health outcomes. Bereavement care interventions that include health promotions activities such as diet and exercise to improve bereaved parents' health outcomes need to be explored. The adaptive challenges, work, and bereaved parents' health status has the potential to change over time and therefore, parental bereavement trajectories need the attention of research and clinical practice.

## 5 Conclusion

### 5.1 *Introduction*

This dissertation is the first to examine the co-occurrence of parental health status, challenges, and related work during the first 6 months of the bereavement period and provide a greater understanding of the concept continuing bonds. Chapter 1 describes parental grief and bereavement and determined the need to assess parental bereavement beyond their grief experience. Thus, this dissertation aimed to describe bereaved parents' challenges and the work they do to address the challenges during the first six months after the death of their child and explore the co-occurrence of the challenges, work, and their health status. In addition, the continuing bonds concept, which is integral to parental grief and bereavement narrative, was examined using Rogers' evolutionary concept analysis method. This analysis identified and described the key attributes of continuing bonds and presented a conceptual model and a theoretical definition. This dissertation also introduced a new theoretical framework in grief and bereavement literature: the Adaptive Leadership framework. Thus a secondary analysis was completed to test the utility of the Adaptive Leadership Framework to understand parental bereavement challenges. This information was used as the building block to achieve the broader goal of understanding the acute parental bereavement period by examining the co-occurrence of bereavement challenges, work done, and bereaved parents health status. This conclusion chapter will synthesize the

dissertation findings in light of the adaptive leadership framework using the model below (Fig. 7).



**Figure 7 Parental Bereavement Framework**

## **5.2 Parental Bereavement Framework**

### **5.2.1 Bereavement Trajectory**

Parental bereavement is the experience of loss of a child through death (Zhang, El-Jawahri, & Prigerson, 2006, p. 1188), and parents whose child is deceased are referred to as bereaved parents (American Cancer Society, 2015). Parental bereavement is complex, intense, highly individualized and *long lasting* (Arnold & Gemma, 2008), with the first 6 months of bereavement identified as the most stressful time (Meert et al., 2010). However, bereaved parents like any bereaved individual are expected to carry out day-to-day activities after their child's death. Thus parental bereavement trajectories involve all aspects of the bereaved parent's life including their challenges and the work they do to address these challenges. Additionally, since any bereavement and in particular parental bereavement is associated with negative health outcomes, the bereaved parent's health

status becomes an important aspect of parental bereavement trajectories. This dissertation focused on the first 6 months after the death of their child and therefore assessed their current health status to lay a foundation for future studies that need to examine bereaved parents health outcomes over time.

### **5.2.2 Challenges**

Bereaved parents face challenges that are unique to their individual circumstances, complex, interrelated with no easy fix and therefore adaptive as per the adaptive leadership framework. As anticipated, bereaved parents challenges were related to their emotional struggles after their child's death but they also included challenges pertinent to their everyday life after the child's death. These bereaved parents' challenges were classified as challenges related to: a) grief, b) continuing bonds, c) life demands, d) health concerns, f) interactions, and g) gaps in the health care system.

Consistent with existing grief literature parents in this study shared similar challenges around their grief response, which related to their emotional turmoil (Snaman, 2016). Parents' compared their grief experience to the "white elephant in the room" which people around them were uncomfortable to address. Therefore, some bereaved parents felt "lonely" in their grief. Stroebe (2005 p. 409) highlighted that bereaved individuals are most affected by "emotional loneliness" even when surrounded with a support network of friends and families. Consequentially, this can transpire into the social isolation shared by bereaved parents as demonstrated through this dissertation finding. This can be

compounded by the “sense of abandonment” (Tan, 2012) that bereaved parents experience from the health care system after their child dies due to the discontinuation of a relationship with the child’s health care team. Additional stressors that are identified by studies such as financial situations (Corden, 2013; Corden, 2004; Fox, 2014), cultural difference in grieving (Hass, 2006), challenges related to their interactions with people around them (Snaman, 2016; Rogers, 2008) were also confirmed through these dissertation findings. While, the use of social media to grieve is recognized by existing literature, some of the challenges related to using social media as a platform to grieve were highlighted in this dissertation (Degroot, 2013).

Similarly, while existing literature has identified various health risk indicators such as increased blood pressure, blood sugar, lack of sleep, the challenges related to their health concerns such as their anxiety, lethargy, and exhaustion that affected every day functioning at home and at work were brought to attention through this dissertation. Existing bereavement literature previously identified challenges highlighted in this dissertation, however the adaptive leadership framework helps showcase bereaved parents challenges through a lens that also highlights their capacity for adaptive work to address these challenges and thus identify areas that need the assistance from adaptive leaders in the healthcare system.

### 5.2.3 *Work*

Both parental bereavement challenges and work were based on the individual situation of the parents underscoring the individualized nature of parental bereavement (Arnold et al., 2005). Just like bereaved parents challenges, their work was categorized as; a) grief work, b) continuing bonds acts, c) altruism, d) interactions, e) healthy living, f) health care services. Grief and bereavement literature has often discussed grief work (Bonanno, 1999; Davies, 2004; Stroebe, 2005) that bereaved parents engage in in order to attain grief resolution. This dissertation echoes similar tasks that bereaved parents engage in to help them selves. Strategies, such as keeping busy, attending to their grief by crying as needed, renewing their faith and spirituality, attaining a positive approach to life, giving back or becoming altruistic were some of the adaptive work identified in this dissertation too. In addition, parents used community resources such as massage therapy, chiropractor services, support groups and social media networks to help them selves. However, one significant finding this dissertaion highlights is that bereaved parents engaged in weight management strategies including healthy diet and exercise to feel a sense of well-being. Thus bereaved parents intuitively engaged in adaptive work to help them selves.

Finally, parents used the bereavement care services offered by their deceased child's health care system to help themselves. Bereavement care services, such as condolence cards, remembrance events, support groups, and counseling are common approaches used by some health systems as part of their beravement care interventions (Morris, 2015).



Additionally these parents also desired to stay connected with their child's pediatric team. Thus in addition to tapping resources available such as a supportive network of family, friends, community, staying connected with the health care team was also part of the adaptive work done by bereaved parents (Donovan, 2015).

No definite conclusion could be drawn that specific challenges resulted in specific work and the number of challenges did not necessarily correspond to the amount of work done, as each case was unique in the challenge number, type, intensity, and work done by the parents. However, parents who experienced moderate challenge intensity did more work to address their challenges when compared to parents with challenge intensity as severe. This is significant as it reiterates the perspective that bereaved parents who have intense grief or need help might not tap into available resources and therefore need the support of adaptive leaders through the health care system (Morris, 2015).

#### ***5.2.4 Continuing Bonds: Challenge and Work***

The concept of continuing bonds emphasizes that bereaved individuals and more specifically bereaved parents hold on to the memories of their child in order to continue their relationship with the deceased child (Field, 2006; Stroebe, Schut, & Boerner, 2010). Thus, continuing bonds normalizes continuing a relationship with the deceased. This analysis identified the critical attributes of continuing bonds and presented a theoretical definition that contains these attributes, including normal, ongoing, evolving, embodying grief and manifested through acts performed by the bereaved.

In addition this dissertation, described bereaved parents' challenges related to their continuing relationship with their deceased child. These challenges were basically focused around their dilemma regarding wanting to "move on" without forgetting their child. While they did not want their life to completely revolve around their deceased child, they also did not want to lead their "new normal" without the presence of their deceased child. Thus they maintained continued bonds with their deceased child through acts such as memorializing their child through some memorabilia or by engaging in "random acts of kindness."

It is unclear however, if to "move on" parents must also detach from their child's memories and memorabilia, which are objects parents' use to continue their relationship with their child. Hence, while "moving on" seemed like a goal bereaved parents wanted to achieve and since they can never really forget their child, the challenges highlighted in chapters 3 and 4 underscore the dilemma of continuing bonds consequences. Thus, the concept analysis presented in this dissertation, provides the framework needed to develop the continuing bonds science and clarify the adaptive and maladaptive nature of continuing bonds.

### **5.2.5 *Health Status***

Health status is an early indicator of health outcomes and was included as a study aim in this dissertation to determine the relationship between parent challenges and health. Consistent with some recent findings, our findings indicated that bereaved parents did not clinically manifest any psychological symptoms such as somatization, anxiety, or

depression. However, at nearly 40% of parents scored below the population mean in the PROMIS health surveys. Additionally all parents were below the population mean score in their social health at both the time-points. So from a global health perspective bereaved parents have at least one area of concern during the first six months following their child's death. However, most parents perceived that their overall health was at 7 or 8 on a scale of 0 to 10 (0=worst health and 10=best health.), with improved health at 6 months. No patterns of similarity or difference were noted when health status was compared with challenges and work. However, these study findings indicate a need to monitor bereaved parents health status and also study health outcomes over time.

#### ***5.2.6 Adaptive Leadership***

According to the Adaptive Leadership Framework, the adaptive leader accentuates the adaptive capacity of an individual (Bailey, 2012). The great majority of parental bereavement challenges were adaptive in nature, as they require that the individual experiencing the challenge do adaptive work. The inter-related and complex nature of adaptive challenges and work underscores the need for health experts to serve as adaptive leaders to develop shared meaning of the challenges and then to guide and support (Anderson et al., 2015) these parents as they learn to move forward, thrive, and not succumb to the health deficits that have been described in previous literature.

Thus, interventions are needed that facilitate bereaved parents' transition to care services that are supportive and can take on the adaptive leader role. Adaptive leaders can

work with parents to identify strategies to address their adaptive challenges over time. Multiple strategies can be used to address this expansion of bereavement care services including the addition of transition care services for bereaved parents through community support groups, hospice and palliative care programs (Donovan, 2015). The focus of these services should be both health promotion and prevention. Since, this study identified that bereaved parents engaged in weight management strategies to help themselves, health promotion interventions such as diet and exercise should be included in bereavement care services. Similarly, health prevention strategies such as regular assessment of bereaved parents health to identify conditions that can increase bereaved parents' morbidity and mortality such as hypertension, diabetes, cardiac diseases, cancer need to be included.

Pediatric providers in collaboration with adult health care provider and community agents can be trained to take some responsibility to ensure that bereaved parents receive health promotion and prevention services, in addition to the grief counseling and support. Personal health care for these families can be part of an ongoing palliative and end-of-life program and continue after the death of the child. Thus, bereavement programs that empower the parents and their adaptive capacity through adaptive leadership are needed to assist bereaved parents to manage their challenges and consequently improve their health outcomes.

### **5.3 *Study Implications***

Findings from this study can be used to address the gaps in bereavement care areas

including knowledge, practice, and research:

### ***5.3.1 Study Implications-Knowledge***

#### ***5.3.1.1 Bereavement Trajectories***

Findings from this help understand the challenges bereaved parents face. In addition it has shed light on the work bereaved parents do to address these challenges. The bereaved parents' health status data from this study highlights the need for additional assistance for these parents and therefore acknowledges the role of the health care provider as an adaptive leader to ensure bereaved parents maintain a positive health status and do not have poor health outcomes as documented in bereavement literature.

#### ***5.3.1.2 Continuing Bonds Concept Analysis***

While continuing bonds continues to be widely studied and included in clinical practice, a comprehensive examination of the concept was absent. The concept analysis presented in this dissertation has helped identify and define the key attributes of continuing bonds and presented a model to advance the science related to this phenomenon.

