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Bereavement and Parents Who Have Experienced the Sudden Death of a Child

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Walden University

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Thomas Fulbrook

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Walden University
2015

Abstract

Bereavement and Parents Who Have Experienced the Sudden Death of a Child

by

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BSW, University of Nevada, Las Vegas, 2003

MSW, University of Nevada, Las Vegas, 2006

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Health Psychology

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Abstract

In studies, grief due to the loss of a child is recognized as a complex process, one whose trajectory is influenced by a variety of factors. One factor, the age of the child at the time of death, may be an important influence in the trajectory of grief. The purpose of this interpretive phenomenological study was to explore the experiences of loss for 15 bereaved mothers and fathers whose children suddenly died between the ages of 2 and 12 years. This age range was selected to explore bereavement in parents of young and preteen children because they may feel a greater sense of daily care and responsibility for the safety of their children in comparison to bereaved mothers and fathers of older children or adults. The psychosocial transition theory was used to develop the research questions, which framed the exploration of the experiences and adaptive responses of the parent participants. There were 15 recorded semistructured interviews from which the data were collected. The transcribed data were validated with member checking. Data analysis was completed using open and hierarchical coding to identify meanings and recurrent themes in the participant narratives. Recurrent themes included that grieving was emotional and physical for these parents, and that grief made it difficult for them to do everyday tasks or care for surviving children. Mothers and fathers identified viewing their world as less safe and experienced a reevaluation or complete abandonment of their spiritual beliefs. Implications for positive social change include increasing social awareness in the general public about grief due to child death and challenging unrealistic expectations of grief trajectory. Furthermore, the findings of this study may be used by mental health professionals to create interventions specific to this type of loss.

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Dedication

I dedicate this study to my daughter Adasha who left us too soon and will forever live in our hearts. I also dedicate this work to my incredibly supportive wife Pam, my parents Marie and Edward, and children Brian, Brandon, and Tammy. Their love, inspiration, encouragement, and understanding, empowered me to complete this research. They were truly the driving force behind my ambition.

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Chapter 1

Introduction

The death of a child is often described as a parent's worst fear. Parents who lose a child must navigate the devastation, and find new ways of coping and adapting to an event that is viewed as outside of the natural order of life. The bereaved parents must also come to terms with their unmet hopes and expectations for the future (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012). These experiences are more intense when a death is sudden and unexpected.

Bereaved parents may experience feelings of isolation because of stigmatization or the inability of family and friends to listen and be present with the bereaved. This may frustrate parents as they attempt to maintain a connection with their deceased children through their memories and sharing of individual stories (Hunt & Greeff, 2011). My focus in this study included children who have died suddenly during the developmental stages, ages 2 through 12 years, in which parents feel that their primary responsibility is to ensure the safety of their child. These developmental stages occur prior to the increased autonomy witnessed as children move into adolescence. My omission of children younger than 2 years, excludes sudden infant death syndrome (SIDS) and sleep-related disorders that are already prominent in the current body of literature (Finlay & Kruegar, 2011; Lawrence, 2010; Warland, O'Leary, McCutcheon, & Williamson, 2011). In relationship to coping styles, Harper et al. (2011) found that the trajectory of grieving due to the death of a child, may be influenced by the time since the loss occurred and the age of the child at the time of death.

In this chapter, I explored the existing literature related to parental bereavement. In each study, I considered the specific variables identified as important areas of focus. I also explored parental bereavement as a complex phenomenon that is individually unique and requires an adaptive process. This included previously identified gaps in the literature, such as the loss of an only child, sudden infant death, death due to illness such as cancer, the role of support for extended family members, and the absence of studies in the subpopulation of bereaved parents identified by this study.

Background

The complexity and trajectory of grief from child death is subject to a myriad of variables. These variables include the age of the child at the time of death, unrealistic social expectations, and the lack of social support. These factors may exacerbate the grieving experiences of bereaved parents and intensify suffering. The loss of someone who creates a specific role identity, such as being a parent, may also increase the suffering associated with bereavement (Meert et al., 2011).

In this study, I explored the experiences of bereaved parents. Although existing literature does not focus on the subgroup of bereaved parents identified for this study, this gap is not the only justification for this research. Children between the ages of 2 and 12 years at the time of death have not reached a developmental state of individuation witnessed in adolescence. For children who have not begun to separate from their caregivers, parents may expect to have a great deal of control over their child's behaviors and safety. This sense of control may result in bereaved parents' experiencing strong feelings of guilt regarding the death of their child. Such feelings may influence the

trajectory of bereavement in this group. Parents who perceive that they failed to maintain the safety of their child, may experience increased pain and suffering related to grief.

The unexpected death of a child that occurs beyond the age associated with child mortality risk factors, such as SIDS, may also affect the grieving experiences of the bereaved. Exploring the lived experiences of this identified group of bereaved parents may uncover unique factors not found in more generalized studies, and was consistent with the objectives of this study. This in-depth exploration is also consistent with the purpose of other qualitative studies that explore parental bereavement (Hunt & Greeff, 2011; Parker, 2011; Umphrey & Cacciatore, 2011).

The consequences of persistent feelings of distress, emotional numbness, and yearnings for the lost child, may indicate the onset of the pathology associated with complicated grief (Meert et al., 2011; Simon et al., 2011). These emotional experiences may impair the individual's ability to process the reality of his or her loss. The sudden severing of the parent-child bond may also result in a loss of identity, as parents may feel significant loss of one's self or a part of one's self (Giannini, 2011).

The importance and influence of family support on the trajectory of bereavement as part of the lived experiences of bereaved parents, is well established in parental bereavement studies (Alam et al., 2012; McBride & Toller, 2011). Although the availability of family support is essential for bereaved parents, the devastation of sudden child loss can affect both nuclear and extended family members. Extended family members, such as grandparents, may rally to provide support for their adult children while processing their own feelings of loss (Gilrane-McGarry & O'Grady, 2011).

Grandparents will often put their own needs for support aside while being present with their children, even though they are experiencing their own disbelief and sense of loss from the death of their grandchildren. The willingness of grandparents to recognize the loss and be present with the bereaved, despite their own grieving experiences, is most helpful at such times. Researchers acknowledge that this support is crucial, especially during the early period of loss and the onset of the grieving process (Gilrane-McGarry & O'Grady, 2011).

Family history also determines how families respond to the sudden death of a child. This history includes the quality of relationships prior to the loss and established family norms of how feelings are shared. These established grief related norms are modeled in the family and then passed on through subsequent generations. Family history, norms, and expectations are significant when other incidents of child loss occur within a family (Anderson, 2010).

The existence of other children in the home may influence the trajectory of parental bereavement. Continuing to care for other children after the loss of a child, maintains the role of parents as caregivers. Preserving this identity can help parents mitigate the intensity of parental bereavement (Meert et al., 2011). The relationship between parents and remaining children may become negative as grieving parents may become emotionally unavailable to their children (Harper, O'Connor, Dickson, & O'Carroll, 2011). Parents often seek to establish a spiritual connection with their deceased child as an adaptive response to child loss, while renegotiating their relationships with social networks and surviving children (Ungureanu and Sandberg,

2010). As previously noted, caring for other children helps maintain the role identity of parents; however, the presence of surviving siblings does not necessarily mitigate the risks associated with the onset of pathology or complicated grief responses (Meert et al., 2011).

The importance and effect of the availability of social support are prevalent themes in the parental bereavement research (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2009; Cacciatore & Flint, 2012; McBride & Toller, 2011). Bereavement takes place in interpersonal, social, and cultural contexts. The unique factors that constitute the social settings in which bereavement takes place, both influence and are influenced by the social interactions of the bereaved (Cacciatore & Flint, 2012).

Another factor that may influence the trajectory of parental bereavement, is the expectations of others in the individual's social circle. Such expectations may include the willingness of the bereaved to accept social support, beliefs regarding how long grief may continue, gender variations in the expression of grief, and how grief is expressed publically (McBride & Toller, 2011). When the bereaved perceive that social expectations are unrealistic or unhelpful, they may believe that others are unwilling to listen to their experiences and are unsupportive. As a result, bereaved parents may view their social networks as unsafe or judgmental. Social cues that discourage open sharing and expression of their grief, may result in the bereaved feeling ostracized, thus increasing the likelihood of social isolation and a reluctance to reach out for support. A sense of aloneness and frustration that others will simply not understand their needs, may

have a negative influence on how bereaved parents come to terms with their loss (McBride & Toller, 2011).

Social expectations of bereavement due to child death, may also include the appropriate length of time during which parents may grieve. Social expectations of a specific timeline in which the grieving process will begin and end, may further frustrate the bereaved as they attempt to adapt to their loss. Perceptions that social beliefs and expectations are rigid or inflexible may also limit the availability of social support when it is most needed (McBride & Toller, 2011). These expectations may influence the extent to which parents believe they have social permission to express their grief openly.

As outlined in this introduction, many contributing factors influence and are influenced by the trajectory of parental bereavement. The identification of such factors is complicated by the scarcity of recent parental bereavement research (Harper et al., 2011). Generalizations, such as the age of the child at the time of death, may fail to represent the nuances of grief for this identified subpopulation of bereaved parents. This study contrasts with other research that generalizes the age of the child when considering potential influences related to the trajectory of grieving for bereaved parents (Cacciatore & Flint, 2012; Breen and O'Connor, 2011).

Problem Statement

Parents who have experienced the death of a child must come to terms with a reality for which they are ill prepared, in part, due to a lack of social dialogue and information. The focus of much of the existing parental bereavement research literature includes the experiences of bereaved parents by including the death of a child who was in

utero to 18 years and older (Essakow & Miller, 2013; McBride & Toller, 2011; Titus & de Souza, 2011). This generalization, found in many of the existing studies, fails to recognize the complexity and nuances of parental bereavement and the significance of the child's age at the time of death. The problem addressed by this study is representative of the broad scope of ages found in previous parental bereavement studies. This is fundamentally how the concept of *child* is defined in the research and may lead to generalizations related to bereavement due to child loss. Toward the end of presenting clarity, I have explored a subpopulation of grieving parents whose children have died suddenly and were between the ages of 2 and 12 years.

Exploring the lived experiences of the bereaved, uncovered the individual, familial, and social factors that influence the trajectory of bereavement from child loss. In the existing research related to child death, *child* is often defined as in utero to 18 years and older at the time of death (Essakow & Miller, 2013; McBride & Toller, 2011; Titus & de Souza, 2011). The sample participants for this study represented bereaved parents whose deceased children were between the ages of 2 and 12 years at the time of death. The rationale for narrowing the selection criteria, related to the age of the deceased children, allowed for exploring a subset of bereaved parents who do not typically have a voice in the research literature. This addresses the previously identified gap in the literature. A child typically does not achieve independence from his or her primary caregivers at age 12 years. Selection beginning at the age of 2 years excludes causes of death related in in utero loss and SIDS, which is well represented in the body of literature.

Expanding the subjective experiences of this subpopulation of bereaved parents provided an opportunity, through which, I identified the lived experiences and potential needs of these grieving parents. Greater social awareness related to this specific type of loss may also improve the availability of support for the bereaved. A further delineation of the deceased child's age at the time of death, allows for exploring theories in future research specific to this subpopulation of bereaved parents.

It is difficult to establish a consensus regarding the significance or need for this study. This is due to the absence of existing literature that specifically addresses the age of the child at the time of death. As frequently observed in other studies, the range of ages for the decedents was broader in scope.

Purpose of the Study

The purpose of this phenomenological study was to uncover the subjective experiences of a subgroup of bereaved parents, whose children between the ages of 2 and 12 years, suddenly died. I gained insight into this specific type of loss through exploration, documentation, and analysis of the subjective experiences of bereaved parents. The information I obtained from their documented experiences, including audio recordings and interview transcripts, addressed a gap in the current research that does not traditionally focus on this subgroup of bereaved parents. In addition, I identified the individual, familial, and social aspects of parental bereavement for the identified group.

Research Questions

I framed this study with the following research questions:

1. What were the initial experiences of parents who lost their child?

2. What are the familial experiences of bereaved parents selected for this study?
3. What are the social experiences of bereaved parents selected for this study?
4. How did parents respond to their loss in an attempt to adapt to a new reality?

Theoretical Foundation

Early life experiences and attachments establish internal working models or schemata that frame ones' world, including strategies to cope with tragedy. These worldviews can be extremely resistant to restructuring and challenge. The experience of trauma or sudden loss can shatter established worldviews (Hibberd, 2013).

This shattering of one's sense of reality may be explored within the theoretical constructs of grief and bereavement for parents who have experienced the sudden death of a child. These experiences include the recognition of the grieving process while exploring the parents' subjective experiences of grief. Parkes (1988) explored grief work as an adaptive process and developed psychosocial transition theory. In this theory, grief is framed as a complex process that includes both physical and psychological components. The work of Kubler-Ross (1973) was a significant contribution to thanatology research. However, Kubler-Ross expanded on how the dying came to terms with their impending death and not the experiences of the bereaved. The frame of this study reflects postloss adaptation of the bereaved, which is better represented by the work of Parkes (1988). This theory posits that individuals establish internal working models of their world. These beliefs are resistant to change and establish a foundation for coping with difficult situations. Bereavement because of sudden child loss, shatters the individual's worldview without warning or opportunity to prepare emotionally. As a

result, bereavement includes the necessity to restructure or change existing beliefs as a process of transition and adaptation (Parkes, 1988). This process is consistent with the loss of a child, especially at a developmental stages in which sudden death is unexpected.

Nature of the Study

The selected research methodology for this study was a phenomenological model. As an inductive method of inquiry (Creswell, 2012), this methodology was consistent with the objectives of this study to explore the lived experiences of the bereaved parents selected for participation. This exploration was based on a constructivist paradigm and facilitated through the analysis of individual narratives, recorded during the data collection process. The meanings associated with the respondent's experiences are often varied, complex, and guided by the individual's social experiences and interactions (Gilrane-McGarry et al., 2011). This study fit well with phenomenological methods as the experiences of the participants were captured within the context of their stories and recollections. Exploring the narratives for the participants allowed for an unbiased, in-depth exploration of their subjective and unique experiences (Creswell, 2012).

In qualitative studies, researchers also seek to identify emerging themes and develop meanings related to human experiences (Creswell, 2012). The use of a qualitative methodology facilitated the exploration of the experiences of bereaved parents while providing an opportunity to give them a voice in the literature (Willig, 2013). A qualitative approach was a good fit for the present study due to the lack of available information regarding this subpopulation of bereaved parents.