### ***5.3.2 Study Implications-Practice***

#### ***5.3.2.1 Bereavement Care Interventions***

This study highlights both the adaptive challenges and adaptive work bereaved parents do during the 6 months after the loss of their child. The findings from this study can be used to identify and test adaptive work strategies such as weight management strategies

including diet and exercise, stress management strategies such as yoga, meditation, and mindfulness based therapy, which are directed to address bereaved parents challenges through using their adaptive capacity to help them selves. Thus, this study highlights the need to enhance bereavement care services focused not only to emotionally support bereaved parents but also improving their global health. Therefore, bereavement care interventions that promote health and prevent disease need to be considered.

Additionally, this study underscores the role of the health care system as an adaptive leader. The health care system through their hospital and community based bereavement programs can network, collaborate, and share resources to help bereaved parents. The collaboration between hospital and community resources can be used to provide bereavement care services for bereaved parents and their families, thus minimizing the burden on health care system and health care providers. Community volunteers with varied expertise (practitioners, nurses, social workers, chaplains, psychologist, psychiatrists, advance nurse practitioners, etc.) in conjunction with bereaved parents can serve as adaptive leaders to help develop the adaptive potentials of bereaved parents (Donovan, 2015).

Finally, there is evidence that bereavement care programs lack theoretical models to address bereaved parents needs and challenges (Morris, 2015; Morris, 2016). This study showcases the use of the adaptive leadership framework to understand bereaved parents needs and challenges and also provides a health trajectory research model that can include

interventions that tap the adaptive capacity of bereaved parents and also evaluate the effectiveness of interventions by assessing health outcomes.

### ***5.3.3 Study Implications-Future Research***

The long-term goal of this research is to develop and test interventions for bereaved parents and their families with a goal to improving bereaved parent's health outcomes. The findings from this study provide a categorization of challenges bereaved parents face and the adaptive work bereaved parents engage in. Since, these study findings were unable to identify patterns of similarities or challenges based on the work done or health status, the role of the challenges and work as mediators or moderators, or predictors of health outcomes cannot be ruled out. Therefore, a longitudinal study with large sample sizes needs to examine the relationship between bereaved parents challenges, work, and health outcomes. Additionally, since parents used weight management strategies to help themselves, this study can hypothesize and proposes to test that the use of health management strategies such as healthy diet and exercise to improve bereaved parents health outcomes. Further, this dissertation proposes to test the use of the Adaptive leadership framework as a bereavement care, research trajectory model (Wyman, 2011), to provide intervention focused on improving health care outcomes. Finally, the continuing bonds concept analysis too provides direction for future concept development, instrumentation, and testing the adaptive and maladaptive nature of continuing bonds by using the continuing bonds model presented in this dissertation.

## 5.4 *Conclusions*

This dissertation emphasized the complexities and the cumulative nature of the challenges that arise from a parent's life changes following the death of their child. The challenges highlight the individual nuances of parental bereavement and sheds light on how bereaved parents attempt to manage their lives amidst their grief. Bereavement interventions should include health promotions activities such as diet and exercise to improve overall health. The adaptive challenges, work and bereaved parents health status has the potential to change overtime. Therefore, future research is needed to identify the trajectories of the complexities of parent's bereavement challenges over a longer period of time. The role of primary care providers, in partnership with transition community bereavement services as adaptive leaders for bereaved parents is proposed and needs to be examined using the Adaptive Leadership framework.



# Appendix A

## *Introduction Letter*

Date

Dear

Please accept my deepest condolences to you and your family for the profound loss and grief you are experiencing at this time. I was deeply saddened to hear about (child's name) death. I know how difficult this must be for you and you are in my thoughts. I know how much you will miss (child's name). I encourage you to draw on memories of joyful times with (child's name), your strength and the strength of your family.

I would also like to tell you about a study being conducted by the Duke University School of Nursing. We are aware that the death of a child is a tragedy for parents and can impact the life of family members for years. This study is exploring the challenges parents experience following the death of their child and if there are any changes in parents' health over time after their child's death. This study will give us an opportunity to stay in touch and also learn from your experience with the hope that the findings will help us better serve grieving parents in the future. Even though we understand that this topic may be difficult for you, we hope you will consider participating. Sadly, you have a unique perspective that cannot be gained from parents that have not experienced the death of a child. For this reason, the Pediatric Quality of Life Program and I believe this work is important.

Research studies are voluntary and include only people who choose to take part. If you choose to participate the study team will collect data from both you and your significant other (husband or any significant other). Data collection consists of questionnaires about your health, measurement of your height and weight, and interviews about your experiences at three time-points over approximately six months.

The study will be conducted by Ms. Nancy Dias, a seasoned pediatric nurse with 15 years of experience, under the supervision of Drs. Debra Brandon and Ray Barfield. Dr. Brandon is the Director of the PhD program in the School of Nursing (2011-present), co-developer of the Duke Intensive Care Nursery's Infant Palliative Care Program, and a member of Duke Hospital's Pediatric Quality of Life Program. Dr. Barfield is the Associate Professor of Pediatrics and Christian Philosophy, and a member of Duke Hospital's Pediatric Quality of Life Program. They have successfully conducted research on improving the outcomes of high-risk infants and young children with life-threatening conditions and their families for over 15 years.

If you choose to participate in the study you will be asked to sign an informed written consent prior to any data collection. We understand if you prefer not to participate in this study. If you choose not to participate please contact Dr. Debra Brandon or Ms. Nancy Dias on a secured toll free number, dedicated solely for this study, 1-855-659-6673 (Awaiting confirmation of the number) or send an email to Nancy Dias ([nancy.dias@duke.edu](mailto:nancy.dias@duke.edu)). We will follow up with you in one to two weeks by phone, if we do

not hear from you to give you an opportunity to ask further questions. You can also decline to participate during this phone call. If you do not hear from us in two weeks, and you are interested in participating, you can also contact us on the same number.

This study is fully supported by Duke University and the Pediatric Quality of Life Program. Thank you for considering participation and may you and your family find strength during this difficult time.

Sincerely,

(Signature of a Duke PQoL member)

## Appendix B

### *Demographic Data*

Please indicate your response with a check mark (✓) in the circles besides the right response.

1. Gender ☐ Male<sup>0</sup> ☐ Female<sup>1</sup>

2. What is your age? \_\_\_\_ Years

3. Marital Status ☐ Married<sup>1</sup> ☐ Widowed<sup>2</sup> ☐ Divorced<sup>3</sup> ☐ Separated<sup>4</sup> ☐ never Married<sup>5</sup>

4. Relationship to the child. ☐ Mother<sup>1</sup> ☐ Father<sup>2</sup> ☐ Other<sup>3</sup>

5. What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received?

- ☐ No schooling completed<sup>1</sup>
- ☐ Kindergarten to 12th grade, no diploma<sup>2</sup>
- ☐ High school graduate - high school diploma or the equivalent<sup>3</sup> (for example: GED)
- ☐ 1 or more years of college, no degree<sup>4</sup>
- ☐ Bachelor's degree<sup>5</sup> (for example: BA, AB, BS)
- ☐ Master's degree<sup>6</sup> (for example: MA, MS, MEng, MEd, MSW, MBA)
- ☐ Professional degree<sup>7</sup> (for example: MD, DDS, DVM, LLB, JD)

6. Current Employment Status

- ☐ Employed for wages<sup>1</sup> ☐ Self-employed<sup>2</sup> ☐ Out of work<sup>3</sup>
- ☐ A homemaker<sup>4</sup> ☐ A student<sup>5</sup> ☐ Retired<sup>6</sup>
- ☐ Unable to work<sup>7</sup>

7. Please specify your ethnicity. ☐ Hispanic or Latino<sup>1</sup> ☐ Not Hispanic or Latino<sup>0</sup>

8. Please specify your race.

- ☐ White<sup>1</sup> ☐ Black or African American<sup>2</sup> ☐ Asian<sup>3</sup>

☐ American Indian or Alaska Native<sup>4</sup>

☐ Other <sup>5</sup>

**9. What is your total household income?**

☐ Less than \$10,000<sup>1</sup>

☐ \$10,000 to \$29,999<sup>2</sup>

☐ \$30,000 to \$59,999<sup>3</sup>

☐ \$60,000 to \$100,000<sup>4</sup>

☐ \$100,000 or more<sup>5</sup>

**10. How many living children do you have? \_\_\_\_\_**

**11. What is your preferred method of contact?** ☐ Telephone<sup>1</sup> ☐ Email<sup>2</sup> ☐ Postal

mail<sup>3</sup>

**12. Zip code \_\_\_\_\_**

**Medical History Inventory**

**Please indicate your response with a check mark (✓) in the circles wherever applicable:**

1. Have you been told you should be treated for the following conditions **before** the death of your child?

☐ Pain

☐ Hypertension or High Blood Pressure

☐ Diabetes

☐ Cardiovascular (heart) disease

☐ Cancer

☐ Kidney disease

☐ Lung disease

☐ Thyroid disease

☐ Depression

☐ Anxiety

☐ Sleep Disorders

☐ Mood disorders

☐ Any other If "yes" name the condition; \_\_\_\_\_

2. Have you been told you should be treated for the following conditions **after** the death of your child?

☐ Pain

☐ Hypertension or High Blood Pressure

☐ Diabetes

☐ Cardiovascular (heart) disease

☐ Cancer

☐ Kidney disease

- o Lung disease
- o Depression
- o Sleep Disorders
- o Any other If "yes" name the condition; \_\_\_\_\_
- o Thyroid disease
- o Anxiety
- o Mood disorders

3. Have you been referred to any specialist (cardiologist, psychologist, psychiatrist, grief counselor etc.) after the death of your child? \_\_\_\_\_

If "Yes" Please specify: \_\_\_\_\_

4. How many times have you been to an emergency department over the last two years **before** the death of your child? \_\_\_\_\_

5. How many times have you been to an emergency department **since** the death of your child? \_\_\_\_\_

6. How many times have you had to be in the hospital overnight over the last two years **before** the death of your child? \_\_\_\_\_

7. How many times have you had to be in the hospital overnight over the last two years **after** the death of your child? \_\_\_\_\_

8. Do you smoke? \_\_\_\_\_

If "Yes" Please specify the amount: \_\_\_\_\_ (# per day)

9. Did you change your smoking habit after the death of your child?

If "Yes" Please specify the change

\_\_\_\_\_

10. Do you drink alcohol? \_\_\_\_\_

If "Yes" Please specify: \_\_\_\_\_ (e.g. 2 beer bottles per day/per week)

11. Did you change your smoking habit after the death of your child?

If "Yes" Please specify the change

\_\_\_\_\_

11. Are you currently a member of any support group? \_\_\_\_\_ (Yes/No)

If "Yes" Please specify: \_\_\_\_\_

12. Are you currently receiving any grief counseling? \_\_\_\_\_(Yes/No)

13. Did you have any previous losses? \_\_\_\_\_ (Yes/No)

If "Yes" please specify: \_\_\_\_\_ (e.g. death

## Appendix C

### *Interview Guide: T1*

**Directions:** This is a narrative interview to be conducted about 3 months after the death of the child. This interview will acknowledge parents' loss and grief. Participants will be encouraged to tell the story of their child's death, talk about their grief if they wish, and explore the every-day life challenges. Throughout the interview, the interviewer will be assessing for any behaviors of undue parent distress. Re/Introduce self. Remind participants that they do not have to answer any question that makes them uncomfortable. Remind participant about taping the interview and that contents will be kept confidential and not shared with your doctor.

**Focus:** The initial focus will be on acknowledging parents' loss and listening to their grief. Explore parents' challenges after the death of their child.

**Main Narration: (turn on audio recorder)**

Begin with acknowledging parents' loss and grief.

Eg., **We are sorry about the death of [name of child] in [date]. We appreciate your willingness to share your experience with us.**

Ask parent a broad question that will initiate their story about how he/she has been doing since their infant's death.

**Grand tour question. E.g.**



How have you been since “(child’s name)” death?

*Be aware that this may cause distress. Be sensitive and follow their guide.*

*Once the parent has appeared to complete her/his story, questions should be asked to fill in areas that may not have been covered.*

### **Questioning Phase:**

#### **Probes to assess the Challenges faced and Related Work**

##### **Probes to assess the Challenges faced and Related Work**

- What is the most difficult thing for you now?
  - Probe about challenges with memories of the child, child’s belongings, memorabilia
- Can you talk about your relationships with people around you
  - Has anything changed, if yes how and why?
- Can you share with me moments or times that are most difficult for you
- Can you talk to me of what are your emotional struggles
- Has anything changed for you as a person, if yes how has it changed, what brought about the change, and how has that affected your daily life?
- What else is difficult for you?
- What do you do to deal with these difficulties?
- What do you do to take care of yourself?
- Do you get help from anyone? Who? (family, friends or professionals)
- Is there anything that the hospital or any other related services are doing that helps
- What daily activities are difficult for you now?
- Is there anything that you would have liked to be done to help you with your difficult thing

##### **Probes to assess the spouse’s hardships:**

- How is your spouse (significant other) doing?
- What do you think is the most difficult thing for your spouse/significant other?
- What does he/her do to take care of themselves?

The interview will end with parents being given the opportunity to share anything else that is on their mind

E.g. Thank you so much for sharing this with us.

We have learned so much from you and your family. It is our hope that our findings will be helpful for other parents and health care providers in the future.

- Is there anything else you would like to share?

#### **Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information. Do you have anything else you want to talk with me about, or tell me about today? Thank you again for your time. I would like to call you next \_\_\_\_\_. Would that work for you? What time?

**Field Notes:** Record information describing the interview experience and any impressions or events that occurred during the interview by using the field notes guide

**Note:** For parents that show serious signs of depression or voice possible suicidal ideation, follow screening protocol below.

### ***Interview Guide: T2***

#### **Parent Interview Post-Death (6 months)**

**Directions:** This is a narrative interview to be conducted 6 months after the death of their child. Re /Introduce self. This interview will acknowledge parents' loss and grief. Parents will be encouraged to explore the every-day life challenges and how the challenges have changes since we last spoke. Remind participant about taping the

interview and that content will be kept confidential and not shared with your doctor.

Remind parents' that the interview can be stopped at any time, if they feel distressed or uncomfortable. **Acknowledge difficulty with passing of recent events, holidays, mother's day,**

**Focus:** Explore parents' challenges after the death of their child and how the challenges have changed (if any).

**Main Narration: (turn on audio recorder)**

Initiate a broad question to get the parent to tell their story since we last spoke.

**Grand Tour Question:** When we talked the last time you described how you were doing.

- How are you doing now?
- How have you been doing since the last time we spoke?
- Has anything changed in the way you feel?

Encourage the parent to talk about their grief to the extent they wish. Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

**Questioning Phase:**

**Probes to assess the Challenges faced and Related Work**

- What is the most difficult thing for you now?

- Probe about challenges with memories of the child, child's belongings, memorabilia
- Can you talk about your relationships with people around you
  - Has anything changed, if yes how and why?
- Can you share with me moments or times that are most difficult for you
- Can you share with me how was it for you on ----- day (If there was any special occasion: child's birthday, holidays, mother's day etc. that just passed by)
- Can you talk to me of what are your emotional struggles
- Has anything changed for you as a person, if yes how has it changed, what brought about the change, and how has that affected your daily life?
- What else is difficult for you?
- Last time you mentioned .....(mention the difficulty), is this still difficult for you, has it changed, if yes how?
- What do you do to deal with these difficulties?
- What do you do to take care of yourself?
- Do you get help from anyone? Who? (family, friends or professionals)
- Is there anything that the hospital or any other related services are doing that helps
- What daily activities are difficult for you now?

- Is there anything that you would have liked to be done to help you with your difficult thing?
- What are you doing different since are last conversation?
- Why did you change what you are doing?

**Probes to assess the spouse's hardships:**

- How is your spouse (significant other) doing?
- What do you think is the most difficult thing for your spouse/significant other?
- What does he/her do to take care of themselves?

The interview will end with parents being given the opportunity to share anything else that is on their mind. e.g., thank you so much for sharing this with us. We have learned so much from you and your family. It is our hope that our findings will be helpful for other parents and health care providers in the future.

- Is there anything else you would like to share?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:** Record information describing the interview experience and any impressions or events that occurred during the interview by using the field notes guide

**Note:** For parents that show serious signs of depression or voice possible suicidal ideation, follow screening protocol below.

**Note:** Conclude the general interview and then ask parents for their perceptions of being in the study:

E.g. We would like to know what it has been like for you to be in this study. Can you tell us a little bit about your experience?

**Probes**

- Did you feel that the interviews were difficult?
- Were they helpful in anyway?
- Is there anything else you'd like to discuss about being in the study: (listen for issues such as scheduling, time commitment, emotional, tough questions etc.?)
- Do you feel that this experience was worth it?

## Appendix D

### *Field Notes*

Please complete for each interview completed.

Field notes should be documented within 60 minutes following completion of interview.

Participant Code:                      Interviewers' initials:                      Date:

Interview Type:    \_\_\_ Parent Interview at 1 month post death (T1)

                                 \_\_\_ Parent Interview at 3 months post death (T2)

                                 \_\_\_ Parent Interview at 6 months post death (T3)

Length of Interview: \_\_\_\_\_

Where did interview take place? (State place and describe room)

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Who was present during the interview?

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Describe any interruptions that occurred.

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Describe Parent's emotional and/or physical state during interview.

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Describe any observations or reflections that you have about this interview that you feel are relevant to this analysis of this interview.

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## Appendix E

### *Suicide screen protocol*

SCRIPT:

\_\_\_\_\_(parents' name), You seem (tense, anxious, sad) ....., following the death of a child some parents may have thoughts of harming themselves. (Proceed as follows):

1) Are you having thoughts like that? If parent says "no" follow with this question:

2) Have you had thoughts like that in the past? If parent says "no" proceed with script below that begins with..."okay, if you...." If parent says "yes" follow with this question:

3) When? Before or after your child died?

If parent has answered "no" to the above questions, proceed as follows:

"Okay, if you were to start thinking that way, or if the thoughts begin to occur more frequently, it's important you feel safe enough to tell someone. Do you have someone you could tell?" If says "no" let him/her know that you would be someone he/she can call, and give the contact number.

If parent says "yes" to the 1st question above, or has been having suicidal thoughts since the child's death, proceed as follows:

1) Do you have a plan? If so, what is your plan?

2) Do you have access to (method of choice)? Have you used it before?

3) Have you had past suicidal ideas or attempts? How recent?

4) How physically close is the nearest person to you

**SCORING:**

Non-existent: No suicidal thoughts/plans.

Mild: Some ideations present, but no specific or concrete plans. Few risk factors are present.

Moderate: Some ideations present, and a general plan exists. Some risk factors are present.

Severe: Suicidal thoughts are frequent and intense. There is a specific and lethal plan. The means are available. Many risk factors are present

Extreme: Same as severe, along with the expression of a clear intent to kill self as soon as the opportunity presents itself. Many risk factors are present.

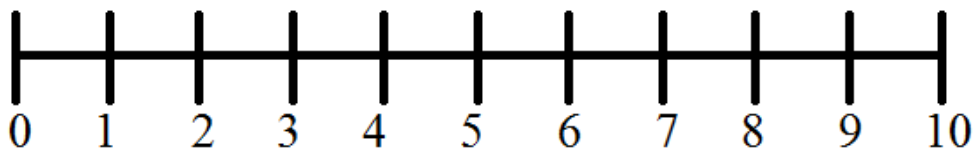
If the participant scores severe, or extreme suicidal ideations, I will continue to stay with the participant and help the participant contact a family member, so they can take him/her to the nearest emergency department.

If the participant does not want me to summon a family member, then I will contact the bereavement counselor from the Duke Pediatric Quality of Life Program to counsel or help the parent as needed. A statement indicating this step will also be included in the informed consent.

## Appendix F

### *Continuity Line*

Place an X on this line to indicate your perception of your overall health, from zero for worst possible health, to 10 for best possible health.



## Appendix G

### Case Matrix: Challenges and Work

Case\_2 Matrix: Type of Challenges and Work

Case 1	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	1. Child's illness trajectory; 2. The why's; 3. It is hard; 4. Changed relationships; 5. Gaps in health care system and bereavement care services 6. It is hard 7. Accepting the death 8. Emotional response	1. Resuming work; 2. Peoples responses/ reminders 3. Changed relationships; 4. Unanswered questions – child illness trajectory; 5. Why's and what if's 6. Gaps in health care system and bereavement care services 7. Celebrating or memorializing 8. Pregnancy now and in future	1. No closure; 2. The what if's; 3. Pregnancy now and in future; 4. Changed relationships; 5. People's responses;	1. No closure; 2. The what if's, why's (karma, why did it happen) 3. Other children- no siblings 4. Changed as a parent 5. Pregnancy now and in future; 6. Busy; 7. Gaps in health care-check list approach, insensitivity with bills recovery; 8. Changed relationships 9. People's responses 10. Busy 11. Getting back to routines 12. Grief Nature
Total	8	8	5	12
Challenge Intensity	Moderate	Mild	Moderate	Mild
Work	1. Support network; 2. Other children; 3. Coming to terms with the death/accepting the death; 4. Spirituality; 5. Busy; 6. Changed me as a person-compassionate 7. Memorabilia 8. Spousal relationships 9. Emotional response – crying 10. Giving back	1. Time heals; 2. Support network; 3. Spirituality; 4. Busy 5. Spouses relationships 6. Continuing bonds 7. Changed me as a person	1. Spirituality; 2. Busy; 3. Past experience with death, 4. Other children; 5. Support network 6. Continuing bonds 7. Memorabilia	1. Time heals; 2. Changed me as a person- "peoples oriented manager" 3. Support network
Total	10	7	7	3

Case\_3 Matrix: Type of Challenges and Work

Case 3	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	1. Emotional response: crying and sadness 2. Exhausted due to lethargy 3. Other children: Care of children and explaining death to siblings 4. Getting back to routine/ 5. Resuming work- not feeling guilty 6. Celebrating or memorializing 7. Anxiety and panic attack 8. People's response 9. Changed as a parent 10. Future pregnancy 11. Child's belongings 12. Memorabilia 13. Continuing bond	1. Changed as a person (sadder) 2. Emotional response- crying 3. Lethargy 4. Anxiety and panic attacks 5. Grief comes in waves (grief nature) 6. Memorabilia- nursing child 7. Changed relationship- friend 8. Future pregnancy 9. New normal 10. Celebrating or memorializing	1. Getting back to routine 2. Emotional response- Missing child yearning 3. Changed relationship with father 4. New normal	1. Changed relationship with Dad, and friends
Total	13	10	4	1
Challenge Intensity	Severe	Moderate	Moderate	Mild
Work	1. Celebrating and memorializing (random acts of kindness) 2. Crying –emotional response 3. Weight management 4. Child's belongings	1. Grief Counselor 2. Other children – sibling reminiscing about child 3. Support network 4. Hospital bereavement service- Remembrance Day – staying connected 5. Weight management 6. Changed me as a person 7. Continuing bonds	1. Other children 2. Support network 3. Child illness trajectory helped with accepting death 4. Memorabilia - +ve way of missing child 5. Celebrating or memorializing 6. Hospital bereavement services: staying connected 7. Continuing bonds	1. Other children 2. Different perspective: Focus on the good things (positive stuff) 3. Weight management 4. Busy 5. Hospital bereavement services: Continue relationship with health care team 6. Memorabilia. 7. Continuing bonds
Total	4	7	7	7