Researchers who explore the experiences of bereaved parents, often include as their selection criteria, parents whose deceased children range in age from in utero to 18 years or older (Harper et al., 2011; Lichtenthal, Currier, Neimeyer, & Keesee, 2010). In this phenomenological study, an in-depth understanding of the lived experiences of bereaved parents was sought in a specific subset of parents who experienced the sudden death of their child. More specifically, the focus of this study included bereaved parents who experienced the sudden death of a child who was between the ages of 2 and 12 years at the time of death. The criteria for participant selection intentionally omitted other subgroups of bereaved parents, such as early infant and adolescent deaths, already a focus in other studies (Finlay & Kruegar, 2011; Meert et al., 2011; Lawrence, 2010). Narrowing the selection criteria allowed for the exploration of a subset of bereaved parents who do not typically have a voice in the research literature. The selected cutoff age of 12 years is typically before independence is achieved from the child's primary caregivers.

The geographic location for this study included the continental United States. Initially a sample size of 10 participants was recruited for this study; however, a total of 15 respondents were necessary to achieve saturation of the data categories. Theoretical saturation will occur when recurrent patterns are consistent within the data and sampling saturation will reflect when participant responses are consistent (Omar, Hamid, Alias, & Islam, 2010).

The individual, familial, and social realities of the participants was explored through individual interviews. Respondents related their grief experiences through

semistructured interviews and personal narratives, beginning at the time of their loss. I categorized the collected data to identify specific themes, followed by a summation of the participants' unique and shared experiences.

I utilized the research and interview questions outlined in Chapter 3, to guide the exploration of the factors that influence and are influenced by the grieving process for this subpopulation of bereaved parents. I uncovered the subjective experiences of the participants through the interview questions. I also utilized the semistructured participant interviews to examine aspects of this type of loss.

Finally, exploring the experiences of this selected population of bereaved parents, provided an opportunity to examine the effect of child loss on the parents and their families. This included the opportunity to explore the needs of these families, while discovering what was most helpful. The complex nature of parental bereavement for the population selected for this study, included the co-occurrence of individual crisis and the shared experience of grief as a family (Essakow & Miller, 2013).

Data analysis was based on the transcripts of the participant responses and was facilitated through an interpretive phenomenological approach. The objective of the analysis included identification and categorization of key terms and phrases that are shared within the transcripts. This discovery process is discussed in detail in Chapter 3.

Definitions

Bereavement: Bereavement is the phenomenon or state of being, associated with experiencing a loss. Traditionally, this state resolves over time without intervention (Buglass, 2010).

Child: For the purposes of this study, child will be defined as an individual who is between the ages of 2 and 12 years.

Complicated grief: This phenomenon, as experienced by bereaved individuals, represents an extended period of grieving in which the griever is unable to adapt to his or her loss. This experience must persist for at least 6 months and cause impairment in a number of domains, such as social or occupational settings. Four out of eight symptoms must be identified for the following: difficulty accepting, lack of trust, excessive anger, feeling stuck, dissociated sense of numbness, feelings that life is meaningless, irritability, and sense of diminished future (Drenth, Herbst, & Strydom, 2010; Nagraj & Barclay, 2009).

Extended family: For the purpose of this study, extended family will be defined as family members who do not consist of parental figures and their children.

Grief: Grief is the emotional and somatic experiences associated with loss (Graneek, 2010).

Grief-related pathology: Grief-related pathology is an experience that represents a nonadaptive, intense, and extended period of grieving and includes psychological or physical manifestations (Rando et. al., 2012).

Nuclear family: For the purpose of this study, a nuclear family includes parents and their children (Flores & Dowell, 2010).

Paired partners: For the purpose of this study, paired partners are defined as two individuals who mutually agree to raise a child.

Sudden child death: For the purposes of this study, is defined as the unexpected and sudden loss of a child because of accidental or other causes.

Symbolic interactionism: This theory identifies human experiences as subjective, derived from social interaction and language (McCreddie & Payne, 2010).

Thanatology: Thanatology is the field of study and clinical practice that explores the experiences of death, dying, and bereavement (Fonseca & Testoni, 2011).

Assumptions

Assumptions included the facts that the participants are representative of the general population, reliable historians, and capable of accurately recalling the events and emotions of their loss at the time the death occurred. Another assumption was that the volunteer participants were truthful in their responses to the interview questions. The contributions of this study also depend on the assumption that I, as the primary data collection instrument, recorded and reported the data accurately. I assumed that the transcriptionist accurately reproduce the interview transcripts of the respondents. The significance of these assumptions reflects directly upon the accurate reporting and validity of the data, obtained from the research questions. This includes my objectivity as the primary data collection instrument. The absence of these assumptions and care to ensure careful data collection, may call into question the relevance and value related to the findings of this study.

Scope and Delimitations

The research problem addressed by this study focused on the lived experiences of a subpopulation of bereaved parents and documented their individual narratives. These

narratives included the individual, shared partner, familial, and social experiences of the bereaved through transcript analysis of telephonic interviews with the participants. This focus was identified as a gap in the current literature, resulting in this subpopulation of bereaved parents who lack a voice in the body of research. The scope of this study included bereaved parents whose child died suddenly and was between the ages of 2 and 12 at the time of death. All participants were at least 2 years beyond the date of their child's death. Parkes' (1988) work, which represents psychosocial transition theory, was used to frame this study, and other theories were not included. These theories included stage-based theories, such as Kubler-Ross (1973), and attachment theory, such as Bowlby (2005). Because of the specific nature and focus of this study, the results may not be transferrable to child death in other subpopulations of bereaved parents.

Limitations

Study limitations reflects the narrow scope of this study, which includes participants who are a parent(s) and paired partner(s) whose children, between the ages of 2 and 12 years have suddenly died. All participants were at least 2 years after the loss of their child. Limitations also include the participant sample size, initially set at 10 participants, and specific focus regarding the type of loss explored. Study participant exclusionary criteria further limit the study to parents of children who suddenly died and did not include death from prolonged illness. Potential study participants who had a professional or social relationship with the primary researcher were disqualified from the study.

The patterns that were discovered within the research results may not be generalizable to broader population because of the small sample size. The identified themes that emerged from the data may not generalize to other types of loss. Because of the potential shock associated with the experiences of child loss, memories of the event as related by the participants, may be inaccurate. Potential biases included my own experiences regarding the loss of a child and preconceived expectations of study outcomes and participant responses. These potential biases will be addressed by member checking described further in Chapter 3.

Significance

The significance of this study is framed within its unique focus of the selected participants, a subpopulation of bereaved parents who are not traditionally the focus of existing parental bereavement studies. Exploring the experiences of the selected population provided an opportunity for increasing awareness of the nuances of their lived grief experiences. The goal of this research was to uncover the uniqueness and nuances of the population of bereaved parents included in this study.

Documenting and reporting the lived experiences of the study participants, may challenge existing biases and presuppositions of bereavement due to child loss. Such perceptions may influence the availability of social support and social awareness for the bereaved. As discussed further in subsequent chapters, exploring the nuances of their loss may increase social support and contribute to developing specific loss related interventions. Advancing social awareness related to this type of loss may help to reduce feelings of social isolation for this subpopulation of bereaved parents.

Providing the research participants with a voice in the academic literature, addressed the underrepresentation of this subgroup of bereaved parents while focusing on underlying factors related to their grief experiences. The participants shared their individual experiences by relating their grief stories and the uniqueness of their beloved children. The stories and experiences of participants can communicate to other parents, that they are not alone in their grief. Indirectly, the respondents will provide support for others who are also grieving, by relating their own experiences.

Professional Application

The exploratory nature of this research may identify and direct loss-specific interventions for the bereaved. Supportive services should target specific vulnerabilities and difficulties related to griever, as specific factors may influence the trajectory of grieving (Breen & O'Connor, 2011). Such interventions may help grievers to avoid maladaptive grief responses that may increase levels of psychological, social, and physical impairment (Warland, et al., 2011). These interventions will be framed by what is found to be most helpful for this subpopulation of bereaved parents.

This research may also increase understanding of a group of bereaved parents, who are not well represented in the current literature. The outcome of this increased knowledge may help professionals, who provide services to this population, by increasing their understanding of the specific vulnerabilities for this group. This increased understanding may help professionals when completing assessments and developing treatment plans for parents who have experienced the loss of a child.

Positive Social Change

Grieving individuals may find themselves vulnerable to physical and mental health issues and subject to a number of stereotypes, social expectations, and generalizations of how their grief should be experienced and expressed (Breen & O'Connor, 2011; Cacciatore, Lacasse, Lietz, & McPherson, 2013). Increasing social awareness of bereavement within this specific subpopulation of bereaved parents, may help to dispel unrealistic social expectations of the trajectory of child loss. Increasing insight into the nuances of loss for the selected participants in this study, can help to lend meaning and understanding to those who are grieving the loss of a child within the age group identified by this study.

Summary

In Chapter 1 of this research project, the subjective experiences of bereaved parents were explored as a complex phenomenon that includes many potential variables (Thompson et al., 2011). Exploring this phenomenon included the identification of a subgroup of bereaved parents, who are underrepresented in bereavement studies and not the focus of current research. The identified gap in the literature relates to child loss studies that traditionally include bereaved parents whose children were in utero to age 18 years at the time of their death (Essakow & Miller, 2013; McBride & Toller, 2011; Titus & de Souza, 2011). Representative of the problem statement and research questions, this study seeks to explore the individual, familial, social, and adaptation to grief for bereaved parents without assuming that all child loss represents a homogeneous experience regardless of the age of the child. The qualitative methodology selected for this study

allowed for the exploration of the lived experiences of the bereaved, through in-depth narratives.

In Chapter 2, I included a review of the relevant literature that outlines sudden child loss from a variety of perspectives and theories. I also included the potential psychological and physiological consequences of nonadaptive grief. Finally, I have discussed the significance of familial and social factors that may influence the trajectory of parental bereavement.

Chapter 2

Introduction

The problem I addressed with this research relates to the gap in the current literature regarding a specific subpopulation of bereaved parents. This subpopulation includes parents whose child has suddenly died and was between the ages of 2 and 12 years at the time of death. I documented the experiences of the bereaved through their individual narratives.

In this review, I explored the potential variables that influence the trajectory of parental bereavement, within the context of the existing literature. The theoretical foundation for this study included the work of Parkes (1988), such as psychosocial transition theory. The scope of this literature review explored parental bereavement from various perspectives, such as social, familial, psychological, and physiological points of view.

Literature Search Strategy

The search strategy for this literature review was comprised of journal articles in the academic databases of Pubmed, PsychInfo, PsychArticles, PsychExtra, Psychology: A SAGE Full-Text Collection, SocIndex with Full Text, and Academic Search Complete. Keywords I used in the database searches included *historical perspective and grief*, *history and grief*, *grief and pathology*, *parental grief*, *complicated grief*, *complicated grief and couples*, *historical and bereavement*, *child death and qualitative*, *parental bereavement*, *gender*, and *child loss*. In my comprehensive and systematic search, I

identified various theories, gap in the current literature and need for an exploratory study of the subjective experiences of this subpopulation of bereaved parents.

Theoretical Foundation

Early life experiences and attachments establish internal working models or schemata that frame one's world and help create strategies to cope with tragedy. These worldviews can be resistant to restructuring and challenge. The experience of trauma or sudden loss can shatter established worldviews or reinforce negative worldviews, further complicating adaption to loss (Gerrish et al., 2014).

This shattering of one's sense of reality may be explored in the theoretical constructs of grief and bereavement for parents who have experienced the sudden death of a child. These experiences include recognizing the grieving process while exploring the parents' subjective experiences of grief. Parkes (1998) explored grief work as an adaptive process, reflective of psychosocial transition theory. In this theory, grief is framed as a complex process that includes both physical and psychological components. Other theorists such as Kubler-Ross (1973) made significant contributions to thanatology research; however, Kubler-Ross's work expanded on how the dying came to terms with their own demise and not the experiences of the bereaved. The frame of this study is more reflective of postloss adaptation of the bereaved and is better represented by the work of Parkes (1988). Parkes posited that individuals establish internal working models of their world. As previously noted, these beliefs are resistant to change and establish a foundation for coping with difficult situations.

Bereavement from sudden child loss shatters the individual's worldview without warning or opportunity to prepare emotionally. As a result, bereavement includes the need to restructure or change existing beliefs as a process of transition and adaptation (Parkes, 1988). This process is consistent with the loss of a child, especially when the child is at a developmental stage in which death is unexpected. Bereavement is a process that requires reinterpreting life meanings and continues throughout the remainder of the parent's life. These meanings included attempts to make sense of the loss of their child (Lichtenthal et al., 2010). I applied psychosocial transition theory to other bereavement studies on the adaptive response of the bereaved, as they face a shattered reality of their assumptive world. In this study, the research questions were based on psychosocial transition theory by exploring the lived experiences of the bereaved. In addition, considering that all participants were at least 2 years beyond the loss of their child, I explored their attempts to adapt to the loss.

Literature Review: The Experience of Child Loss

The loss of a loved one is an inevitable experience, especially in later life stages. Experiencing loss is a culturally universal; however, the expression and experience of grief is complex and often misunderstood. Attempts to capture the many variables to develop meaning and understanding, reflect the various theories that provide a conceptual framework. These theories, which occupy their respective places within the academic literature, were conceived by scholars to understand the complexity of the subjective experiences of grief. Such theories include the classic works of Freud (1961), Bowlby (2005), Kubler-Ross (1973), and Parkes (1988).

Modernism

The late 19th and early 20th centuries ushered in a period of increased personal mobility, interest in technology, and beliefs in science. As extended families became more geographically distant, support for grief came from professionals or experts in the field of psychiatry or medicine, who understood bereavement. This shift moved grief from a public to a private experience and, as a result, unfamiliarity with how to socially respond and support those who were grieving (Walter, 2007). Grieving became socially recognized as a problematic experience that interfered with productivity and one that must be resolved quickly. The results of this paradigm shift were the myriad of grief theories that sought to bring understanding to the process of grieving and the experience of loss (Walter, 2007).

The influences of modernism also framed grief as a goal-oriented process in which individuals experience a full recovery from the pangs of loss and a general expectation that life, after experiencing grief, would return to a state of preloss normality. This modernist view of grieving also proffered a release from attachment with the deceased loved one to return to a preloss state of functioning (Stroebe, Gergen, Gergen, & Stroebe, 1992; Walter, 2007).

The work of Parkes (1988) reflects a modernist paradigm and relies on empirical data to explore the phenomenon of grief. Psychiatry is a valuable resource in identifying effective treatment when *grief* is defined as an affliction. This scientific approach to exploring the variables, which include the social realities and cultural constructs of

bereavement, represents a more complex view of the phenomenon of grief and bereavement (Stroebe et al., 1992).