Case\_4 Matrix: Type of Challenges and Work

Case 4	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	<ol style="list-style-type: none"> <li>1. Different why – why am I not missing role of caregiver</li> <li>2. Emotional response and sensitivity-goes to temple, sees small babies.</li> <li>3. Child illness trajectory</li> <li>4. Celebrating/memorializing festivals</li> <li>5. People's responses/comments</li> <li>6. Changed relationship with friends</li> </ol>	<ol style="list-style-type: none"> <li>1. Emotional response (missing her)</li> <li>2. Yearning in grief</li> <li>3. Fear of forgetting child and memories</li> <li>4. Child's illness trajectory</li> <li>5. People's responses/comments</li> <li>6. Celebrating or memorializing</li> <li>7. What if's (born normal)</li> </ol>	<ol style="list-style-type: none"> <li>1. People's Response/Comments- time passes, you'll forget</li> <li>2. Fear of forgetting/not wanting to forget</li> <li>3. Memorabilia (reminder of illness)</li> <li>4. The what ifs</li> <li>5. Child's illness trajectory/Unexpected death</li> <li>6. Emotional response</li> <li>7. Yearning in grief</li> <li>8. Changed habit- back to drinking</li> <li>9. Spirituality- don't give a defective gift (child as God's gift)</li> <li>10. Gaps in healthcare</li> </ol>	<ol style="list-style-type: none"> <li>1. Emotional response /sensitivity</li> <li>2. Yearning "miss her a lot"</li> <li>3. Gaps in health care- no feedback, Follow protocol/check list</li> <li>4. The what ifs</li> </ol>
Total	6	7	10	4
Challenge Intensity	Severe	Moderate	Moderate	Mild
Work	<ol style="list-style-type: none"> <li>1. Accepting the death as fate</li> <li>2. Moving on</li> <li>3. Bereavement service - Sent cards, remembrance day</li> </ol>	<ol style="list-style-type: none"> <li>1. Becoming pregnant again</li> <li>2. CB- talking to child</li> <li>3. Giving back</li> <li>4. Weight management: Eat healthy</li> <li>5. Different perspective; think positive</li> <li>6. Self care: Watching TV (distract)</li> <li>7. Busy</li> </ol>	<ol style="list-style-type: none"> <li>1. Weight management</li> <li>2. Self care: Yoga</li> <li>3. Busy</li> <li>4. Memorabilia</li> </ol>	<ol style="list-style-type: none"> <li>1. Weight management</li> <li>2. Self Care: Yoga</li> <li>3. A different approach- (Positive approach)</li> <li>4. Changed habit: drink less was possible donor for deceased child</li> <li>5. Changed me as a person</li> </ol>
Total	3	7	4	5

Case\_5 Matrix: Type of Challenges and Work

Case 5	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	1. Emotional response (see memo in ATLAS) 2. Being alone in grief 3. Inability to be happy and enjoy life 4. Lethargy 5. Changed relationship with family, friends and spouse 6. People's response comments- how are you doing? 7. Spousal relationship 8. Changed as a parent (more fearful) 9. Grief and culture 10. Changed me as a person 1. Accepting the death 2. It is hard	1. Accepting the death 2. Emotional response: yearning 3. Grief nature 4. Changed me as a person- new person 5. Lethargy 6. Inability to be happy 7. Busy – balance of life and grief 8. Pregnancy questions- do we have other children? 9. Spouse and spousal relationship 10. Other children miss the sibling, remember child 1. Celebrating or memorializing 2. Social media as a platform to grieve- will be forgotten by people 3. Gaps in healthcare services	1. Emotional response heavy with feeling- Sad, yearning in grief; emotional sensitivity to music 2. Lethargy- energy feel sluggish, no motivation 3. Child's belongings 4. Inability to be happy and enjoy life 5. Being alone in grief (alienating), brings back memories 6. Spouse and spousal relationship, don't see each other due to work schedule (trying to regroup) 7. It's hard. 8. Celebrating and memorializing (anxiety and depression) strange giving gifts to the dead. 9. Busy- does not work. 10. People's response- you are so strong. 11. Memorabilia 12. Child's illness trajectory 13. Other children 14. Gaps in healthcare	1. Grief and self-identity I don't want to play victim "OMG I'm a grieving parent" 2. Emotional response - disbelief, sorrow. 3. It is hard; doing routines 4. Grief nature (waves- up and down peaks and troughs) 5. Inability to be happy 6. Other child (reminder of missing child) 7. Yearning in grief 8. Guilt to enjoy 9. Memorabilia (ashes- missing and crying) 10. Spouse or spousal relationship – blame, grieving differently- can't take on her grief – mine is enough, feeling neglect 11. Celebrating on memorializing (ann. and milestones) difficult 12. Changed me as a person- "I'm a lost person" 13. People's response/ comments- how are you doing. 14. Grief culture- grief is a taboo, nobody talks/ educates about death. 15. Lethargy 16. Gaps in health care services: no contact with team 17. Continuing bonds
Total	12	13	14	17
Challenge Intensity	Severe	Moderate	Moderate	Mild

### Case 5. Matrix Challenges and Work Ctd.

Work	1. Other children 2. Support network 3. Hospital bereavement service 4. Weight management, exercise, yoga, eat healthy 5. Self care: Trip, massage, chiropractor adjustments	1. Support network 2. Emotional response (see memo), crying to let out 3. A different perspective: a positive approach 4. Changed relationship with sis (got close) 5. Changed person (less judgmental) 6. Grief counseling and support group 7. Continuing bonds 8. Memorabilia 9. Self care 10. Giving back 11. Grief and culture: educate	1. Grief nature- do grief work 2. Busy. 3. Different perspective, stay positive. 4. Self-care: Chiropractor- rebalances your energy. 5. Bereavement services: Hospice care 6. Other children 7. Time heals. 8. Changed person- I am coal trying to be a diamond.	1. Other children 2. Emotional response: Crying- don't want to bottle things 3. Support network: Socializing with friends 4. Grief counseling 5. Self care: Taking a trip- self-exploration, explore nature, 6. A different perspective: positive approach 7. Continuing bonds 8. Grief as transforming and evolving
Total	5	10	8	8



Case\_6 Matrix: Type of Challenges and Work

Case 6	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	1. Grief nature- it's a rollercoaster, Hard days unpredictable 2. Spousal relationship- he's escaping, grieves differently, works a lot 3. Other children- separate anxiety/daughter talks about the deceased child 4. Being alone in grief 5. People's response- white elephant, get over it; move on, nobody wants to talk about it. 6. Changed as a parent- not as patient, insecure, not working, not enough for my husband 7. Gaps in healthcare- prepare husband/wife that they grieve differently. 8. Grief culture- people are scared, or people want you to move on 9. What if's: Folic acid tabs	4th and 5 <sup>th</sup> month hardest 1. Anxiety 2. Spouse and spousal relationship 3. Other daughter 4. Lack of motivation- lethargy 5. Pregnancy decision (fear) 6. Emotional response 7. Peoples response – it's been long enough-like chop, chop 8. Grief culture: Perception that people want her to move on 9. Other children and siblings talking about the deceased child 10. Yearning - miss her 11. Social media as a platform to grieve 12. Gaps in health care: 6 month reach out call	1. Busy 2. Yearning- empty and loss 3. *Support group- I realize how much I miss child 4. Fear of forgetting child 5. Spirituality – going to church is hard (sorrow- misses her and hopes to see her again) 6. Spouse and spousal relationship- communication issues 7. Guilt 8. Grief affected by other stressors: busy- didn't have time to grieve/I wasn't grieving enough 9. Resuming work * Both AC and AW	1. Emotional response (cry ) 2. Fear of forgetting 3. Celebrating or Memorializing 4. Spouse and spousal relationship (wife anxiety. 5. Resuming work- unable to spend time grieving 6. Grief affected by other stressors: busy at work, family responsibility
Total	9	12	9	6
Challenge Intensity	Severe	Moderate	Moderate	Mild

Case 6. Matrix Challenges and Work Ctd.

Work	<ol style="list-style-type: none"> <li>1. Spirituality-relationship with God – pray</li> <li>2. Grief support group</li> <li>3. Self care: Get away trip (first 2 weeks)</li> <li>4. Hospital bereavement services: free counseling services, support group ref</li> <li>5. Emotional response: Experience the grief=doing the grief work- go through the emotions, allow yourself to be selfish</li> </ol>	<ol style="list-style-type: none"> <li>1. Grief counseling/ support group</li> <li>2. Marriage counselor</li> <li>3. Self care: Essentials oils, massages, reading</li> <li>4. Different perspective- “mantra-celebrate everything” “everything happens for a reason”</li> <li>5. Changed person “joy and peace with what happened”</li> <li>6. “new norm”- easier than before</li> <li>7. Support network</li> <li>8. Memorabilia</li> <li>9. Continuing bonds</li> <li>10. Changed relationships – new friends</li> <li>11. Weight management</li> </ol>	<ol style="list-style-type: none"> <li>1. Other child</li> <li>2. Grief support</li> <li>3. Memorabilia-reminder of her life rather than her death</li> <li>4. Different perspective: Other people grieve similar to me, I’m not alone</li> <li>5. Changed parent – spend more time</li> <li>6. Support network</li> <li>7. Hospital bereavement services</li> <li>8. Accepting the death- aware of outcomes</li> <li>9. Weight management (runs to work)</li> <li>10. Continuing bonds: memorabilia, chime as though child is talking to us</li> <li>11. Child’s illness trajectory</li> </ol>	<ol style="list-style-type: none"> <li>1. Grief support group</li> <li>2. Other children- joy as other child remembers sibling</li> <li>3. Memorabilia</li> <li>4. Continuing bonds</li> <li>5. Marriage counselor</li> <li>6. Weight management</li> </ol>
Total	5	11	11	6

Case\_7 Matrix: Type of Challenges and Work

Case7	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	1. Apprehensive to 2. Celebrate/memorabilia 3. Emotional response- sad/ emotional sensitivity –quietness in the house 4. Guilt: for feeling relieved 5. New normal-extra time, new routines 6. Other children- more involved play 7. Fear of forgetting child 8. Changed person” numb to my feelings” 9. Childs illness trajectory- joy of having her, shock of her birth and illness and pain of losing her 10. Grief affected by other stressors-past history 11. Gaps in health care, end of life	1. Grief nature up and down, surreal 2. Guilt for the relief that I feel 3. Grief response, affected by other stressors 4. Yearning in grief 5. Childs belongings- room the same 6. Fear of forgetting = moving on. Want to move forward and hold onto the memories 7. Future pregnancy= uncertainty	1. Yearning 2. Great nature up and down 3. Getting used to the new normal free time 4. Guilty – forgetting and for feeling relieved 5. Emotional sensitivity- holidays 6. Fear of forgetting 7. People’s responsiveness – as reminder 8. The what if- treatment decision 9. Balance between not forgetting and moving 10. Childs belongings- room intact 11. Celebrating or memorializing	1. Emotional response, think about child miss child 2. Yearning – void 3. It is hard, just to lose a child 4. Pregnancy- nervousness
Total	11	7	11	4
Challenge Intensity	Moderate	Mild	Moderate	Mild
Work	1. Different perspective- everybody has a purpose 2. Childs illness trajectory: Did our best 3. Other daughter- more attention’ 4. Memorabilia- sad and happy 5. Support network 6. Changed person- purpose in life and open to spirituality 7. Weight management 8. Self care: Take some time – a day for myself.	1. Spirituality- grateful for her 2. Counselor: Therapist 3. Support network- friends 4. Changed as a person/parent 5. Attention to spirituality 6. Giving back 7. Weight management	1. Other child 2. Childs illness trajectory happy to the end parents did their best 3. Memorabilia – feel positive 4. Changed as a person for better, slow down, appreciate things in life. 5. Changed relationships- reconnecting with friends 6. Emotional support 7. Staying busy 8. HBS	1. Everyday is a new day 2. Other children, spend time with child 3. Guilt – realized that it is OK to forget the details A different perspective- stay positive 4. Emotional support for wife 5. Improved spouse and spousal relationship 6. Emotional support 7. Going out as a family- new normal
Total	8	7	8	7

Case\_8 Matrix: Type of Challenges and Work

Case 8	T1_Mother	T2_Mother	T1_Father	T2_Father
Challenge	<p>1. Its hard: -</p> <p>2. Getting back to routines</p> <p>3. . Inability to be happy and enjoy life</p> <p>4 Yearning in grief: missing child, awareness he'll never come back.</p> <p>5. Spouse and spousal relationships: communication</p> <p>6. Emotional response: frequent crying</p> <p>7. Child's unexpected death: child's illness trajectory</p> <p>8. Celebrating and memorializing</p> <p>9. Grief identity: don't cry at work – "I don't want people to say, "Oh you know I'm staying away from here because I don't want to deal with crying all the time." So I just try to stay as positive as I can. And- and just deal with it."</p> <p>10. Peoples responses: People don't understand</p> <p>11. Child's belongings</p> <p>12. Memorabilia</p> <p>13. Continuing bonds</p> <p>14. The what if's</p> <p>15. Guilt: did not pay attention to his complains, may be die!? Did I have a hand in it??</p>	<p>1. Emotional response: I still cry every day, emotional sensitivity</p> <p>2. Yearning in grief</p> <p>3. Grief nature</p> <p>4. Guilt: for not finding help sooner</p> <p>5. Changed as a parent: more fearful</p> <p>6. Child's belongings: changed home- too many memories</p> <p>7. Inability to be happy and enjoy life</p> <p>8. Lethargy</p> <p>9. Changed me as a person: no motivation/enthusiasm, unable to go back to school or do things she would enjoy</p> <p>10. Spirituality: question God but need Him too, why? what purpose?</p> <p>11. The why's: why did this happen</p> <p>12. Being alone in grief: people don't understand, put a bold face for others</p> <p>13. Celebrating or memorializing: birthday was hard</p> <p>14. Gap in healthcare: too may materials, not targeted for the family/person; unsure how the bereavement service will be</p> <p>15. Continuing bonds: going to the grave</p>	<p>1. Emotional response: emotional sensitivity; Watching games, child not on passenger seat</p> <p>2. It is hard: "its been rough", just waking up and doing things,</p> <p>3. Busy both AC and AW</p> <p>4. Other children</p> <p>5. Changed as a parent: "dad's boy"</p> <p>6. Memorabilia: "This is for you." I was like, "What's this?" He said, "It's for your birthday, Father's day, Christmas, all of it." It was another Apple watch. And he asked for an Apple watch for me and I- I wear it every day.</p> <p>7. Spousal relationships: less communication</p> <p>8. Yearning in grief</p> <p>9. Changed person: Now I try still to keep a smile on my face but it's not the same smile I think- you know I think it's just masking the feelings that I have you know? But I still try to you know take it um one day at a time.</p> <p>10. Child illness trajectory:</p> <p>11. What if? And why? What if he would survive? live to tell his story</p> <p>12. gaps in health care: give reference to someone specific</p>	<p>1. It is hard</p> <p>2. Emotional response; Emotional sensitivity: duke games</p> <p>3. Yearning in grief</p> <p>4. Getting back to routines</p> <p>5. Other children</p> <p>6. Staying strong for others</p> <p>7. Child's belongings AC and AW</p> <p>8. Peoples reminders; Peoples responses</p> <p>9. Grief and Identity: not crying in front of others</p> <p>10. Celebrating or memorializing</p> <p>11. Changed as a parent: its an adjustment</p> <p>12. The what if's: Illness trajectory</p>
Total	15	15	12	12
Challenge Intensity	Severe	Severe	Severe	Moderate

### Case 8. Matrix Challenges and Work Ctd.

Work	1. Weight management 2. Resuming work 3. A different perspective: Staying positive 4. Changed habits: wine to sleep 5. Technical work: meds 6. Support network: family	1. Support network: family 2. Emotional response: 3. Other children 4. Weight mgmt. 5. Busy 6. Spousal relationship	1. Weight management: 2. Other child 3. Different perspective: stay positive, reflect on good times 4. Changed me as a person	1. Busy 2. Giving back 3. Other children 4. Weight Mgmt 5. Emotional response: Crying 6. Spousal relationships 7. Spirituality 8. Different perspective: focus on the happy memories 9. Support network 10. Continuing bonds 11. Child's belongings 12. Memorabilia:
Total	6	6	4	12

## Appendix H

### *Joint Matrix: Challenges, Work, and Health Scores*

Time	Case	Gender	PRO_Ph	PRO_Mer	PRO_Slee	PRO_Soc	BSI_Som	BSI_Dep	BSI_An	BSI_Glo	Cont_L	BMI	Chall_#	Chal_In	Work
t1	1	Mother	42.3	36.3	48.9	48	59	63	54	60	7	29.3	7	Mod	7
t1	1	Father	54.1	36.3	50.3	43	48	66	65	63	6	31.2	7	Mod	2
t1	2	Mother	50.8	48.3	38.7	33.6	50	45	52	48	7	24.9	8	Mod	10
t1	2	Father	47.7	45.8	55.1	40.2	42	45	50	48	8	31.2	5	Mod	7
t1	3	Mother	54.1	53.3	48.9	29.7	48	45	38	48	7	28.1	13	Sev	4
t1	3	Father	57.7	53.3	41.4	31.3	42	50	48	50	8	24.3	4	Mod	7
t1	4	Mother	54.1	53.3	41.4	31.3	41	50	46	47	8	22.05	6	Mod	3
t1	4	Father	54.1	48.3	50.3	36.9	48	59	50	53	7.5	22.9	10	Mod	4
t1	5	Mother	50.8	50.8	35.1	43	55	70	53	62	7	30.4	12	Sev	5
t1	5	Father	47.7	45.8	45.5	25.9	61	61	48	59	8	30	14	Sev	8
t1	6	Mother	54.1	41.1	52.9	44	55	61	66	62	7	27.4	9	Sev	5
t1	6	Father	54.1	45.8	47.3	31.3	50	48	48	51	7	24	9	Mod	11
t1	7	Mother	54.1	45.8	45.5	43.5	50	58	57	56	7	21.6	11	Mod	8
t1	7	Father	47.7	43.5	54	37.7	61	62	61	62	8	23.6	11	Mod	8
t1	8	Mother	47.7	43.5	56.1	41.1	48	57	52	50	8	45.5	15	Sev	6
t1	8	Father	39.8	33.8	66.3	36	50	70	66	67	8	35.7	12	Sev	4
t2	1	Mother	50.8	38.8	59.3	44	59	67	59	63	8	30	12	Mild	7
t2	1	Father	50.8	41.1	54	39.3	64	65	48	62	7	31.2	4	Mild	3
t2	2	Mother	47.7	50.8	35.1	25.9	41	40	46	39	8	24.8	8	Mild	7
t2	2	Father	42.3	43.5	59.3	41.1	42	48	47	47	7	31.2	12	Mild	3
t2	3	Mother	54.1	50.8	43.6	38.5	50	48	45	48	8	27.1	10	Mod	7
t2	3	Father	61.9	59	41.4	25.9	42	41	39	36	7	23.5	1	Mild	7
t2	4	Mother	54.1	50.8	48.9	36.9	41	56	48	48	8	23.9	7	Mild	7
t2	4	Father	47.7	45.8	41.4	36.2	42	50	48	50	8	23	4	Mild	5
t2	5	Mother	50.8	53.3	30	40.2	50	62	54	58	7	31	13	Sev	11
t2	5	Father	44.9	41.1	47.3	40.2	50	65	48	58	8	30.5	17	Sev	8
t2	6	Mother	44.9	43.5	57.2	38.5	41	50	52	48	7	25.7	12	Mod	11
t2	6	Father	57.7	48.3	52.9	38.5	42	41	39	36	8	23.8	6	Mild	6
t2	7	Mother	54.1	45.8	55.1	33.6	55	56	48	54	8	21.4	7	Mild	7
t2	7	Father	54.1	45.8	55.1	38.5	43	41	47	42	8	23.6	4	Mild	7
t2	8	Mother	42.3	38.8	60.3	42	48	62	48	55	5	45	15	Sev	6
t2	8	Father	44.9	38.8	60.3	44	48	66	57	61	7	31.7	12	Mod	12

Red: < population mean

Green: => population mean

# Appendix I

## Health Scores: Matrices for all cases

### Case 1: Exemplar case 1- Connor's case

### Case 2

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	47.7	42.3	50.8	47.7
	Mental	45.8	43.5	48.3	50.8
	Sleep	55.1	59.3	38.7	35.1
	Social	40.2	41.1	33.6	25.9
Brief Symptom Inventory (BSI) -18	Somatization	42	42	50	41
	Depression	45	48	45	40
	Anxiety	50	47	52	46
	Global	48	47	48	39
Continuity Line	Self-health Perception	Scale 0 to 10			
		0 = Worst health, 10 = best health			
		8	7	7	8
Height and Weight	BMI	30.5	30.5	24.3	24.2
PROMIS: Population mean T scores =50					
BSI-18: If any 2 subscale score or Global score =/ $\leq$ 63, indicated need for further evaluation					
Red Score: PROMIS: Below population mean					
BSI-18 Need for further evaluation					
Green Score: PROMIS: At or above population mean scores					
BSI-18 No indication for further evaluation					

### Case 3

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	57.7	61.9	54.1	54.1
	Mental	53.3	59.0	53.3	50.8
	Sleep	41.4	41.4	48.9	43.6
	Social	31.3	25.9	29.7	38.5
Brief Symptom Inventory (BSI) -18	Somatization	42	42	48	50
	Depression	50	41	45	48
	Anxiety	48	39	38	45
	Global	50	36	48	48
Continuity Line	Self-health Perception	Scale 0 to 10 0 = Worst health, 10 = best health			
Height and Weight	BMI	23.8	23	27.4	26.5
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score $\leq$ 63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					



### Case 4

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	54.1	47.7	54.1	54.1
	Mental	48.3	45.8	53.3	50.8
	Sleep	50.3	41.4	41.4	48.9
	Social	36.9	36.2	31.3	36.9
Brief Symptom Inventory (BSI) -18	Somatization	48	42	41	41
	Depression	59	50	50	56
	Anxiety	50	48	46	48
	Global	53	50	47	48
Continuity Line	Self-health Perception	Scale 0 to 10 0 = Worst health, 10 = best health			
		7.5	8	8	8
Height and Weight	BMI	22.3	22.5	21.5	23.3
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score =/<63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					