Stage-Based Theories

Stage-based theories create an organized framework within which grief has a well-defined beginning and end. This framework infers predictability and expectations for the bereaved regarding their grieving experiences. Stage-based models conceptualized grief through a framework from which to explore normal versus abnormal grieving (Maciejewski, Zhang, Block, & Prigerson, 2007). Grief responses that do not fit this model, such as those found in complicated grief, may be identified and treated (Maciejewski et al., 2007). Stage-based frameworks may provide solace for those thrust into the uncharted water of grief. However, they may also deny the uniqueness of individual aspects of loss (Buglass, 2010).

One example of a stage-based theory is the work of Kubler-Ross (1973), who explored and documented the experiences of more than 200 dying people. Kubler-Ross acknowledged a cultural unfamiliarity with death that occurred because of advancements in medicine that subsequently improved longevity. Her research focused on those who were dying and documented how they came to terms with the reality of their eminent death (Love, 2007). The experiences of the terminally ill participants were captured through their individual narratives, that were then communicated to Kubler-Ross and her students. Engaging the participants and exploring their responses expanded the body of knowledge regarding the lived experiences of dying patients (Kubler-Ross, 1973).

Kubler-Ross (1973) framed death as a natural experience in which the community and family actively participate. Through in-depth interviews, Kubler-Ross categorized the subjective experiences of her dying subjects into five specific stages. These transitional stages represent a linear progression from denial, anger, bargaining, depression, and finally acceptance (Kubler-Ross, 1973). The work of Kubler-Ross was a significant contribution to the study of thanatology; however, her results were limited to the experiences of those who were dying and not the bereaved survivors. As a result, this work does not provide an understanding of the subjective experiences of the bereaved (Love, 2007).

Bowlby (2005) also explored the significance of bereavement through attachment theory. The loss of attachment and release of relationships because of death, represents the human experience of the making and the breaking of affectional bonds. This severing of bonds, especially related to sudden loss, triggers an intense protest that is typically followed by attempts to regain the lost loved one in order to reproach him or her for his or her absence. Finally, bereaved individuals experience despair and a sense of disorientation because of the failed attempts to regain what is lost. Bowlby described the futile efforts of the griever to regain proximity with the lost loved one, as an experience that diminishes over time through a series of specific stages.

Bowlby's (2005) stages of grieving include a sense of numbness that may persist for several hours to several weeks. This numbness is followed by a yearning and searching for the lost loved one, often continuing for several months and up to several years. Finally, a sense of despair and disorganization is experienced, followed by an

eventual return to baseline levels of functioning. A failure to adapt to the loss and to navigate the grieving process successfully, is often identified as grief-related pathology (Bowlby, 2005).

Stage-based models also provide a sense of order at a time when order or normalcy is threatened (Cacciatore et al., 2013). Compartmentalizing grief into stages, provides both a framework and expectation of the trajectory of bereavement. The negative aspect of this framework includes the possibility of setting unrealistic expectations for the bereaved, which may result in increased social isolation for those whose grief does not fit a stage model. This may be indicative of the internal conflict between what is felt by the bereaved and the adaptation of a false persona due to social expectations (Breen & O'Connor, 2011).

Attachment styles also have a significant influence on the processing of and adaptation to loss. Styles that are problematic include avoidant and anxious attachments. Anxious attachment styles are evidenced by anxiety when faced with separations, lack of trust in self, intense emotional feelings, and a tendency to be overly attached or clingy in relationships. In opposition, avoidant attachment style is reflective of a distrust of others, extreme independence, and tendency to internalize or suppress feelings (Delespaulx, Ryckebosch-Dayez, Heeren, & Zech, 2013). Attachment styles, as explored by Van Der Houwen et al. (2010), represent other variables that potentially influence the adaptive ability of bereaved parents. Van Der Houwen et al. (2010) conducted a longitudinal study of 195 bereaved parents. Participants were surveyed three times during a 6-month period. A multivariate approach was utilized to explore multiple

outcomes related to grief, depression, and emotional loneliness in relationship to interpersonal, social environment, and bereavement related variables. As part of their study, interpersonal predictors were explored related to adult attachment. It was noted that in the category of interpersonal predictors, attachment avoidance was significantly related to the prediction of depressive symptoms, grief, and emotional loneliness.

Anxious attachment was noted to increase the prevalence of emotional loneliness and depressive symptoms. However, these relationships were not significant when explored within the context of social environmental predictors and bereavement related predictors.

Grief as Psychosocial Transition

Parkes (1988) recognized the variability in the grieving process. Bereavement causes individuals to question their assumptive world. This dissolution of the familiar and replacement with the unknown, may leave the bereaved feeling unsafe. Traditional coping skills, such as experiential avoidance or isolation, may initially reduce anxiety. However, the long-term results of these defense mechanisms may cause a delay in the adaptive process. This shattering of reality requires an adaptation to a new understanding of the world of the bereaved. The required process of rebuilding is a psychological and social experience in which the individual must engage as part of healthy grieving. Parkes identified and described transition as a journey through grief and recognized the significance of attachments, especially in circumstances such as the death of a child.

Parker and Dunn (2011) explored the lived experiences of six mothers who experienced the sudden death of their child and were participants in a previous study in 2001. Exploring their adaptive response to loss, participants discussed what behaviors

were helpful and unhelpful to coping with their grief. Participants were also asked if the passing of time had helped and if they were still actively grieving their loss. Six specific themes emerged from the data analysis. Mothers reported that it was important to be engaged in positive activities, both socially and in their solitary pursuits. Faith or spirituality were noted as a positive way of coping or adapting to their loss. Having faith included hopes that they would see or be reunited with their children one day. Consistent with maintaining emotional bonds with their deceased children, participants reported a sense of everlasting love that transcends death. Parents also noted that taking solace in pleasant or happy memories, was also a factor in adapting and coping. Finding a sense of significance in giving back or helping others, was a way to honor their deceased children while proving a positive way of coping. Mothers noted that maintaining a connection with their deceased child was accomplished by visiting the gravesite and performing maintenance tasks. Over time, mothers did not want to ruminate on the death itself or the events that led up to the loss of their child. As far as time since the loss, the mothers interviewed, expressed that time helped only because of their participation in things that were comforting. In general, there was a sense of acceptance of their loss.

Other theories that contrasted stage-based models, included the dual process model of grieving (Stroebe & Schut, 2010). The premise of this theory is that attempts to cope with loss by avoidance, may have both positive and negative results. Attempts to cope with loss involves alternating between two phases. These phases are indicative of loss orientation and restoration orientation, that is, both confronting and avoiding specific features related to the death, as bereaved individuals work towards adapting to the reality

of their loss (Worden, 2008). Failure to adapt, may leave individuals in a state of high arousal and vulnerable to physical illnesses (Worden, 2008). Prolonged grieving experiences, such as panic, exhaustion, or becoming overwhelmed, may threaten physical health. Other prolonged and persistent grieving experiences, such as intrusive memories of the deceased, may result in bereaved individuals becoming emotionally flooded (Worden, 2008).

Coping Strategies

Bereaved parents will regain balance when faced with their darkest hour, by relying on previously learned coping strategies. Reestablishing stability includes adapting to the reality of their loss. Within the framework of Parkes' (1988) psychosocial transition theory, in this section, I will explore how the bereaved adapt to the reality of their world, which has changed forever.

Parkes (1988) explained psychosocial transition theory as a process in which individuals must acknowledge a shattered worldview. Parkes's theory is consistent with experiencing a spiritual crisis in which a profound sense of loss reshapes the individual's worldview (Maple, Edwards, Minichiello, & Plummer, 2010). As bereaved parents attempt to understand the reality of child loss, the use of spiritual support may provide another effective coping strategy. One aspect of this support includes the comfort that the bereaved may find in the existence of an afterlife (Van Der Houwen, 2010). Faith in beliefs that are consistent with a variety of religions, may provide an ability to gain meaning out of a tragic event.

Hunt and Greeff (2011) explored parental bereavement using a qualitative methodology. The authors sought to identify the experiences of bereaved parents selected for participation in this study. One theme that emerged from the interviews and data analysis, was spirituality. Participant recruitment included a snowball sampling of middle income bereaved parents in Cape Town, South Africa. Recruitment resulted in a total of 22 participants who had lost children due to natural and accidental causes. The age of the children at the time of death ranged from newborns to young adults. Data collection was facilitated through face-to-face interviews with the participants, utilizing semistructured interviews. Emotionally, when anger or disappointment was identified, the feelings were focused on someone else. Such projections may include medical professionals and God. Behavioral reactions included the contexts of familial, relational and the acknowledgement of gender differences regarding how loss is expressed. One of the themes identified through the data analysis, included the participants' interest in the afterlife and the possibility of reuniting with their lost children. Spirituality was also noted as the respondents discussed their ability to forgive others who were responsible for the loss of their child, such as in the case of a child who was murdered. It is in the context of meaning making and adapting to the loss that spirituality may be viewed as part of a repertoire of coping skills that help to facilitate these processes.

Adaptation to loss is also consistent with factors that include individual optimism and hopes for the future. Optimism, as a coping strategy, is the acknowledgement and recognition of hope for the future (Harper, O'Connor, & O'Carroll, 2013). Harper et al. (2013) explored the lived experiences of 64 bereaved parents who were between 2 and 59

months postloss. One of the variables associated with exacerbated grief symptoms, included low levels of optimism. Other factors negatively correlated with higher levels of depression and exacerbated grief, included low levels of cognitive restructuring and poor problem focused coping.

Physiological Responses to Child Loss

Grief is often thought of as a psychological construct; however, the physical manifestation of bereavement can cause considerable pain and suffering for the bereaved. The physical or somatic experiences may accompany the psychological pain encountered by the bereaved. These somatic experiences are often expressed as physical pain associated with headaches and fatigue (Cacciatore et al., 2013).

Hunt and Greeff (2011) explored the lived experiences of 22 bereaved parents. As part of this qualitative study, bereaved parents, 18 female and 4 male, were recruited within the geographic area of Capetown, South Africa. The predominant ethnic makeup of the study was Caucasian ($n = 12$). The ages of the deceased children ranged from 3 years, 6 months to 9 years. Parents ranged in age from 30 to 63 years of age. The cause of death included both natural and nonnatural causes. Data was collected utilizing semistructured interviews that were later transcribed verbatim. The physical experiences associated with their grief was one of the significant themes identified in the coding of the data. The majority of participants reported physical experiences that were consistent with fatigue and intense pain that might be associated with a severe injury.

Cacciatore et al. (2013) explored the health, mental health, family functioning and resiliency of a sample of bereaved parents. Participants included 503 respondents who

were recruited from an online bereavement support resource. The majority of respondents were parents who had experienced the death of a child and the overwhelming majority of participants were Caucasian and female. In relationship to wellness, one third of the participants reported a decline in their physical health. A majority of the respondents noted weight gain. Issues related to poor self care, changes in diet, and not caring about their health, were indicative of the participants' responses. Other issues included high blood pressure, headaches, and problems that centered around the heart.

Complicated Grief

Grief is a normal reaction to experiencing a loss. Complicated grief is loss that deviates from traditional grief in duration or trajectory (Ghesquiere, 2014). This nonremitting or complicated grief is persistent, chronic, and does not result in adaptation to loss in the life of the bereaved. Often the bereaved experience a continued and persistent yearning for the deceased that results in intrusive thoughts or avoidance of reminders. These experiences may not abate with the passage of time thus leaving individuals feeling immobilized and stuck in their grief (Fujisawa et al., 2010).

Additional risk factors associated with complicated grief include sudden and unexpected loss and stigmatizing events, such as the cause of death from suicide. The subsequent onset of complicated grief in such instances may exacerbate depression and create a higher risk for posttraumatic stress disorder (Groos & Shakespeare-Finch, 2013).

Lichtenthal et al. (2010) explored the risk of complicated grief within the framework of meaning making for bereaved parents in a mixed methods study. The objective of the study was to explore how bereaved parents seek to establish meaning

after the loss of their child and to understand the grieving process of bereaved parents. Ninety-five bereaved parents volunteered to complete surveys. Participant demographics included an age range of 23 to 77 years. A majority (81%) of the participants were mothers, 91% were Caucasian, 4% were African American, and 3% Latino or biracial. The age of the child at the time of death was from age 0 to 40 years and the mean age was 17 years. Cause of death included stillbirth, death from illness, and sudden death from accidents. An emerging theme in the study results was respondents attempting to create meaning from their loss. Seventy respondents (45%) indicated that they were unable to find any meaning in the death of their child. Thirty-three participants (15%) noted their child was relieved from suffering due to medical issues that caused their child's death. Examples of meaning making included that the death ended suffering or that death was due to the child's high-risk behaviors. Attempts to identify some positive aspect of their loss included insight that the respondents became more sensitive to others who had experienced a similar loss. Increased spirituality and a desire to help others was another significant theme that was negatively correlated with the occurrence of complicated grief. In contrast, participants who were unable to find a sense of meaning regarding their loss were up to four times at a greater risk of complicated grief (Lichtenthal et al., 2010). The onset of complicated grief can have a devastating effect upon individual and family functioning and have significant health implications.

Potential Variants and Adaptive Process

The trajectory of grieving for bereaved parents represents an individually unique and complex process, influenced by a myriad of potential variables (Thompson et al.,

2011). Understanding the trajectory and complexity of parental bereavement, includes exploring the many factors that affect this process. In the sections that follow, the factors of deceased child's age, causes of death, social constructs and support, cultural expectations, ethnicity and diversity, social identity, and family constructs will be discussed.

Deceased Child's Age

One variable that is frequently generalized in the current parental bereavement literature, is the age of the child at the time of death (Cacciatore & Flint, 2012; McBride & Toller, 2011; Giannini, 2011). In a study conducted by Giannini (2011), five bereaved married couples were interviewed to explore the trajectory of their grieving and communications with others that were identified as helpful and supportive of recovery. The age of the children at the time of death varied from 3 to 22 years of age. Participants were identified through snowball sampling from a variety of grief support organizations. Themes identified within the narratives included acknowledgement, compassion, and inclusion. Acknowledgement was defined as the communications by the parents and their supporters that expressed that their child was remembered and thought of. Compassion was defined as the ability to listen and understand the bereaved, in part, by bearing witness to their grief stories. Inclusion was expressed as others included the bereaved in their lives. Communicating inclusion was supportive of recovery and was an act that mitigated the tendency of bereaved parents to become socially isolated.