### Case 5: Exemplar case 2- Maggie's case

## Case 6

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	54.1	57.7	54.1	44.9
	Mental	45.8	48.3	41.1	43.5
	Sleep	47.3	52.9	52.9	57.2
	Social	31.3	38.5	44	38.5
Brief Symptom Inventory (BSI) -18	Somatization	50	42	55	41
	Depression	48	41	61	50
	Anxiety	48	39	66	52
	Global	51	36	62	48
Continuity Line	Self-health Perception	Scale 0 to 10 0 = Worst health, 10 = best health			
		7	8	7	7
Height and Weight	BMI	23.5	23.2	26.8	25.1
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score $\leq$ 63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					

## Case 7

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	47.7	54.1	54.1	54.1
	Mental	43.5	45.8	45.8	45.8
	Sleep	54	55.1	45.5	55.1
	Social	37.7	38.5	43.5	33.6
Brief Symptom Inventory (BSI) -18	Somatization	61	43	50	55
	Depression	62	41	58	56
	Anxiety	61	47	57	48
	Global	62	42	56	54
Continuity Line	Self-health Perception	Scale 0 to 10 0 = Worst health, 10 = best health			
		8	8	7	8
Height and Weight	BMI	23.1	23.1	21.1	20.9
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score $\geq$ 63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					

## Case 8

Measures	Variable	T1_Dad	T2_Dad	T1_Mom	T2_Mom
		T Scores			
PROMIS	Physical	39.8	44.9	47.7	42.3
	Mental	33.8	38.8	43.5	38.8
	Sleep	66.3	60.3	56.1	60.3
	Social	46	44	41.1	42
Brief Symptom Inventory (BSI) -18	Somatization	50	48	48	48
	Depression	70	66	57	62
	Anxiety	66	57	52	48
	Global	67	61	50	55
Continuity Line	Self-health Perception	Scale 0 to 10			
		0 = Worst health, 10 = best health			
		8	7	8	5
Height and Weight	BMI	25.4	22.6	44	44.4
PROMIS: Population mean T scores =50 BSI-18: If any 2 subscale score or Global score =<63, indicated need for further evaluation <b>Red Score:</b> PROMIS: Below population mean BSI-18 Need for further evaluation <b>Green Score:</b> PROMIS: At or above population mean scores BSI-18 No indication for further evaluation					

## Appendix J

### *Atlas Ti Codes and Definitions*

Code	Code Definition
A Different perspective: a positive approach	Parents talk about the good or positive things in their life as a result of the experience of losing their child.
Accepting the death	Parents' comments related to accepting the death of the child. Sometimes as AW (e.g.: "you accept the death to move on") or as AC comments in which parents describe it as a challenge. AC/AW will be added as a code to identify if comment is AC or AW. *** Merged Comment from: This is a bad dream (2016-04-01T14:11:29) Parents state that they still are not able to accept the reality of the death of their child and they think that the death "is a dream"
Adaptive Challenge (AC)	Quotes that identify challenges that are complex and not easily defined.
Adaptive Work (AW)	All activities that parents identify as Adaptive Work
Anxiety	Parents mention that they have anxiety related to their grief and death of their child.
Being alone in grief	Parent expresses a feeling of social isolation as not many parents lose their children. a sense of feeling lonely in parental grief. AC added if parents describe challenge as AC *** Merged Comment from: Being alone brings memories (2016-05-28T09:57:13) Quotes in which parents mention that when they are alone and by themselves, it brings memories of their child. Labeled as AC if parents describe it as AC
Busy	This code can either be AC or AW. AC: if parent identifies staying busy as not helpful AW: If parent indicates staying busy was helpful Additional code of AC or AW will be added to identify if AC or AW
Celebrating or memorializing Special days	Parents describe how they celebrate/memorialize special days or occasions, after the death of the child. e.g. child's birthday or holidays like Christmas. AC or AW added based on how parents describe the event
Changed as a parent	Quotes that reference changed habits such as drinking or smoking or any habits that are detrimental to health and cannot be categorized as AW
Changed me as a person	Quotes in which parents talk about how they have changed as a person after the death of their child.
Changed relationships: Friends, family, and community	Parents discuss about their changed relationships with friends and family after the death of their child

Child's belongings	Parents share their views about the deceased child's belongings and their feelings about it now. AC/AW will be added to the quote if parents describe that the belongings as a challenge or as therapeutic
Child's unexpected death	Unexpected nature of their child's death leading to AC
Child's illness trajectory	Quotes which reflect on the child's illness trajectory: AC/AW will be added based on how parents describe the illness trajectory *** Merged Comment from: Unattended grief and consequence (2016-04-01T19:38:50) Parents discuss what are the consequences of grief
Continuing Bonds	Any activities that are examples of CB act/expressions or any thing that identifies the attributes of CB. Attributes of CB (CB as Normal, ongoing relationship, transformative, dynamic, includes grief)
Different " Why"	Quotes in which parents question their response to the death of their child. e.g. why no tears, or why I am not missing doing things for the child etc. as opposed to "Why me, Why my child, the typical Why's as described in the grief process
Emotional Response	This is the response of the parent to the death of the child in the form of crying, sadness, and panic attacks. Any expression of grief, which is identified as a challenge. AC will be added to the quotes if these emotional expressions are described as a challenge. AW will be added if parents identify this response as doing the AW to help themselves. *** Merged Comment from: Emotional response: anger (2016-04-01T13:43:32) *** This code indicates the emotional response to the death of a child. Anger identified as part of the stages of grief. it could be AC or AW and is indicated with the additional code of AC or AW *** Merged Comment from: Crying as AW (2016-04-01T13:45:49) *** Parents talk about using crying to make them feel better or using crying as AW. AW will be added to the quotes too *** Merged Comment from: Denial (2016-04-01T19:36:20) *** Parents mention that they are in denial about the death of their child. AC will be added to quotes if parents identify denial as a challenge *** Merged Comment from: Emotional Sensitivity (2016-05-27T20:44:25) *** Any trigger that leads to an emotional response. e.g. seeing babies or attending birthdays. AC added if described as challenge
End of Life care	Quote that describe end-of life care
Fear	Comments in which parent mentions just a feeling of fear without specifying the type of fear.
Fear of forgetting child	Parents talk about their fears related to forgetting their deceased child. AC added if parents describe challenge as AC
Gaps in healthcare services	Parents discuss things that are currently missing in the health care services for bereaved families
Getting back to routines	This challenge has a 2 fold definition: 1. Challenges related to getting back to carrying out day to day activities 2. Challenges related to the discomfort with getting back to routines (e.g. Case 3001_T1). AC added to the quotes

Giving back	Parents discuss about their new altruistic attitude to help others. AW added if parents mention this as AW
Grief and culture	Perceptions of differences between their culture's grieve/mourn and the culture of grief/mourning in the US. Quotations include perceptions of grief in the US too
Grief and self-identity	Quotes in which parent do not want to be identified as a "grieving parent".
Grief as transforming or evolving	Parents comment on how their grief has changed or evolved over time
Grief counseling/support group	Reference to any type of support groups or counseling that parents are going to help them
Grief response affected by other stressors	Other circumstances in life that influenced the parents grief response and grieving: financial demand, unemployment, busy life, and illness *** Merged Comment from: Financial Challenge (2016-04-01T19:37:13) *** Parents discuss their financial struggles as their AC *** Merged Comment from: Past experience with loss (2016-04-01T19:37:51) *** Quotations that reference to how past experiences with loss influence the bereavement trajectory. 5.26.16: edited codes, removed codes of past experience with loss and created new code for that.
Grief nature	Parents describe the recurrent nature of their grief response and the pattern of the recurrence: grief is not constant but is episodically and recurrent (described as comes in waves or is cyclical)
Guilt	Parents either stating that they are guilty and talk about their grief experience
Hospice care	Parents talk about hospice services for children
Hospital bereavement services	This code includes both what was offered and ideas proposed by parents as bereavement services for parents *** Merged Comment from: Staying connected to healthcare team_AW (2016-04-01T14:08:45) *** Parents mention about their continued relationship with the health care provider that cared for their child
Inability to be happy and enjoy life	Parents state that they are unable to find joy in anything they do
Life is Hard	The parent expresses the phrase "it is hard" or it is "rough" with reference to their emotional state or functioning. *** Merged Comment from: Everything is "hard" (2016-04-01T13:53:44) Parents specifically state that "every thing is hard" or life in general is hard. Adaptive challenge (AC) added if parents describe challenge as AC
Memorabilia	Any item specifically identified to memorialize the deceased child or ritual created to memorialize the child. AC or AW added based on how parents talk about the memorabilia
Moving on	Whenever the parent mentions "moving on" or "move on" or even "move forward"
New normal	Parents talk about their changed routines after the death of their child and state

	"new normal"
No closure	Parents talk about something that continues to affect their grief, may state "no closure" or imply that they are still looking for closure. AC added as needed
Other children	<p>Quotes related to all aspects of caring for the surviving children, like physically taking care of them. it also includes challenges related to explaining and answering questions about death of their sibling. AC or AW added as needed. e.g. AW if caring for other child is seen as a distractor from grieving the death of the child.</p> <p>*** Merged Comment from: Siblings reminiscing about child (2016-04-01T19:24:57) ***</p> <p>Quotes in which parents describe how a surviving child reminisces on the deceased child. AC or AW added as needed</p>
Past experience with death	Discusses past experience with death
Peoples responses	<p>Quotes that highlight comments made by friends, family or community that can be identified either as AC or AW by the parent.</p> <p>*** Merged Comment from: Peoples reminder (2016-05-28T10:22:53) ***</p> <p>Quotes that talk about comments or action by family/friends/community that remind the bereaved parent of the deceased child and could be labeled as AC or AW.</p>
Pregnancy: Now and future	Parents discuss about their thoughts about getting pregnant again.
Resuming work	<p>Getting back to work: Is identified as both AC and AW.</p> <p>As AC, it includes challenges related to getting back to work.</p> <p>As AW, it includes the therapeutic role of getting back to work, somewhat tying to the notion of "staying busy"</p> <p>The codes AC or AW have been added to identify if this code is AC or AW for the specific quote.</p>
Self care	Parents engage in activities that improve health and wellbeing: e.g. meditation, vacation etc.
Social media as a platform to grieve	Using social network as a platform to do the grief work. Also included pros and cons of using social network as a platform to grieve. AC or AW added based on how parents talk about social networking
Spirituality	Parents discuss their spirituality and its influence on their grieving: AC or AW added as needed
Spousal relationships	<p>Quotes that reference to the relationships between the mom and dad. Changes that have occurred after the death of the child.</p> <p>*** Merged Comment from: Spouse role in grief (2016-05-28T10:57:05) ***</p> <p>The spouse playing a supportive role for the parent. AW added if parents identify spouse as supportive</p>
Spouses_AC and AW	Parents perception of spouses AC and AW
Staying strong for others	Parents talk about their need to stay strong for other family members like spouse or children
Support network	Parents mention about people who serve as emotional support for them. AW added to label if parents mention this support as AW
Technical Challenge	Any challenge that can be labeled as TC
The "Whys"	This code identifies the "why" questions parents tend to ask after the death of a



	child, e.g. "why me?" or "why my child?" This code can be AC as these questions linger on in the bereavement trajectory and may be seen as unanswered questions that contribute to their AC.
The What if's	Quotations in which parents discuss the "what if" moments or things that still affect their grieving
Time heals	Quotes that reference to the role of time with relation to the bereavement trajectory.
Unanswered questions	Parents talk about things for which they have still not got answers. AC added if parents describe this as a challenge
Vertigo	Diagnosis of vertigo
Weight Management	Parents discuss about using measures to manage weight as part of AW. AW added if parents identify it as AW
Yearning in grief	Quotes in which parent talk about missing something in their life after the death of their child, that leads to AC. e.g. missing the child, or missing the care giver role they played prior to the child's death.

## Appendix K

### *Co-occurrence Models*

Key:

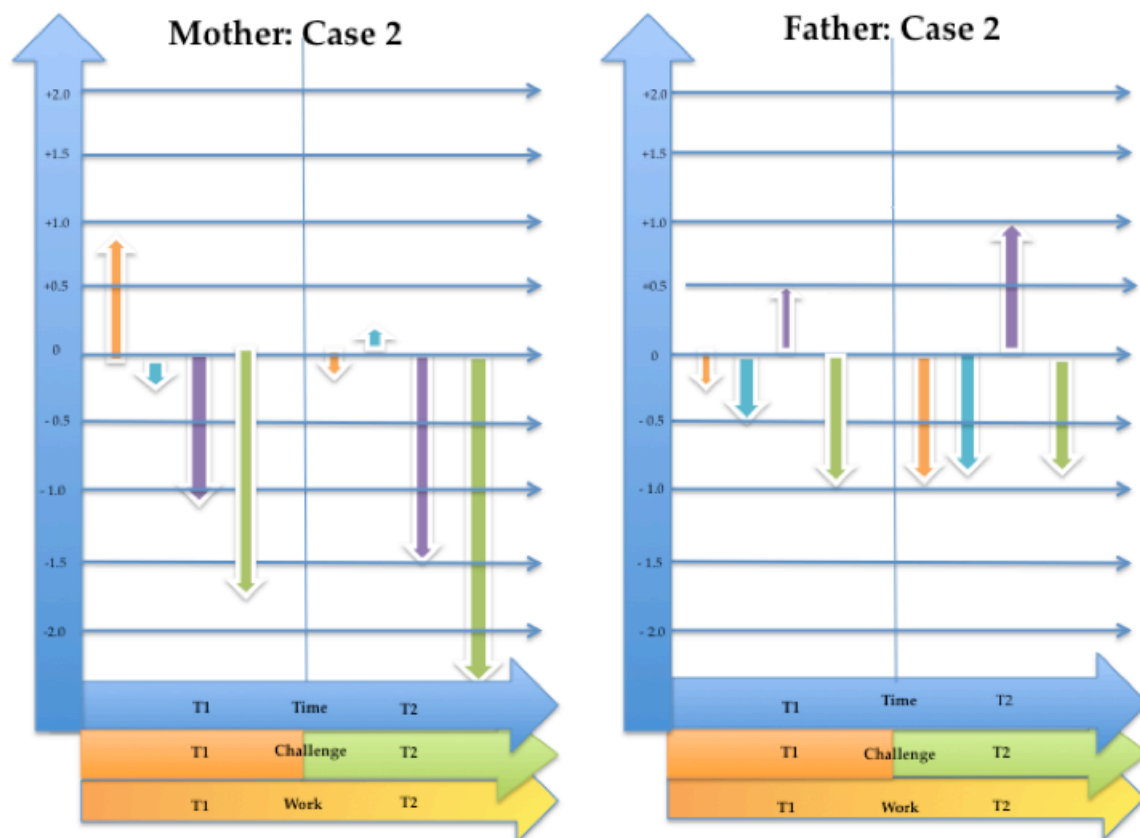
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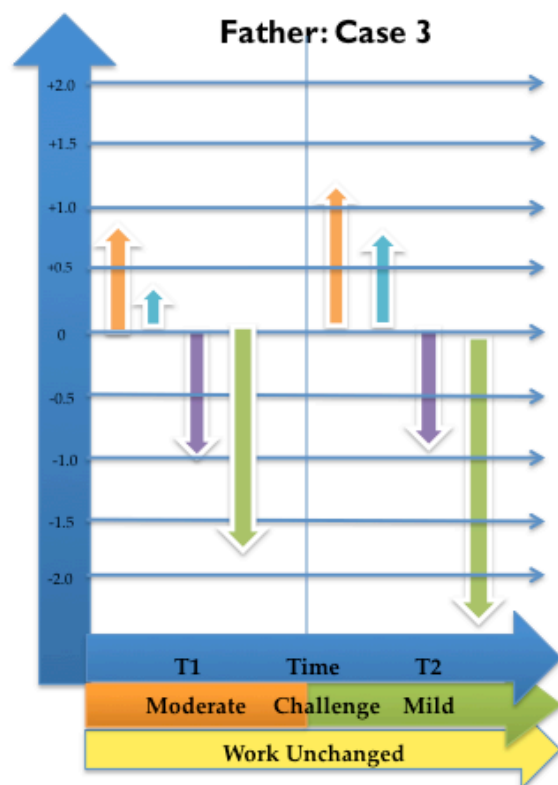
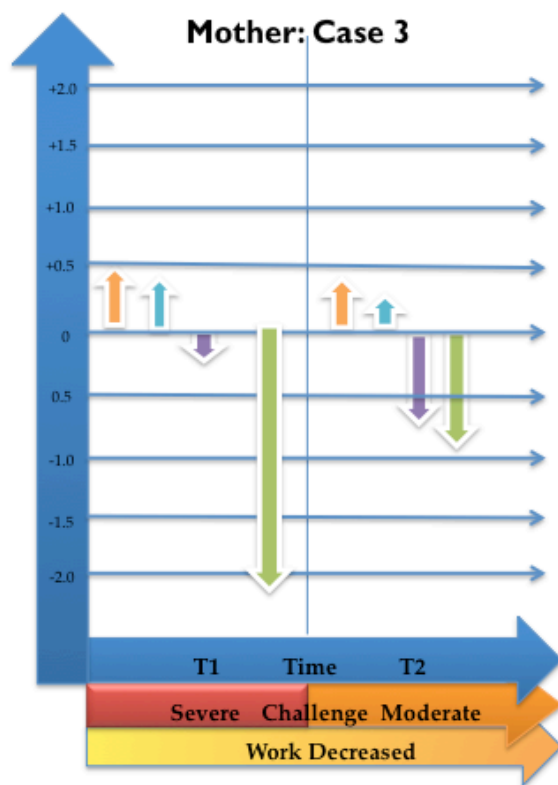
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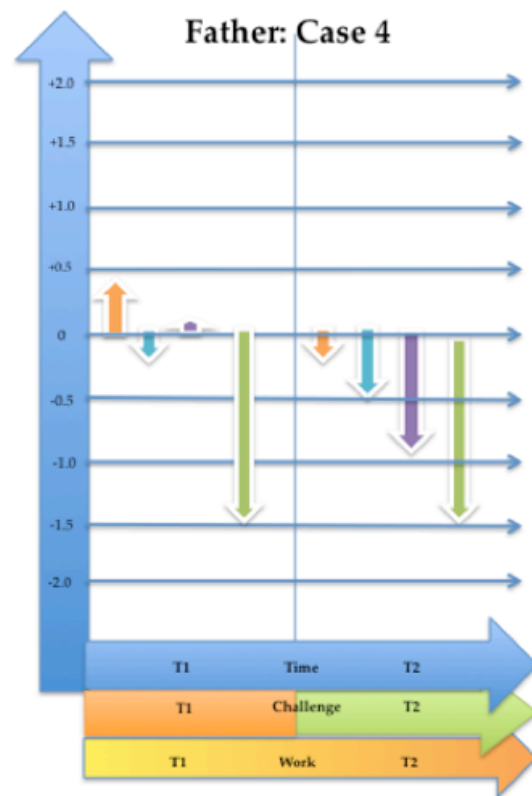
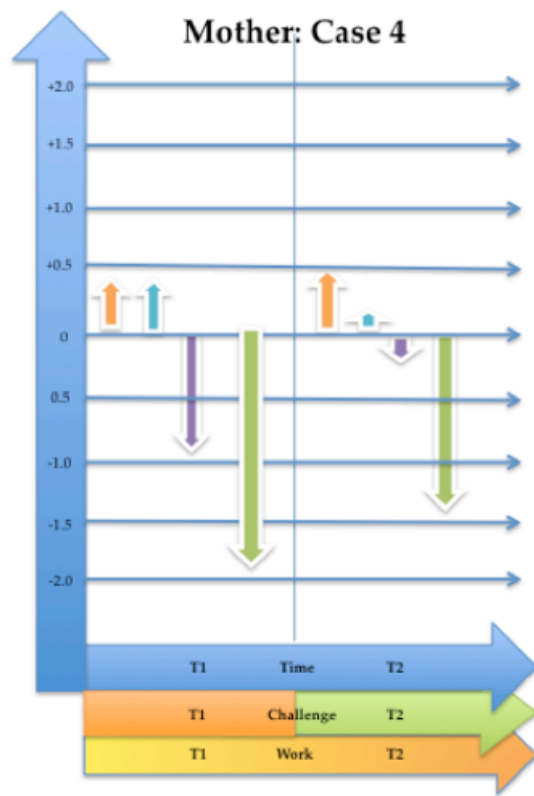
■ = PROMIS\_Sleep

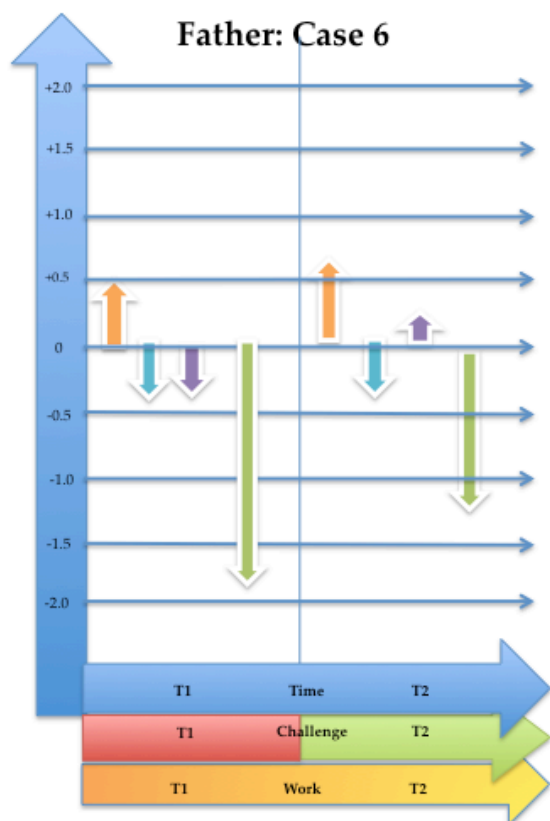
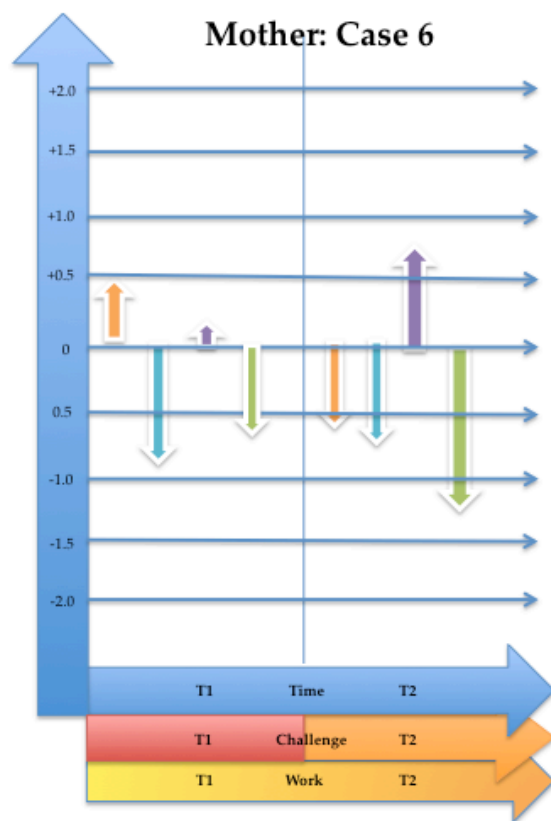
■ = PROMIS\_Social