Hunt and Greeff (2011) explored the lived experiences of 22 bereaved parents, utilizing a qualitative methodology. The ages of the deceased children ranged from

newborns to well into adulthood. The circumstances associated with bereavement included the child's cause of death, circumstances leading up to the death and events following the death. The participant's grief reactions were also coded as emotional, physical, behavioral, relational, spiritual, and cognitive reactions. It was noted that related to grief outcomes, parents who had no time to prepare, such as in sudden and unexpected death, had a strong association with how the news was broken to the parents. Together, the cause of death and how parents were informed of their child's death was linked to grief reactions.

The studies cited thus far, seek to explore various nuances related to parental bereavement. As identified previously and consistent with the studies outlined here, is the broad range of the age of the children at the time of death, often including early infancy to adulthood. These studies represent much of the body of literature associated with parental bereavement (see Table 1).

Table 1***Summary of Child Death Studies***

Study	Author(s)	Research model	Age	Mean age
“Bereavement Experiences of Mothers and Fathers Over Time After the Death of a Child due to Cancer”	Alam et al. (2012)	Qualitative	8 months to 20.7 years	9.2 years
“The Continued Lived Experiences of the Unexpected Death of a Child”	Parker and Dunn (2011)	Qualitative	3.9 to 20 years	Not specifically stated
“Family and Social Networks After Bereavement: Experiences of Support, Change and Isolation”	Breen and O’Connor (2011)	Qualitative, grounded theory	6 to 73 years	30.17 years
“Exploring Maternal Grief: A Mixed Methods Investigation of Mothers’ Responses to the Death of a Child From Cancer”	Gerrish et al. (2014)	Mixed methods	2 to 35 years	14.8 years
“Still Part of the Family: The Importance of Physical, Emotional and Spiritual Memorial Places and Spaces for Parents Bereaved Through the Suicide Death of Their Son or Daughter”	Maple, Edwards, Minichiello, and Palmer (2013)	Qualitative	17 to 31 years	Not specifically stated

(table continues)

Study	Author(s)	Research model	Age	Mean age
“Negotiation of Face Between Bereaved Parents and Their Social Networks”	McBride and Toller (2011)	Qualitative, interpretive	0 to 42 years	7.7 years
“Stigmatization and suicide bereavement”	Feigelman, Jordan, and Gorman (2009)	Qualitative	80% were 16 to 35 years	Not specifically stated
“Sense and Significance: A Mixed Methods Examination of Meaning Making After the Loss of one’s Child”	Lichtenthal, Currier, Neimeyer, and Keesee (2010)	Mixed methods	0 to 47 years	17 years
“Finding Support in a Field of Devastation: Bereaved Parents’ Narratives of Communication and Recovery”	Giannini (2011)	Qualitative	3 years to 22 years	Not identified
“Parental Bereavement: A Panoramic View”	Hunt and Greeff (2011)	Qualitative	Newborn to young adult	Not identified

Causes of Death

The cause of death is a variable that often receives focused attention in parental bereavement literature. Death from childhood cancer (Alam et al., 2012; Gerrish et al., 2014; McCarthy et al., 2010), and childhood suicide (Gibson, Gallagher, & Jenkins, 2010; Maple et al., 2010), are recognized by the authors as areas that need a specific focus. Their objective, in part, was to understand the lived experiences of the participants in their studies. In Gibson et al. (2010), the authors voiced concerns related to the lack of literature related to the trajectory of grief and adaptation over time, as parents return to the workplace. Alam et al. (2012) identified the need for additional exploration of gender differences and the trajectory of grieving due to other causes of death such as accidental, or suicide. However, Gerrish et al. (2014) were not as specific as the authors expressed the hope that their findings would guide future studies on bereavement due to the loss of a child. Considering the need for additional studies, McCarthy et al. (2010) recognized the need for greater diversity and participant sample size for their focus on end of life care and the potential influence on depression and grief. As a consensus, the authors in the aforementioned studies all expressed the need to further explore the complex issue of bereavement due to child loss and the many variables that effect the trajectory of grieving.

Utilizing a mixed methods design, Lichtenthal et al. (2013) focused on parental bereavement within the context of varying causes of death. Study participants included 155 parents who had experienced the death of children due to violent and nonviolent causes. Participants were recruited from Southeastern chapters of Compassionate Friends

and information linked to the Internet sites of bereaved parents. Causes of death as reported by the study participants, included 10 miscarriage or stillbirths, 18 anticipated, 31 natural sudden, 69 motor vehicle accidents, 17 suicides, and 10 deaths due to homicide. Also documented in the study results, was that parents whose child died due to violent causes, were unable to make sense of the loss when compared to nonviolent loss. Related to benefit finding themes, parents who experienced the death of their child due to violence, experienced greater empathy, compassion, and appreciation for life. Approximately three quarters of respondents who experienced this type of loss, reported at least one benefit finding theme, representative of their ability to identify one positive thing related to their trauma experience. This included themes related to personal improvement and growth as a result of their loss. Sixty-one percent of the parents who experienced the nonviolent death of a child, expressed that they were able to identify one example of making sense of the death. The authors noted in their study results that in general, parents whose child died due to violent causes were more likely to express that they were unable to make sense of the death in contrast to those parents who experienced anticipated or nonviolent death of their child.

Parental bereavement due to causes of death that may result in social stigma, is included in a discussion of death due to suicide. Gibson et al. (2010) explored the experiences of 11 bereaved parents who had returned to work after experiencing the death of a child due to suicide. The authors utilized a qualitative methodology and discovered that their study participants who returned to work, experienced ambivalence regarding talking about their loss with colleagues. Respondents expressed a number of

concerns, that included how they or others would respond to discussions related to their loss. The study results included reports that several of the participants avoided social interaction to mitigate their feelings of guilt, anxiety, or being judged by their colleagues (Gibson et al., 2010).

Further exploring the grief experiences of parents whose child committed suicide, Feigelman et al. (2009) considered how bereaved parents in their study were stigmatized, due to their child's suicide. A total of 540 respondents, 458 of whom were female, completed a survey regarding their child's death. Loss due to suicide represented a majority of the respondents with 78 of the participants experiencing other types of sudden loss. In their study, the authors documented that participants had less available support due to higher rates of rejection and stigmatization, due to the nature of the loss versus child death as a result of other causes. As might be expected, these experiences often resulted in the social avoidance and isolation by bereaved parents who experienced the death of a child due to suicide. In addition, a number of factors related to the trajectory of grieving were represented within the study results. These factors or vulnerabilities included the availability versus avoidance of social support and issues related to feelings of guilt or shame associated with specific types of loss (Feigelman et al., 2009; Gibson et al., 2010).

Social and Cultural Constructs and Support

The trajectory of grief influences and is influenced by the social context in which bereavement takes place. Within this context, the lived experiences of bereaved parents are identified as a derivative of both social interaction and language. In this social

context, permission to grieve is facilitated through social cues and interactions. The experiences of the bereaved are framed in the social expectations created by these social exchanges (Breen & O'Connor, 2011; Maple et al., 2013). One venue that continues to grow in popularity, is Internet-based online support for griever. The social context of the online support forums include the establishment of norms related to how grief is expressed and supported. In online support groups, these norms are defined as the acceptance of grief as an extremely variable process. Swartwood, Veatch, Kuhne, Lee, and Ji (2011) investigated the use of websites to provide peer led grief support to those who had suffered a loss. The main premise of online peer support is that others who are grieving, have a greater understanding of the journey. Data collection included 564 original posts or messages that were randomly selected along with their first responses or threads from four bereavement groups, in each of three sites. Parental bereavement represented the majority or 228 of the total messages selected for analysis. Each message was coded for thought units followed by separating the units into response categories. Methods of support used by the online support group participants included self-disclosure and influence responses, which intend to influence specific beliefs or behaviors. Influence responses were the most prominent noted for groups supporting bereaved parents. Self-involving responses were indicative of the supporters' direct response to the bereaved. A positive sense of acceptance and permission to grieve creates an environment in which open expression is facilitated. Online forums, such as described here, can be especially helpful for individuals who fear stigma associated with their loss (Swartwood et al., 2011).

Gear (2014) explored parental bereavement from the perspective of helpful social support. The purpose of their study was to determine what was most helpful regarding the social support received by the bereaved. Utilizing a qualitative methodology, the author sought to recruit participants whose school-aged child, died. Recruitment was conducted using a snow ball sampling method of bereaved parents who knew one another from medical facilities or support organizations. All participants resided in Melbourne Australia and had experienced the loss of their school-age child, who died, from 4 to 11 years prior to the study. Data collection included one-to-one interviews with the researcher who utilized a semistructured interview to frame data collection. As reported in the research findings, significant sources of informal social support included family, teachers and staff, work colleagues, religious leaders, neighbors, and other bereaved parents. Professional and paraprofessional support was also featured as a significant form of informal support that included funeral staff. Support that occurred within the parent's everyday social context were reported as most helpful. This included friends who did not avoid discussions of their child's death. A total of nine supportive themes emerged from the data. Support and activities that allowed for the continued bond with their child was identified as helpful. This might include the sharing of memories or general discussions about the child. Those who committed to the grieving families were also found to be most valued. This was even in the context of the bereaved pushing the supporters away. Proving practical help was identified as valued by the bereaved. This included doing things, without asking parents to identify what was needed. Giving of time and being present was also identified as helpful. This included employers who were

willing to give the bereaved time off work. Boundary crossings by professionals who were flexible in their roles and became more personally involved, was also highly valued. The bereaved also expressed that direct communication, while being sensitive to their feelings, was greatly appreciated. Social interactions that created attuneness due to sharing a common experience of loss, was noted as supportive. Movies and poetry were also identified as a source of attuneness for the bereaved parents. Finally, others who provided distractions by engaging in conversations and activities that did not include the bereaved's loss, were valued as a source of support.

The significance of family and social support was also explored by (Breen & O'Connor, 2011). The authors utilized a grounded theory methodology to explore the experiences of 21 adult participants, who had experienced the loss of a loved one due to an automobile crash. Participant recruitment included the use of a media release and snow ball sampling. The interviews took place in the participant's home to facilitate a sense of comfort for the respondent. The participants noted that in their early grieving, they received strong family support. The fact that other family members were also grieving, created conflicts for family members who were also dealing with their own feelings of loss. It was noted that a number of respondents had to take on a role in the family, that did not allow them to focus on their own grief. It was also noted that the experience of loss sometimes caused long periods of estrangement amongst the family members. In essence, families were forever changed and some relationships, including marriages, did not survive the experience. The informants did report positive support from their social systems and friends. In some cases, the participants receiving help with

everyday tasks such as cleaning or shopping. Also important was the willingness of supporters to listen to stories and memories of the deceased. This form of support was noted to dissipate over time and was related to a perceived timeline associated with grieving. Social expectations and norms related to grieving were also a part of this phenomenon. Participants who did not meet expectations associated with grieving, reported feeling judged. These expectations included framing grief in a stage based model or that it was necessary to find closure through detachment from the deceased (Breen & O'Connor, 2011).

As previously noted, while social support is an important aspect of navigating grief (Gerrish et al., 2014; Thompson et al., 2011), supporters who lack personal insight and understanding regarding grief, can have a negative effect upon the bereaved (Gerrish et al., 2014). In the context of bereavement, social support is a factor that influences the course or trajectory of grieving, increases social awareness of how parents grieve the loss of a child and carries significant potential for creating social changes. Further, it is important to acknowledge the potential variability inclusive of parental bereavement. This paradigm of loss is contrary to grief existing as a predictable and structured construct, and contrasts with a stage based model of grieving that presents a more organized and rational representation of grieving (Holland & Neimeyer, 2010).

Mourning is defined as the practices or rituals used within a specific culture to express loss (Schoulte, 2011). Cultural tenants may dictate how grief is expressed through mourning. However, there are many cultural universals regarding how parents grieve the loss of a child. Utilizing a qualitative method of inquiry, Suhail, Jamil,

Oyebode and Ajmal (2011) explored the experiences and continuing bonds of 10 bereaved family members in Pakistan and the influence of culture and religion. Participant recruitment was conducted in educational settings and workplaces. The focus of this study did not include the death of a child. The bereavement process was influenced by global and personal influences. Both religion and culture were found to influence the bereavement process as well as continuing bonds with the deceased. Cultural factors prompted the bereaved to conduct rituals that allowed them to honor and remember the deceased. Religious influences provided a foundation for grief, which aided in meaning making for the participants. The desire for a continued bond with the deceased was accomplished through sharing stories and attachment to the deceased's possessions.

Ethnicity and Diversity

Sharp, Joe, and Taylor (2013) utilized a qualitative methodology to explore the experiences of African American families who have lost a loved one to suicide or homicide. Study participants included 12 surviving families who were recruited through a community agency in Philadelphia. The primary mechanism of disseminating information related to the study was via flyers. The majority of the participants were amenable to participating in a homogeneous grief support group. Identified as important, is the training of family and community leaders who have an established relationship with the bereaved. This may help to overcome the tendency to suppress feelings, as a coping mechanism. The importance of using preexisting relationships to provide support was also emphasized to overcome issues of distrust while providing ongoing support for

the family. In general, survivors had difficulty engaging in formal support systems, such as individual counseling or support groups, which may be indicative of the need for early outreach to these families. Suicide, as a cause of death, may be in conflict with established spiritual beliefs. This is indicative of the need for further research in this area of study and possibly illustrates the variability of grieving within cultural contexts.

The Hispanic community is representative of individuals from countries, which include a great deal of cultural diversity. Personal expectations regarding direct care providers, in the Hispanic community, is that these professional will be both empathetic and present at the time of their loss. Emoting as a normal and appropriate way to express feelings, may be encouraged by perceived social cues or expectations regarding how grief is expressed. However, this is more acceptable for women while men may be expected to display strength. The intensity of public emotional displays is positively related to how close the bereaved are to the deceased (Schoulte, 2011). Also consistent with maintaining the emotional bonds between the living and the dead, religious beliefs are often consistent with a connectedness with the deceased loved ones through spirituality (Krause & Bastida, 2011).

Social Identity

Maintaining a positive social identity or positive face can be difficult for bereaved parents. A negative social identity may result feelings of rejection or avoidance due to being identified as a bereaved parent. As a result, the bereaved may put on a good front or persona in attempts to maintain a positive self-image. McBride and Toller (2011) explored how bereaved parents negotiated the need to talk about their deceased children

and express their feelings, while managing face needs or perceptions of positive or negative social identities. Utilizing a qualitative methodology, participant recruitment included a purposive sampling of 53 bereaved parents. The majority of the participants were female and the elapsed time since the death of their child ranged from 6 months to 29 years. Results, in part, included that bereaved parents felt the need to avoid the negative or insensitive comments made by others who threatened their positive face. There was also a need to protect the feelings of those in their support groups. As a result, it was noted by the respondents that to avoid judgment, they would strive to not appear too emotional in public. This was indicative of the need to have safe spaces in which bereaved parents felt secure sharing their experiences and grief stories.