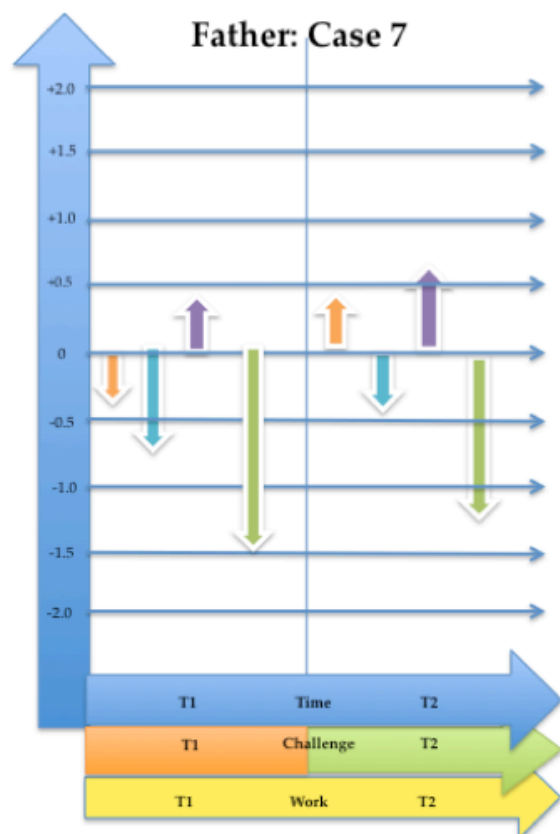
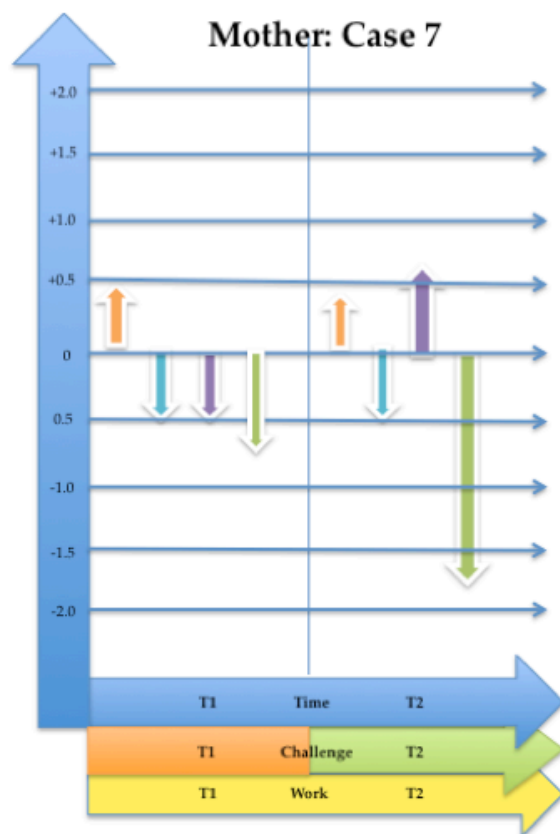
Y Axis: Standard Deviation

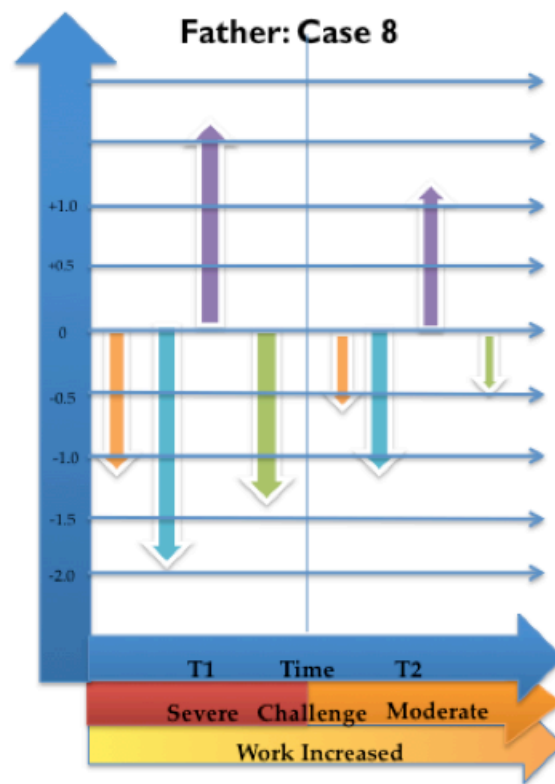
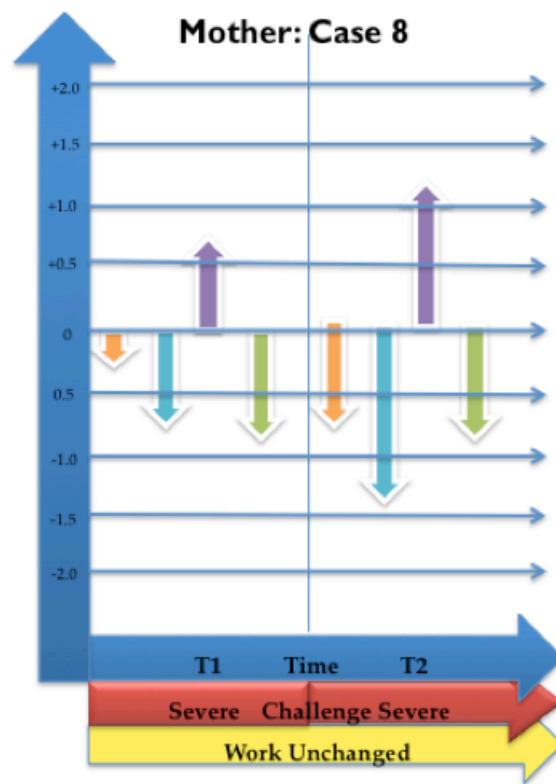












## Appendix L

### *Raw Score Conversion Tables*

<b>Satisfaction with Participation in Social Roles 8a</b> <i>Short Form Conversion Table</i>		
Raw Score	T-score	SE*
8	26.9	4.1
9	30.8	2.5
10	32.5	2.1
11	33.8	1.9
12	34.9	1.8
13	35.8	1.7
14	36.7	1.7
15	37.5	1.6
16	38.3	1.6
17	39.1	1.6
18	39.9	1.6
19	40.6	1.6
20	41.4	1.6
21	42.2	1.7
22	43.0	1.7
23	43.9	1.7
24	44.7	1.7
25	45.5	1.7
26	46.4	1.7
27	47.3	1.7
28	48.2	1.7
29	49.1	1.7
30	50.0	1.7
31	51.0	1.7
32	52.0	1.7
33	53.0	1.7
34	54.0	1.7
35	55.1	1.7
36	56.2	1.8
37	57.4	1.9
38	58.9	2.2
39	61.0	2.7
40	66.1	4.9

\*SE = Standard Error



<b>Sleep-Related Impairment 8a</b> <i>Short Form Conversion Table</i>		
<b>Raw Score</b>	<b>T-score</b>	<b>SE*</b>
8	30.0	5.4
9	35.1	4.6
10	38.7	4.2
11	41.4	3.8
12	43.6	3.6
13	45.5	3.4
14	47.3	3.1
15	48.9	2.9
16	50.3	2.7
17	51.6	2.6
18	52.9	2.6
19	54.0	2.5
20	55.1	2.5
21	56.1	2.5
22	57.2	2.5
23	58.2	2.4
24	59.3	2.4
25	60.3	2.4
26	61.3	2.4
27	62.3	2.3
28	63.3	2.3
29	64.3	2.3
30	65.3	2.3
31	66.3	2.3
32	67.3	2.3
33	68.4	2.3
34	69.5	2.4
35	70.7	2.4
36	71.9	2.5
37	73.3	2.6
38	75.0	2.8
39	76.9	3.1
40	80.0	3.9

\*SE = Standard Error on T-score metric

<b>Physical</b>		
<i>Short Form Conversion Table</i>		
<b>Raw.Score</b>	<b>T.Score</b>	<b>SE*</b>
4	16.2	4.8
5	19.9	4.7
6	23.5	4.5
7	26.7	4.3
8	29.6	4.2
9	32.4	4.2
10	34.9	4.1
11	37.4	4.1
12	39.8	4.1
13	42.3	4.2
14	44.9	4.3
15	47.7	4.4
16	50.8	4.6
17	54.1	4.7
18	57.7	4.9
19	61.9	5.2
20	67.7	5.9

\*SE = Standard Error

<b>Mental</b>		
<i>Short Form Conversion Table</i>		
<b>Raw.Score</b>	<b>T.Score</b>	<b>SE*</b>
4	21.2	4.6
5	25.1	4.1
6	28.4	3.9
7	31.3	3.7
8	33.8	3.7
9	36.3	3.7
10	38.8	3.6
11	41.1	3.6
12	43.5	3.6
13	45.8	3.6
14	48.3	3.7
15	50.8	3.7
16	53.3	3.7
17	56.0	3.8
18	59.0	3.9
19	62.5	4.2
20	67.6	5.3

\*SE = Standard Error

<http://nihpromis.org/measures/domainframework3>

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## Biography

The overarching purpose of my pursuit of a PhD was to develop the knowledge and skills necessary to launch a successful career as a nurse researcher. Through this role I want contribute to advancement of the field of nursing research and education in a complex environment. My research interests are focused in the area of the palliative, end of life, and bereavement care with the aim to develop interventions tailored to address the individual circumstances and cultural nuances of parents of children with chronic illnesses with a goal to improve health outcomes of the parents and the family.

My previous work experience in nursing includes both experiences in the United States and internationally (India and Oman). This experience has allowed me to gain an understanding of cultural differences among individuals. I have nursing experience caring for adults and children in medical surgical units. Before joining the PhD program at Duke, I was a nursing faculty member for 5 years. I have taught fundamentals of nursing, adult health, pediatric nursing, and pharmacology. During this time I developed a clinical work tool (teaching strategy) for senior nursing students. I conducted evaluation research to assess the tool's effectiveness and presented this research at the National Black Nurses Association meeting in August 2010. My interest in a research career stems not only from my master's research, but also from the personal experience of loss.

I have focused my area of interest on understanding the trajectories of challenges grieving parents face during their bereavement period and the confluence of these challenges with several health risk indicators. In summary my strong international clinical and teaching experiences have laid a solid foundation upon which to build my research skills. I intend to maintain my relationship with my mentors to further develop my research skills and progress in my career path. My academic record and personal history reflect my conscientiousness, determination, and ability to master course work and pursue my career in nursing research.