Breen and O'Connor (2011) explored family and social support in relationship to grief as a result of sudden and unexpected loss. In the framework of a qualitative grounded theory methodology, 21 participants who had experienced the loss of a loved one due to an automobile accident, were recruited. The majority of the participants, 16 of the 21, were female. The age of the participants ranged from 24 to 71 years and the age of the decedents ranged from 6 to 73 years. Themes that emerged from the data, relating to social identity, included the difficulty respondents encountered in talking to others about their loss. This included the perceived gender expectations that women were more open to exploring emotions associated with their loss. In contrast, men seemed more interested in discussing the specific details of the crashes. One of the five men in this study specifically related that he intentionally hid his emotional experiences, as this was perceived as socially appropriate. Social assumptions included that the grieving process

is short term and was subject to organized stages that must be worked through. Hurtful platitudes were also identified as a threat to social identity due to unrealistic expectations. In response to their social experiences, it was noted as customary for participants to experience a shift in their social relationships. This shift was evidenced by a change in relationships towards a smaller network in which the participants felt safe talking about their loss.

Family Constructs

The death of a child significantly affects the family system through multiple generations. Cacciatore, Schnebly, and Froen (2009) utilized a quantitative methodology and explored the experiences of mothers who had lost a child due to stillbirth. The authors focused on exploring the relationship between levels of anxiety postloss and receiving social support. Recruitment included 37 Internet-based forums and websites that provide direct support to women who have experienced a stillbirth. In total, 769 mothers, all located in the United States, completed online surveys. As reported in the study results, family is often the most common form of support for women who experienced the death of a stillborn child. As family members come to terms with the reality of their loss, they may rely on experiences resulting from previous losses. This loss history may frame expectations about the experience and expression of grief. Extended family members may also put their own needs aside to provide support for the bereaved parent(s).

Grandparents. Grandparents are one common form of family support. Gilrane-McGarry and O'Grady (2011) utilized a qualitative methodology to explore the

experiences of grandparents whose adult children experience the death of a child. Participants were recruited with the cooperation of local support organizations and announcements in the media. Participants accepted for the study included 13 grandmothers and 4 grandfathers. Data collection was facilitated through face-to-face interviews with the participants. The subsequent coding and analysis of the data reflected major themes of providing and receiving support. It was identified that grandparents sought to delay their own grieving. These caregivers placed their own needs aside to attempt to provide support for their adult children, who were grieving. Even though they may delay their own grieving process, it was noted that being included and recognized as grievers was positively correlated with a reduction in their pain. This inclusion was identified by the grandparents as having a voice in the decision making process, in terms of funeral arrangements. Support by grandparents was often not reciprocated and left grandparents to seek out other available support systems, such as support groups. Other forms of support provided to grandparents were of equal value, such as taking care of specific tasks such as cooking or cleaning.

Grief modeling and the establishment of family traditions or norms to cope with loss are often transmitted from one generation to the next, within family lineage. This is significant for bereaved parents who have experienced other child deaths in the family (Arnold & Gemma, 2008). Arnold and Gemma explored, in part, the phenomenon that family history, based upon other loss experiences, can significantly influence how and what kind of support is available for bereaved parents. Expectations may include how a child's death is recognized within the family. This recognition of the loss by extended

family, such as grandparents, included the honoring of anniversary dates such as when the child was born or died.

Partners. The effect of child loss for couples is significant and partners may have difficulty supporting one another. Grief is unique to each individual and partners may feel misunderstood regarding their individual reactions (Thompson et al., 2011). Cacciatore, Lacasse, Lietz, and McPherson, (2013) explored the health, mental health, family functioning, and resilience of bereaved parents selected for their study. This research was framed in a cross-sectional online survey, representative of 503 respondents. Participant recruitment was facilitated by survey method of online support communities. The majority, 70%, of the interviewees were Caucasian, and 95% female. The age of the children at the time of death was not specifically identified. In regards to partner experiences, 45.5% of the respondents noted negative effects to their partner relationship. This resulted in the need to grieve individually rather than together. In contrast to the aforementioned, the majority or 54.5% of the interviewees expressed that their relationships became stronger as a result of their shared loss. The importance and timing of bereavement support may provide the opportunity for couples to grieve separately before they are able come together to grieve as a couple.

Surviving children. In families who have experienced the death of a child, the presence of surviving children may influence the trajectory of parental bereavement. Harper et al. (2011) reported that the existence of surviving children provided a sense of meaning and a reason to continue living. This is despite the fact that some of the mothers in this study experienced an inability to nurture and take care of the basic needs of their

surviving children. The existence of surviving children may also help to mitigate the loss of role identification as a parent. This loss of role identification is often included as a factor of interest in the current parental bereavement literature (Alam et al., 2012; Harper et al., 2011). Alam et al. (2012) identified that mothers caring for surviving children, may experience the nurturance as a protective factor against complicated grief. When parents are in a caregiving role due to their child's illnesses, such as cancer, the disruption of this role after the child dies may further exacerbate the loss of identity for the parents (Meert et al., 2015). This may be experienced as a secondary loss for the parents. In contrast, Giannini (2011) explored how bereaved parents viewed their role as parents after the death of their child. Many of the respondents found that the continuing bond with their child, allowed them to continue to identify themselves as parents. In one participant narrative found in a study by Harper et al. (2011), the respondent noted that her caregiving role for her deceased child was refocused on caring for her child's grave.

Support Groups

Sharing the story of their loss can be draining and emotionally taxing for the partners and the family of bereaved parents. Nonetheless, encouraging parents to find support outside of their immediate family, is beneficial (Dyregrov, Dyregrov, & Johnsen, 2013). Support organizations include networks such as Compassionate Friends, Grief Share, and Bereaved Parents of the USA. These groups provide support and structured, time-limited groups for a variety of losses (Bereaved Parents of the USA, 2010; Church Initiative, 2014; Compassionate Friends, 2010). Often these groups contain both didactic and experiential components that allow for the open sharing of loss experiences. One

advantage of utilizing support groups offered by these organizations is that other community resources, unknown to the bereaved, may be made available (Dyregrov et al., 2013). Ideally, such groups establish safe places in which individuals may openly talk about their loss without fear of judgment or invalidation (Groos & Shakespeare-Finch, 2013).

The value of sharing grieving experiences includes the normalization of the participant's loss. As group participants share their individual stories, they gain insight that they are not alone in their experiences and that the group is a safe place to explore and share their feelings. The individual's support system often expands as relationships that begin in the group, may become the foundation of new friendships as contact among group members continues beyond the termination of the group (Umphrey & Cacciatore, 2011).

Umphrey and Cacciatore (2011) explored meta-communications within a parental bereavement support group utilizing a qualitative, grounded theory methodology. Participation in the weekly support group meetings varied regarding consistency. Data collection was facilitated through audio recordings, field notes, and final transcription of the recordings. Umphrey and Cacciatore identified three specific themes that structured the support group meetings included in this study. First is the telling of the grief narrative of the loss. Second is the assessment of coping skills of the bereaved. Third is that communicating with other bereaved parents in the group, helps the bereaved develop meaning regarding their loss. While the observations of the primary researcher are

consistent with the predefined structure of how these groups are facilitated, the ability to express their grief and be heard hold a substantial benefit to the bereaved.

Loss-Specific Interventions

The consequences of unremitting parental bereavement may result in both psychological and physiological consequences. Interventions that target specific subgroups of griever, such as bereaved parents, may include grief support groups. Thrisk and Moules (2012) explored grief interventions provided to the bereaved who attended counseling at the Family Nursing Unit. The premise of the study was to gain an understanding of the timing of interventions provided to those who are grieving. The methodology included a qualitative interpretive study in which data reflected the experiences of three families. The first participant noted that the timing of interventions was off, due to her early grief reactions of shock. This experience was in contrast to generalized beliefs, related to the trajectory of grieving occurring within a finite timeline. In general, as related by the participants, this was a time to gain a sense of stability in order to survive. Once again, the timing of interventions was considered significant and was based upon the here and now experiences of the family, rather than based upon a perceived expectation related to how grief should progress. The use of family work as an intervention, was also described by one participant. The benefits of having others who witnessed their experiences, provided alternative ways of looking at their grief. Most significant in the findings related to this study, is that grief interventions should not be done based on some notion of a timeline related to grieving. Effective interventions

should include the supportive families while taking timing into consideration, where the families and individuals are in their grief experiences (Thrisk & Moules, 2012).

Aho, Åstedt-Kurki, and Kaunonen (2013) explored the feasibility of expanding a peer support bereavement intervention program. The study explored the experiences of 16 peer supporters who had provided volunteer services. Program interventions included a predefined package, peer contact with bereaved parents and contact between professionals and the bereaved. The package was made up of didactic material that focused on child death and parental bereavement. Interventions began approximately one week after the child's death and was facilitated by the peer supporters. The age of the deceased children was 3 years and younger. Data collection was accomplished via telephone interviews with the peer supporters. When asked about the information package, supporters noted that the material was not applicable to the loss of older children. Issues related to phone contact were also identified, in that scheduling tended to become an issue and that telephone contact may be too impersonal. As noted in the study by Thrisk and Moules (2012), timing was important based on the parent's willingness to receive support. It was also noted that peer support for fathers was particularly important. The peer supporters surveyed, voiced the need for additional male supporters to fill this need. The purpose of the program was to engage with bereaved parents and provide support, which was deemed as successful.

Dyregrov, Dyregrov, and Johnsen (2013) explored recommendations for improvement, directly from grief support group participants. This study was part of a qualitative study previously conducted in Norway from 2009 to 2011. The results

reflected the importance of targeting interventions towards specific subgroups of griever who have difficulty adapting, such as bereaved parents. This was expressed by the participants who noted that receiving information before participation was very important and that homogeneous groups facilitated cohesiveness within the group (Dyregrov et al., 2013). Exploring specific variables such as the child's age at the time of death, may help to identify the need for loss specific interventions for more targeted groups. Thus, narrowing the focus of broader studies may provide new insight into the subjective experience of bereaved parents while aiding in the development of new interventions.

Aho et al. (2009) further explored the significance of specific variables that may influence the trajectory of grieving and needed interventions. In their qualitative study of bereaved fathers, they explored their perceptions of social support postloss. Family support was identified as particularly important; however, this support may be fleeting because of bereavement experienced by other family members. Acceptance by others was also important and included parents who had experienced the same type of loss. As a result, Aho et al. found that participants' sharing their grief openly with peers was an effective method of relieving their grief experiences.

Summary and Conclusions

Parental bereavement has a complex interaction of variables. Ignoring variables, such as the child's age at the time of death, social experiences of the bereaved and assuming homogeneity of experiences for all grieving parents, may inadequately represent the uniqueness of their loss. Social beliefs that reflect such generalizations may

create unrealistic expectations for bereaved parents. Failing to recognize the nuances of the subjective experiences of these parents, may result in grief-associated pathology.

The many variables that influence the adaptive response of bereaved parents are outlined within the studies included in this literature review. The work of Kubler-Ross (1973) provided an example of a stage-based model that allowed for the exploration and documentation of the experiences of those who were dying. This substantial contribution to the field of thanatology advanced the existing body of literature. Bowlby (2005) also made a significant contribution to understanding the experiences of grieving. Within this body of research, the painful experiences of grieving are framed within the loss of attachment. Parkes (1988) provided a framework that moved grief from a stage-based framework to a more flexible and variable experience, in which individuals adapted to their loss. Within this framework, grief is recognized as a complex process that results in the shattering of the assumptive world of the bereaved. Cacciatore et al. (2013) also explored the physical experiences and manifestations of grief, such as declining health and body tension.

All of these studies contribute to the body of literature regarding bereaved parents; however, none were focused on the subpopulation of bereaved parents addressed within this study. The assumption that the trajectory of grief for all bereaved parents will be homogeneous regardless of the child's age at the time of death, has not been investigated in the current body of literature. The significance of this underrepresented subpopulation of bereaved parents is, in part, outlined by Breen and O'Connor (2011). The authors noted that poor social awareness about parental bereavement may create

rigid expectations about the expression of grief. Such expectations may fail to recognize the social context and other factors, such as the child's age at the time of death, when considering the influences upon trajectory and outcome of parental grief. Individual, familial, and social variations specific to this subpopulation of bereaved parents may lose their meaning in broader studies.

In Chapter 3, I presented the research design and methodology I selected for this study. Chapter 3 also included the rationale for selection of a phenomenological study as the most appropriate model for exploring the lived experiences of the participants. Chapter 3 ended in an outline of participant selection, data collection, and data analysis.

Chapter 3

Introduction

The purpose of this phenomenological study was to uncover the subjective experiences of a subgroup of bereaved parents, whose children between the ages of 2 and 12 years, suddenly died. Exploring how grief is experienced by the bereaved parents selected for this study, required a careful examination of the nuances associated with their loss. Part of this inquiry included a closer examination of a variable frequently generalized in the research literature. This variable represented the child's age at the time of death, often spanning from in utero to 18 years and older in many studies (Essakow & Miller, 2013; McBride & Toller, 2011; Titus & de Souza, 2011). Narrowing this study selection criterion to include parents of deceased children in the identified age range, may provide insight missed in the broader studies.

The research questions and semistructured interview questions framed the objectives of this study and guided the exploration of the lived experiences of this subpopulation of bereaved parents. As identified in Chapter 2, individuals may attempt to provide support for the bereaved based on the prevailing social attitudes or expectations related to parental bereavement (Breen & O'Connor, 2011). How others respond to the bereaved may reflect the prevailing social attitudes of what is considered helpful. For the bereaved, these responses may convey a sense of permission or prohibition to grieve. The following research questions guided the data collection process:

1. What were the initial experiences of parents who lost their child?

2. What are the familial experiences of bereaved parents selected for this study?
3. What are the social experiences of bereaved parents selected for this study?
4. How did parents respond to their loss in an attempt to adapt to a new reality?

Exploring the experiences of grief for the selected participants included the individual, familial, and social context in which grieving is expressed. How bereaved parents respond to each other during this stressful life experience is an area of interest and concern. Investigating this aspect of parental bereavement may help uncover the adaptive process for each partner and their experiences of grieving jointly. How the bereaved engage socially may also reflect changes in the role of parenting, such as those experienced by parents who have lost their only child. Finally, exploring family support may increase social awareness of the needs of grieving families and how these families are changed and adapt to child loss.

In this chapter, I described the research methods I used. I documented the research design, selected paradigm, and justification for its use. Discussion related to the researcher's role included the use of the primary researcher as the data collection tool and potential biases inherent to this methodology. I addressed contextual issues of how and where data collection will take place, and I documented the ethical issues related to protection of the participants. Finally, I discussed participant selection and data analysis.

Research Design and Rationale

The phenomena I explored are the lived experiences of bereaved parents whose child died suddenly and were between the ages of 2 and 12 years at the time of death. The subjective experiences of the bereaved included the participants' individual, familial,

and social experiences, including how they attempted to adapt to their loss. Specific methods for obtaining data are described later in this chapter.

I determined the appropriateness of a phenomenological study after carefully reviewing the research questions and study goals (Creswell, 2012). This methodology allowed me to enter into the world of the participants and data collection was facilitated with semistructured interviews in which participant experiences were recorded, transcribed, and later analyzed (Creswell, 2012). All interviews were audio recorded and transcribed. The rationale and justification for this methodology is discussed in detail in subsequent sections.

Research Paradigm

Qualitative research is an inductive method of inquiry that allows the researcher to explore and document the lived experiences of the participants (Creswell, 2012). I explored the experiences of a subpopulation of bereaved parents, consistent with the social constructivist paradigm. The social constructivist paradigm posits that individuals seek to understand their world by developing meanings associated with their subjective experiences. These meanings are often varied, complex, and guided by the individual's social experiences and interactions (Creswell, 2012). This study fit well with phenomenological methods as the participant's stories and recollections of their experiences were captured (Creswell, 2012). Exploring the narratives for the participants allowed for an unbiased, in-depth exploration of their subjective and unique experiences (Creswell, 2012).

The goal of a qualitative study is to identify emerging themes and develop meanings related to human experiences (Creswell, 2012). The use of a qualitative methodology allowed for the exploration of the experiences of bereaved parents while providing an opportunity to give them a voice in the literature (Willig, 2013). A qualitative study is a good fit because of the lack of available information regarding this subpopulation of bereaved parents.

Justification for Selected Methodology

Initially, grounded theory was considered for this study. Grounded theory studies are appropriate when the researcher seeks to develop theories from the emerging themes grounded in the data. Within this methodology, understanding emerges through the categorization and exploration of the identified themes. These links or connections become tentative hypotheses identified for further exploration (Omar et al., 2010). While the flexibility indicative of this model provides opportunities to explore the interpersonal and social experiences of the participants (Creswell, 2012), theory development was not the goal of this study.

An ethnographic methodology was also considered for this study. This framework allows for the exploration of the experiences of a specific cultural or social group. Understanding and meaning is achieved by the researcher's long-term immersion into the group studied (Creswell, 2012; Schensul & LeCompte, 2012). An ethnographic study was not consistent with the focus or goals of this study because of diverse participant selection criteria and length of time that I will interact with the participants. Other methodologies such as case studies were also not consistent with the focus of this

research and did not align with the research questions. Final selection of a phenomenological methodology was based upon the research questions, goals, and focus of this research. These goals are consistent with the exploration of the lived experiences of this subpopulation of bereaved parents. A phenomenological framework allowed for the illumination of factors that are lost in more generalized studies of parental bereavement.

Design

In this study, I explored the lived experiences of bereaved parents who have experienced the loss of a child who was between the ages of 2 and 12 at the time of death. To achieve this goal, I selected an interpretive phenomenological model for this study. I used a prequalifying survey to establish the appropriateness of the potential participants (see Appendix A). I scheduled study participants to engage in a secure Internet based conference interview with me, facilitated through *Calliflower Connect*. All interviews were conducted via web conference with the exception of the prequalifying surveys that took place via telephone or email. This was a change to the design as interviews were originally focused on the Las Vegas area and were to take place face-to-face. The lack of participant response prompted the change to a broader study that encompassed the continental United States. To qualify for study participation, potential interviewees were required to be a minimum of 2 years postloss. Participant selection is discussed in greater detail in a subsequent section.

The individual interviews consisted of a series of open-ended questions framed by the study's research questions. I did not interview partners together. The single

interviews consisted of a 2-hour session with the stipulation that I would provide additional time at the request of the participants. My effectiveness as the researcher to build a collaborative working relationship with the interviewee, in part, empowered the participants to have a voice in the literature through their individual narratives.

Data analysis was consistent with an interpretive phenomenological study and included a four-step process. The first step included a review of the data to identify meaning within the individual narratives. In the second step, units of meaning that are elements of the phenomenon of interest, were identified. This may be considered the individual parts that make up the essence of the phenomenon of interest. The third step of analysis includes the identification of themes that are shared across multiple cases. Once identified, the shared themes or meanings were placed into clusters. Finally, a summary table was created to present themes and subthemes resulting from the analysis (Willig (2013)).

Role of the Researcher

In this study, my own grief experiences posed a threat to objectivity. Personal grieving experiences include the loss of a stepdaughter and expectations of grieving influenced by this loss. My experiences facilitating grief support groups and working with the bereaved, also posed a potential bias regarding expectations. To mitigate these issues, individuals who have an ongoing relationship with me, such as coworkers and friends, were not eligible for study participation. I also addressed my biases related to expectations of past experiences, especially those working with grieving parents. My

completion of the literature review for this study also has the potential to create a bias related to expectations.

Methodology

Participant Selection

Participants included a purposive sampling of biological and adoptive parents who are over the age of 18 and whose children between the ages of 2 to 12 years, suddenly died. Examples of this type of loss may include auto accidents or sudden heart failure. The agreement to gain access to participants is representative of the Walden University Institutional Review Board (IRB) approval to use public records to identify potential participants. This was approved by the Walden University IRB on June 26, 2014. Additional strategies for recruitment included snowball sampling, to take advantage of word of mouth referrals. The geographic area for participant selection was the continental United States. All participants were at a minimum of 2 years beyond the date of their loss and were able to communicate in English. In addition, participants who had a working or social relationship with the primary researcher, were not eligible for this study.

After obtaining approval from the Walden University IRB, # 90-20-13-0056267, I recruited a purposive sample of 15 participants who have a shared experience of child loss from bereavement support organizations, public records, and word of mouth. This was accomplished by sending letters of interest to potential participants identified in public records (see Appendix B). Recruitment resources also included organizations such as GriefShare, Compassionate Friends, Bereaved Parents of USA, and public records

related to the death of a child. Each of the aforementioned organizations received a letter describing the study in detail. The use of public records included exploring online memorials and information related to foundations that were established after the child's death. This information was shared by the bereaved parents, with the general public, through such venues as websites, books, and publications related to grieving parents. The specific addresses obtained were also part of such postings and correspondence, along with public records searches related to the individual's address. Other methods of disseminating information to these organizations regarding this study, included email and telephone contact. Individuals interested in study participation were instructed to contact the researcher by telephone or email, to obtain a prequalifying survey. After the surveys were completed over the telephone, or returned by mail or email, I contacted the potential participant to arrange for an individual interview. All of the interviews were conducted using Internet based conferencing software called Calliflower Connect. There was an option to utilize an office for interviews located within Compass Behavioral Health, if needed. This resource was not needed as the interviews were conducted utilizing the aforementioned conferencing software. Additional participant recruitment strategies included snowball methods for word-of-mouth referrals. The initial sample size was 10 participants; however, additional respondents were necessary to achieve saturation of the data categories. The sample size is consistent with other phenomenological studies in which the experiences of bereaved parents are explored (Gudmundsdottir, 2009). Theoretical saturation occurs when recurrent patterns are consistent within the data (Omar et al., 2010). The actual sample size was determined by the point at which data

saturation occurred. Data saturation is successful when no new information is identified for the defined data categories (Creswell, 2012).

Data Collection

The study participants signed an informed consent prior to any discussion regarding the research questions or data collection. I initiated data collection during a 2-hour semistructured interview. The semistructured interviews were guided by the four established research questions. Forms of data used for this research included participant interviews and audio recordings. All notes and audio recordings received a numeric code to protect confidentiality of the participant responses. Because of the emotional content of the subject matter, research participants were provided with community grief support resources to mitigate any undue distress caused by the interview (see Appendix C). Participants also received follow up information regarding study results, if they desired them. I secured all data formats during transport and storage to ensure participant confidentiality. I completed audio recordings for each participant interview (see appendix D). After completion of the interviews, I provided each participant an opportunity to debrief regarding his or her experience.

Data Analysis

Data analysis began after the completion of the first semistructured interview. Specific categories, established by the interview questions, directly connected to the respondents' initial subjective, familial, and social experiences, including their adaptive responses. Pamela Fulbrook, a trained transcriptionist, transcribed the audio recording from each interview and I reviewed the transcripts. The primary data for this study was

the individual narratives of the voluntary participants. I used hand coding and NVivo 10 software for data management throughout the data coding process. Incomplete interviews were not used as data for this study.

Willig (2013) described four steps that make up the data analysis process. In the first phase of analysis, the researcher reads the individual narratives to gain meaning as it exists for each of the participants. An essential element of analysis, includes the acceptance of the researcher's existing knowledge as a fundamental necessary to make interpretations or understand the experiences of the participants. Understanding the subjective experiences of the participants, is interpreted by the researcher and includes the collaborative relationship between the participant and researcher.

Following the review of the transcripts to initially identify meaning units, a second review was carried out in order to identify meanings, labels, or themes as they emerged in the data. These meanings represent specific elements of the experiences of the participants, which when put together, represent the phenomena of interest. After themes were identified, these meanings were explored within the context of the specific research questions. The subsequent clustering of themes allowed for making connections within the individual narratives. Finally, a summary table was created to identify themes and subthemes that represent the lived experiences of the participants in relationship to their experiences as bereaved parents (Willig, 2013). Nonrepeating themes may represent areas of further exploration and consideration for research.

Issues of Trustworthiness

The credibility of this research is grounded in specific methods used to ensure the accuracy of the recorded data. There were two methodologies used to ensure the trustworthiness of this research. One method used in this study and described by Creswell (2012), is peer consultation. In this process, the debriefer rigorously seeks to question all aspects of the researcher's data collection and data interpretation methods. Also utilized in this study is member checking, which was used to return study conclusions and interpretations back to selected participants for review. This process allows respondents to provide feedback related to missing content and established themes identified in the preliminary analysis (Creswell, 2012).

Due to the geographic scope of the data collection, this study is generalizable within the specific context included in the research however; the results may not be generalizable to other types of losses. This is not unlike other studies that seek to explore specific types of loss within one social context. The value of such research may be found in its identification of specific grief-related features that help to advance social understanding or inform clinical practice.

Dependability of the study can be addressed through the maintenance of field notes and recorded narratives. Using a transcriptionist who does not have any preconceived expectations of the study outcomes also added to the dependability of this research. The lack of other coders also mitigated concerns regarding intercoder agreement and consistent coding methods. To mitigate issues related to trustworthiness

due to the use of a single coder, both member checking and peer consultation were used to further validate the coding methods and the information being reported.

Confirmability or replication of this study by other researchers is an important component to exploring other contexts. The careful documentation of the interview and coding process can increase the potential replication of this study by others. As previously identified, a peer review process can also help to identify any researcher biases that may also influence the study results and interfere with study replication.

Ethical Procedures

Walden University IRB approval # 90-20-13-0056267, which was extended on August 2, 2014, was obtained before any data collection began and all participants received an informed consent form, outlining the research and potential risks associated with participation. This included their right to refuse participation at the time of the interview or withdraw from the study, at any time. The agreement to gain access to participants is representative of the Walden University IRB approval to use public records to identify potential participants. This was approved by the IRB on June 26, 2014. After I made initial contact with a bereaved parent, I provided a list of community-based grief support organizations to address any issues related to recalling the events at the time of their child's death, whether or not they participate in the study. These agencies are predominantly free of charge and include local support groups, such as GriefShare and Compassionate Friends. I also advised participants of the risks associated with participation, the right to withdraw at any point, potential benefits of participation,

and contact information for administrative individuals at Walden University, if questions arose.

I maintained data security to ensure the confidentiality of the participant information by using locked storage containers during transport from the interview site to my home. After the data reached its destination, I secured the password protected flash drives, written correspondence, and audio recordings in a locked filing cabinet located in my home office. The entrance of the home office is also secured with a digitally coded lock. At the conclusion of data review and analysis, I maintained records in a locked, fire-rated, storage cabinet where it will remain for a period of 5 years and then I will destroy them.

Participants were advised that their confidentiality was maintained in the collection and reporting of their narratives. This included the use of numeric codes that were assigned to each interview. This number was used to identify the various forms of data associated with each case. A list was established that identified the specific codes with the participant prequalifying survey and demographic information. This key was secured in a locked filing cabinet that is separate from the other data.

Summary

In Chapter 3, I included the research methodology for this phenomenological study. Four primary research questions provided a foundation for the participant interview questions. The first research question addressed the subjective social experiences of the bereaved parents. Responses to the second research question evidenced how these lived experiences influence and are influenced by their familial

context. The responses to the final two research questions uncovered how bereaved parents responded or attempted to cope with their familial or social experiences associated with their loss. Participant responses to the research questions, provided a comprehensive view of the subjective experiences of bereaved parents who volunteered to participate in this study.

The aforementioned research questions and data analysis, represent the use of both inductive and deductive methods of discovering themes, that are consistent across individual cases. The exploration of parental bereavement for parents who have experienced the sudden death of a child, who was between the age of 2 and 12 years at the time of death, posed considerable difficulty for the research participants. This chapter outlined the protections that were employed to ensure minimal risk to the participants while protecting confidentiality. The security methods outlined within this section, which included transport and storage of sensitive information, were established to protect the confidentiality of all participants. Participants also had opportunities to benefit from the study by providing consent to receive feedback after completion of the study.

Documenting the lived experiences of the participants in this study was achieved through in depth, semi structured interviews. Chapter 3 outlined participant recruitment, data collection, and analysis methods used to uncover the rich details inclusive of the participation narratives. This includes the use of Nvivo 10 software to manage the data, as coding uncovered themes as they emerged from the transcribed narratives. Other issues of relevance, include the methods used to secure the trustworthiness of this study.

Chapter 4

Introduction

I conducted this qualitative study to explore the experiences of a subpopulation of bereaved parents, who are not well represented in the current literature. The participants who became the focus of this study, represented a gap in the research. This gap included bereaved parents whose child suddenly died and was between the ages of 2 to 12 years at the time of death. Participants included the biological and adoptive parents who have had to navigate the death of their child and were compelled to share their experiences.

I explored the lived experiences of these bereaved parents by utilizing a interpretive phenomenological methodology that included in-depth narratives. I documented these narratives through a series of open-ended questions that comprised each of the semistructured interviews. I captured the lived experiences of each participant through the collected data. I was able to use the structure of the interviews for the exploration of the individual, familial, and social experiences of the bereaved parents. In addition and consistent with the theoretical foundation for this study, psychosocial transition theory, I documented the adaptive attempts of the participants.

There is an abundance of research, which explores the experiences of bereaved parents. However, many of the studies include children who were in utero to 18 years or older at the time of death (Essakow & Miller, 2013; McBride & Toller, 2011; Titus & de Souza, 2011). Exploring this gap in the research provided an opportunity to expand on the current body of knowledge while informing clinical practice regarding more effective ways to support those who are grieving.

I began Chapter 4 with a reiteration of the purpose of this phenomenological study in the context of the research questions. I then discussed the data collection setting related to any influence this may have had on participants' responses or their interview experiences. Basic demographic information was outlined regarding the cause of death and the length of time since the death occurred. I then turned attention to the interview data and subsequent analysis. This includes how these data were coded and themes were identified. I explored issues related to trustworthiness followed by a detailed account of results as framed by the original research questions.

Setting

The setting for this study was the virtual environment of web conferencing. The participants were located in their own homes at the time of the interviews. The original plan was to complete face-to-face interviews with each of the participants. I implemented this method, within a limited geographic area for participant recruitment. Due to the poor response of early efforts to recruit participants, included in the original geographic boundaries, the study was expanded to the continental United States. Expanding the study provided greater variability in participants and allowed for the telephone conduction of interviews. Although this method of collecting data did not allow for face-to-face contact, it provided a comfortable environment in which the participants could share their experiences. Overall, respondents found their home setting convenient; however, this setting could have been more prone to distraction. In one interview of the 15, the participant was distracted by another telephone call.

Demographics

A total of 15 participants were recruited for this study. This included three male and 12 female respondents. Their relationship to the children included three biological fathers, 11 biological mothers, and one adoptive mother. The length of time since their child had died varied between 2 years plus 8 months and 23 years, 1 month. See Table 2 for a summary of the officially determined causes of death and the time since the death occurred. In Table 3 The decedents age at the time of death is also provided.

Table 2

Time Since Death and Officially Determined Cause of Death

Participant No.	Years since death	Cause of death
249	23 years, 1 month	Cardiac arrest
262	7 years	Glioblastoma
3099	4 years, 4 months	Drowning
3771	11 years, 10 months	Car accident
3826	13 years	Head trauma (fall)
5024	10 years	Crushed (furniture)
5122	4 years, 10 months	Drowning
7486	6 years	Car accident
0887	26 years	Drowning
0875	2 years, 8 months	Shot by airsoft gun
3490	12 years, 6 months	Car accident
9302	4 years, 11 months	Drowning
0431	16 years	Drowning
1154	11 years, 6 months	Drowning
1254	11 years, 6 months	Drowning

Table 3

Age of the Child at Time of Death

Child's age at time of death	Participants <i>n</i>
2 to 4 years	6
4 to 6 years	5
6 to 8 years	1
8 to 10 year	2
10 to 12 years	1

Data Collection

Data collection included 15 participants who responded to a letter inviting them to engage in a semi-structured interview. Each of the participants received a letter of invitation (see Appendix E), describing this study. On signing the informed consent, the interviews were conducted by telephone at a time convenient for the participants. The interviews were recorded using a conferencing system, Calliflower Connect. Respondents dialed into a toll-free private area and a voice recording was made of the interview for later transcription. Each participant was fully aware that the interview was being recorded. Upon completion of each interview, the recordings were exported to a Moving Picture Experts Group Layer-3 Audio (MP3), format and then saved on a secure portable storage drive for transcription. Each respondent participated in one interview and the duration of the interviews varied from 44 minutes to 87 minutes.

Variation in the original data collection plan, included using face-to-face semistructured interviews for participants who were in the Nevada area. Originally, recruitment was to include a combination of local grief support organizations, announcements in various local publications, and snowball sampling. After

approximately 1 year of participant recruitment attempts without any viable results, the study was expanded to include the continental United States. Walden University IRB also approved the identification of potential respondents through public records. This allowed for the recruitment of participants by utilizing public records, such as obituaries, blogs, and websites. Queries included searching for events resulting in child deaths that met the study criteria. Invitation letters were sent to 73 potential participants and a total of 14 potential research subjects replied. All 14 respondents met the criteria and were approved for study participation. One potential participant who responded to recruitment, facilitated by an IRB approved video, *Child Loss* (Fulbrook, 2014) did not come to the interview. Attempts to contact the participant were unsuccessful. Another participant who responded to a posting in the Walden University Participant Pool, successfully completed the interview. Once approved by Walden University IRB, these changes in recruitment, that included the use of public records, creation of a YouTube™ video and use of the Walden University Participant Pool, resulted in positive results and completion of data collection within 90 days of implementation. There were no incomplete interviews or unusual circumstances encountered during the data collection process.

Data Analysis

As previously described in Chapter 3, the data analysis process began with a careful review of the interview transcripts. The initial review of the transcripts resulted in the identification of meaning units and labels. Each transcript was reviewed within NVivo 10 with each unit being coded into descriptive nodes. Once the nodes were

established, themes were identified by exploring responses that were consistent across multiple respondents. Text queries were done to identify common themes within the data and a direct review of each node, revealed how many respondents positively identified with the labels contained within each node. This method is consistent with the analysis approach previously defined in Chapter 3. The only changes to the originally approved data analysis, was the use of Nvivo 10 rather than NVivo 9. The updated version of the software was still under development at the time this dissertation was approved by the Walden University, University Research Reviewer. In addition, while open coding allowed me to identify codes as they emerged from the data, a hierarchical coding was also used to derive codes from the research questions.

As identified by Willig (2013), the steps used to analyze the data included an immersion and initial review of the recorded data. At this stage of discovery, notes were maintained regarding the researcher's initial impressions and thoughts. Once the initial review is complete, a second read was completed to identify themes that emerged from the data. These themes were captured via nodes in NVivo 10 to facilitate further analysis. The third stage of data analysis includes a comparison of themes including query searches that would eventually link themes and their meanings. The final stage of analysis included the identification of significant themes and the discarding of themes, which have no shared meaning within the individual cases.

There were many themes that emerged from the interview data. The subsequent analysis formed a representation of the individual, familial, and social experiences of the

bereaved parents. This also included how the bereaved attempted to adapt or gain a sense of balance after the loss of their child.

Question 1: Initial Experiences

Early grieving. I began the data analysis by focusing on the initial reactions of the bereaved to loss, within the context of the participants psychological and physical experiences. As might be expected, feelings of shock and disbelief were prominent throughout the transcripts (see Table 4).

Table 4

Parents Initial Response to Child Loss

Initial response	Theme occurrences
Could not function	8
Not being present	8
Isolation	5
Numb	4
Shock	4
Sleepless	3
Reactive to others	1
Could not cry	1

Note. N = 15.

Interviewer: How did you feel in those early days of grieving?

Participant 0875: I had more energy. It was almost like my mind was a fire of just, activity. I think it was just almost complete overstimulation.

Participant 3099: The first time I felt was actually about three years afterwards when I found out my first granddaughter was going to be born.

Participant 3771: I was exhausted. I really didn't have any energy.

Participant 3826: I was in a fog. I didn't have any energy.

Participant 5024: I was the only one not crying. I couldn't. It really ticked me off that I couldn't cry. What's wrong with me?

Physical feelings. While psychological features related to grieving were noted, a majority of the participants, over 50%, also experienced physical symptoms. These physical manifestations of grief were not always recognized as part of the grieving experience, resulting in the bereaved consulting with their physicians. The intensity of these somatic responses caused significant physical distress for the bereaved and exacerbated their psychological suffering.

Interviewer: What do you recall regarding how you felt physically?

Participant 5024: It was very physical. I felt very much like I was having a heart attack. I had intense tightness in my chest. It was difficult to breathe and I remember trying to walk and I felt like my legs weighed a thousand pounds each. I think from a physical standpoint, the only other thing that was a challenge for me was that I couldn't sleep.

Participant 0875: Lack of sleep, high energy, and I had a hard time breathing for a while. Kind of like shortness of breath.

Participant 249: I was really cold. Freezing cold and shaking. Shattering cold; I was cold and never got warm. I was cold for probably a year. I would walk around with like jackets on and I'd be shaking. It was freezing all the time.

The majority of the respondents noted that they were unable to function or felt as they were just going through the motions. This was described by a number of the

respondents as being a zombie or not present. For a number of the participants, this resulted in difficulty parenting their surviving children. The somatic or physical manifestations of grieving for the interview participants is documented in a succinct summary (see Table 5).

Table 5

Physical Symptoms Reported by Parents

Physical symptoms	Theme frequency
Anxiety	6
Insomnia	5
Heart pain	5
Low energy	4
Difficulty breathing	3
Generally feeling	3
Sick	
Poor appetite	3
Dizziness	2
Heaviness	2
Stomach upset	2
Feeling cold	1
Involuntary vocal	1
Tics	
More energy	1

Note. $n = 13$

Spiritual beliefs. When facing the death of a child, many of the participants experienced a shift in their spiritual beliefs. Having a spiritual foundation and belief system was identified as a strength or was identified as too restrictive, in the context of their grief. Regardless of the spiritual orientation of the respondents, the majority experienced a shift in their established beliefs (see Table 6).

Table 6

Reported Change in Spiritual Beliefs

Change in spiritual beliefs	Theme frequency
New understanding or reevaluation	5
Abandonment	4
Increased or Renewed beliefs	4
No change	1

Note. $n = 14$

Participant 0875: Yes. One hundred percent, yes. I don't know how much you want to hear.

Interviewer: Please, go right ahead.

Participant 0875: Honestly, I pretty much didn't want to live anymore. I had just hit the bottom. To go from a normal life with everything being fine to that position three or four days later, whatever it was... Anyway, in that moment, I realized somewhere and somehow I couldn't do it anymore by myself. Basically this is where I wound up living life my way. It was either I wasn't going to live anymore or I needed something else. I just felt God's presence and I felt all of <deceased child's name> prayers and her... She'd pray with me and she was a Christian. I just felt everything leading me right to God. Basically my wife came and my pastor and my dad and other people I trusted and I basically wanted Christ to lead my

life. Anyway, so that's kind of my conversion story and it all happened pretty quickly. I think it saved me. I didn't have anything else.

Participant 262: You know, so a lot of the religions that I did embrace were kind of out the window because I don't like that only the good die young.

What the hell kind of idea is that? Am I offending you with language?

Interviewer: Absolutely not. Please do not worry about that.

Participant 262: Ok, so I am just saying that my attitude was like... What the hell? Why, if there is a God? Why would God do this to people and take them young? It doesn't make any sense.

Participant 3099: Well, off and on, I would get... 'cause I am a Christian and I am a strong believer in faith and prayers. In fact, his twin sister, her middle name is named after a Bible verse and her middle name is <middle name> so... I have always had a strong faith but I would get mad at God. I would lash out at God. You know, why is my son not worthy of a miracle but yet all these other people, they are? It's like I gave him so much more than a miracle, the miracle of life and he's in my presence. That comforts some but it doesn't make me miss him any less.

Participant 3490: I thought that as long as you were doing the right thing and you were a good person, life is going to be better and better. You were going to be provided for and God was going to take care of you. God was... I don't know, I just thought that everything was going to be ok. I just never... How I think of it is naïve now and after <deceased child's name>

passed away, I realized that I was being a good person and just bad things can happen to anybody, even if you are doing all the right things in life. You can't just pray for protection from God and that nothing bad is ever going to happen or be a good person and nothing ever is going to happen to you. For me, I just moved from the idea that God as an entity that controls to be more of a spirit that connects you more to like, connected me. Knew how to connect me or figured out how to connect me to the sources I needed to keep going or to heal or figure out what to do in the aftermath of anything.

Participant 3771: I think I don't affiliate with a religion differently but I do believe that we are sort of tied in and stuff like that. A little more liberal but I don't identify with Christianity tighter or better.

Participant 7486: My faith absolutely deepened because I was at the end of my rope. I had nowhere else to go. There was no other hope. I started immediately praying to God and reading the Bible. I knew I couldn't survive without it. It has done some remarkable things for me. I have had some amazing and incredible things happen. God has been there and worked through me, and showed me some things that my job here is not done. Amazing things, so it has been great.

Interviewer: It sounds like your faith and your spirituality was such a big part of dealing with whatever came your way.

Participant 7486: Yes it was. I would not have survived if I didn't have God.

World view. While the majority of participants experienced a shift in their spiritual beliefs, it was also noted that most of the participants experienced a change in their world view. The significance of this was documented in the data recorded from the transcripts. This included becoming more disconnected or isolated (see table 7).

Table 7

Reported Changes in World View

Change in assumptive world view	Theme occurrences
Bitter or more Cynical	4
See the world as more unsafe	3
Wanting to help Others	2
Loss of innocence	1
No change	1
Uncertain	1

Note. $n = 12$

Interviewer: Did your experiences change your beliefs regarding the world in general?

Participant 887: I became pretty cynical after that. I took quite a long time and I couldn't give you exact months or years that it took, but after that, I became cynical. Understanding that people are not who they say they are.

Participant 9032: I feel like maybe at first, I may have hardened but eventually, I want to help people because of what I have been through. I felt like I didn't get a lot of help. Not a lot of people know how to help people who have lost a child. It's very awkward like; what do you say?

Participant 1254: From my perspective, I would say yeah, it changes your outlook some. I still think that most people are good. As I mentioned before, human beings are the only creatures that have a free will. I came to the conclusion that the people there, for whatever reason, chose to use their free will to do evil.

Question 2: Family Experiences

Grieving with their partner. The interview participants related their experiences as they grieved with their partners. The majority of the participants, 93%, reported that they were unable to openly grieve with their partners. While grieving together may have been possible very early on in their loss, eventually couples would drift apart or separate. In general, the most frequently reported difference related to problems with communication. This was frequently noted as a partner's willingness or unwillingness to talk about their shared loss with their partner.

Interviewer: What do you remember about the differences regarding how you and your partner grieved?

Participant 875: Probably just about everything.

Participant 875: I needed people so I became a social butterfly on steroids. It was almost my therapy and it was what I needed, to just be with people. I did and it was great. I think I spread myself around to enough people so they didn't get tired of me. I think it was what I needed and it worked for me. She kind of withdrew and didn't want to talk to anybody. She devoured

books about grief and I couldn't focus on a book if I tried. I couldn't sit and read; there was no way.

Participant 262: I feel that he grieved more than I did. I mean, he just couldn't even believe that she was dead. He couldn't say the word. He kept saying she was sleeping.

Participant 3099: I shut myself away and became numb but he will lash out. He quit drinking but when he has episodes, because he is an alcoholic, he will turn to that. Yeah, we do grieve a lot differently.

Participant 3490: It seemed like in the beginning we were a lot more gentle with each other. Just a lot more compassionate, caring, and understanding. You know, just there for each other. That just changed over time.

Three participants noted that over time, their marriages ended for a variety of reasons. One of the participants alluded to her husband getting remarried due to how his spouse had changed after the loss of their child. Other problems included differences in the trajectory of grieving for each individual in the relationship.

Participant 249: The amazing thing is that he got married again and I kind of knew the girl that he married. I talk to her and stuff. She said, you know why he married me? I said why? She said, because I remind him of you before <deceased child's name> died.

Participant 9302: I think the main problem why we split up and got divorced was I felt that I needed him to be stronger even though he was grieving. Maybe it's a little bit selfish. I needed him to be stronger.

Reactions of family. In regards to how bereaved parents perceived the reaction of family members to their sudden child loss, most related disbelief and not knowing what to do. This included lacking the knowledge of how to provide support. Family members also related dealing with their own grief while trying to support the bereaved parents.

Interviewer: Can you tell me how your family responded to your loss?

Participant 249: They were bewildered and didn't know what to do.

Participant 3099: They were devastated. Me being an only child and my four other children and my parents, they were devastated. The extended family, they were as well. My dad, since that day, his health has declined.

Participant 5024: I remember my parents came and they hugged me and I had nothing to give.

Participant 431: I'd say my parents were in shock. They were probably in shock for many, many, months.

Surviving children. The majority of participants noted a change in their relationships with their surviving children. There was a split in the majority of responses that were in complete opposition to one another. These included reports of becoming detached or unavailable to their children or becoming closer. Of the 11 respondents who answered this question, four noted being unable to care for the surviving children and needing others to step in while four respondents reported becoming closer to their children. Only two of the respondents noted no change in relationship and one participant reported becoming closer and more appreciative.

Interviewer: Did you experience a change in your relationship with your child?

Participant #3099: It made me appreciate them a little bit more. Then, in the same sense, the older children, it made me a little more distant from them because they could not understand the isolation and everything more than <deceased child's name> twin sister. Her being 3, she's 7 now, and she understood that mommy still took care of her or mommy still did everything she could for her.

Becoming closer to their children was not the same experience voiced by other participants. This included feeling absent as a parent or children who voiced concerns that their parents were not the same people. Other experiences included complete disengagement from parenting and even abdicating parental responsibilities to other family members.

Participant #3826: Well... We have always been close and we probably got closer.

Participant #1154: So, <child's name> said to me... You know mom, I know you are not the same mom. She goes... I don't even know who you are anymore. I know <deceased child's name> wouldn't be happy and she said... What about me and <child's name>? We still need a mom.

Participant #249: One of my sons, my son that has the MS, right now he's not even speaking to me because he said that I was a zombie parent. That I just went through the motions.

Participant #1254: I know we both had the thought that, for us to pull away from them and not try to help them have the best life they can have would not be fair. How could we take that aspect of their lives away from them?

Family expectations. Another theme that emerged from the data included the absence of any grieving expectations expressed by family members. At least, when the loss was first experienced or in early grieving, most of the supportive families did not attempt to influence the trajectory of the parent(s) grieving process. This was evidenced in many of the participant transcripts. The interview data reflected that families who expressed expectations were in the minority for this study (see table 8).

Table 8

Family Reactions to Child Death

Family expectations	Theme occurrences
No expressed Expectations	10
Need to get over it and move on	1
Unhappy with Decisions made by parent(s)	1

Note. $n = 12$

Interviewer: Did you family voice any expectations regarding how you should grieve?

Participant #249: I think they basically stood back and watched.

Participant #3826: Not to my face and I wouldn't have cared.

Participant #431: No. No. I think they were... They were in disbelief and they didn't know how to process this either. No. No one ever told us move on or it's time to do this or that.

Participant #3490: No. No. I really didn't have that.

Participant #9302: I had people in my family that were like telling me... It was almost like their actions were telling me... You should be over this by now. This is not 1 year afterwards; this is like months, weeks or months afterwards. Everything I did, I would break down and cry and I would start talking about it and like... You know <interviewer's name>, you don't need to use <deceased child's name> against this. You don't need to... It's so hard to make people understand that, that's not it. You can't just get over it. It's not something you get over.

Participant 0875: I just think the willingness to come at the spur of the moment, to just come here. Be here for the services for days and just whatever we needed to do.

Participant 3099: I mean they were very supportive except for my husband. He chose to be drunk and deal with it that way. He showed up at the hospital one time and he was not very supportive. As far as my family, my children, and my parents, they were as supportive as they could be.

Participant 3771: Yeah, I did. Yup. No one expected anything other than whatever it takes, let's get it done.

Partner differences. When asked about their partners grieving experiences, the majority of the participants noted that they were unable to grieve together due to being in different places regarding their grief. This insight included acknowledgment that each of them had to cope with issues that stemmed from past losses or events. In some cases, their experiences caused a separation as grief was dealt with individually rather than as a couple (see table 9).

Table 9

Differences in Partner Response

Partners reactions	Theme occurrences
Refused or resistant to talking	6
No difference	1
Need for didactic information / Reading	1
Drugs or alcohol to cope	1
Unable to support Partner	1
Unable to emote	1
Isolative	1

Note. $n = 12$

Interviewer: What do you remember about the differences regarding the way you both grieved?

Participant 7486: Yeah, I mean we were on the verge of divorce for quite a while.

There was a lot of arguing and fighting because he was dealing with his own issues of grief. There were issues that resurfaced because of child loss. We both had a lot of personal issues going on and we couldn't

handle ourselves nether less the marriage. That was impossible. So that was our only hope was to go to counseling 'cause we also had another child we needed to take care of. Yeah, that would be an underlying factor, having another child and getting healthy individually before coming together as a couple.

Participant 431: I would say for a while, we were quite distant. We didn't talk about how we felt. I never felt like threatened or like I said earlier, like our marriage was bad. We were kind of in a stalemate for a while. We each kind of did what we wanted to do to survive.

As noted previously by participant 0875, the participant expressed how important it was to have social support. This included the need to be in the presence of others. His social needs were in contrast to his partner who valued time alone to read books related to grief and loss.

Participant 262, in a previously noted response, included her partner's inability to say the words that their child had died. He would express that she was sleeping but could not bring himself to say the actual words. Participant 3099 also explained that her partner had difficulty expressing his feelings and would lash out. The participant made sense of this by labeling it as one way that men and women grieve differently.

Interviewer: Did you find that you had to hold back a lot of your grief because of his lashing out?

Participant 3099: Yes. Not only because of him but because of my other children and the rest of the family. I felt that because they always did see me as the rock, therefore I have had to try to hide that.

Participant 3771: Fascinating. That's a good question. She never cried.

Unbelievably super strong person. Unbelievable and I know that when she went to pick up the death certificate, she broke down. You know, when somebody, when your child dies, somebody dies, you have to lean on somebody. Your spouse, if you are an adult and you are married. A child dies and both spouses are down. Who are you going to lean on?

Participant 3826: He could talk about what he wanted to with his customers and I didn't see, I really didn't see much of it. Then you know our marriage... But I do think for a year... Once again, somehow this numbness, I think on both of our parts, kept the marriage together. I was hopeful for that. I really didn't see him grieve. I saw him put up a strong front. I saw him try to blame the church. I saw... I never really, he wasn't really about to talk to me about it.

Participant 9302: Like if he was weak then I was being strong or if I was being weak and he was being strong. I felt like we just didn't have that with each other. I felt like I wanted to cry on his shoulder and I understand that he wanted to cry with me, but sometimes I needed him to be different. I needed him to be stronger and let me get it out.

Expressing feeling to their partner. A secondary theme was identified regarding how partners were able to express their feelings to one another. There were nine responses to this question and 67% of the respondents reported that they were unable to express their feelings to their partner. Of the respondents who reported an inability to discuss their feelings with their partners, all of the partners were male.

Interviewer: Were you able to express your feelings to your partner?

Participant 0875: I think so but I am not sure they were always listened to, but I would try.

Participant 3099: Because he is not as strong as me, as I was, not as much as I probably needed to; so no.

Participant 3826: At the time, my husband and I were still married. He traveled on the road and so he was gone four days a week. He did not want to talk about <deceased child's name> when he came home on the weekend. So I think for me, my first year to be perfectly honest, I'm not sure that I really remember it.

Partner support. When exploring relationships and differences in grieving, a specific theme that emerged included how the respondents attempted to support their partners in their grief. A total of 12 participants responded to this question and the majority of the participants noted being present and sharing emotions. At least three of the participants expressed that they were not supported or they were unable to provide support to their partners. This was also evidence of the needs of the bereaved to sometimes find support outside of the relationship or family.

Interviewer: I wanted to ask you what you remember about how <spouse's name> was feeling and what you did to support her? What was it you were able to do for her that was helpful?

Participant 875: I'd go sit with her and be with her at night. Try to talk to her, help bring her food, and try to get the things she needed.

Participant 249: Nothing. Not a thing. He didn't need any support. It was like it was all about me because I couldn't function.

Participant 1254: I think that, to me, all we could do to support each other was to try and be around each other and try to understand. I guess I'm at a loss with how to answer that because I don't know that I did anything brave and noble. Maybe quite to the contrary, I tried her patience a lot. I think that ultimately, we both felt that we had to support each other the best we can. We needed to know that neither of us is the same person we used to be but there is certainly no reason for us to intentionally tear each other apart.

Support received from partner. In relationship to how they were supported by their partners, respondents noted that being able to seek outside support or just being heard, was very important to them. Being present with their partner was also noted as a theme in the data. In addition, being able to seek community-based support or the support of other bereaved parents was also valued.

Participant 249: He let me have friends who were bereaved.

Participant 262: Well, it brought us way closer. He was the one person in the world who knew exactly how I felt. He was the one person in the world who never got tired of talking about <deceased child's name>, thinking about <deceased child's name>, looking at pictures of <deceased child's name>.

Participant 431: I mean, he was very supportive in that he was always around. He took time off from work. <Deceased child's name> family went away on a vacation for about a week. He was always supportive and saying that it will be ok and we will get through this. Then after a while, he kind of went into his own world and he would go into his workshop in the basement for hours on end and pattered around to do projects. Kind of in his own little world and I was kind of upstairs with the kids kind of thing. He went back to work. I never felt like our marriage was in trouble. We have various other things over the years where we have gotten through them but I never felt our marriage was in trouble. It was strong before our son died.

Participant 3099: I mean, they were very supportive expect for my husband. He chose to be drunk and deal with it that way. He showed up at the hospital one time and he was not very supportive.

Question 3: Social Experiences

There were several themes that emerged regarding the social experiences for the participants. These experiences included their work environments and relationships with

friends. In general, a majority of the participants noted a significant change in friendships that represented their lack of how to relate, avoidance, or a desire and expectation to quickly move on.

Participant 3099: They were supportive although, unless someone has been there, they don't understand.

Participant 3771: Some rose to the occasion and said... Let us spend time with you. Let us cook you dinners. You just hold a special place and they were there when we needed them. So I will always be there for them when they need me. You know they fade out quick, as you remember, right? They're on, a week later or a few weeks later they are let's move on; let's go. You're not and you're still stuck back there. If it's a running race, they are out at the two-mile mark and you're still putting your shoes on.

Interviewer: That's a great analogy.

Participant 3771: So you just have to understand that.

Participant 5024: So yeah, our really close friends, some of them, however were not able to handle it and desperately wanted to come but couldn't. I remember one really dear friend of mine and she called but she really couldn't talk to me and she was crying. I'm like, that's ok and I understand. When you are ready, I am still going to be here.

Participant 5024: My other friends, some of them didn't tell their kids for like six months. They would come over and would ask.. Where is <deceased child's name>? They were like... Oh, she's not here? I'm like, whew!

You didn't tell him? You've got to tell him eventually. It's just like boggles my mind and it was like... Well you know, my husband and I just don't want to upset him. It was too upsetting for them to have to explain it.

Interviewer: Do you feel that, that's kind of a theme in our culture regarding grief in general?

Participant 5024: You know, it seems to be... It never really occurred to me beforehand but I see that now.

Participant 887: The death itself did not but as time went on and people, don't want to say, stopped caring but stopped actively caring. Stopped actively being involved in my life, trying to be there and be supportive. As those people drifted away, I became disheartened at the... It's funny. I call it the don't get it on my syndrome.

Participant 1154: Needless to say that there were people who we considered friends prior to <deceased child's name> death that we have no association with whatsoever. None.

Most helpful interventions. While friendships often changed, many of the participants related how important it was for them to be allowed to express their grief in their own way. What was expressed by the participants as particularly helpful, was being able to talk about their deceased children or their grief experiences. It was also noted that a majority of the participants did not want to hear clichés that were often the result of friends not knowing what to say (see table 10).

Table 10

*Most Supportive Interventions
as Reported by Parents*

Most Helpful	Theme Occurrences
Doing things Without being asked	9
Being listened to	5
Cards and notes	4
Support groups	3
Prayers	1

Note. $n = 13$

Interviewer: What was most helpful regarding the support you received from others?

Participant 0875: Just being able to say what was on my mind and tell them about my frustrations. It wasn't always my grief that was discussed but probably half the time or more. I was trying to figure out how to work with the kids and help my wife. It was all of the dynamics of the situation. I needed people to bounce ideas off of.

Participant 249: The most helpful things is when people let you talk about your kid without trying to change the subject or let's talk about something cheerful instead. It's the pink elephant in the room. Whether we talk about it or not, I had a child and the child died and I still need to talk about the child. Does that make any sense?

Interviewer: That makes perfect sense.

Participant 249: Yeah

Interviewer: You are talking about people feeling uncomfortable and it's their own discomfort. When you talk about your child, they want to move away from or change the subject to redirect you.

Participant 249: Exactly.

Participant 3099: Prayer because as I said earlier, I am a strong believer in the power of prayer. Like Facebook friends and different things. People just saying that they are remembering me in their prayers, because to me, that has been the only thing that basically could help me through. It's that spiritual part of it to kind of bring me out of it.

Interviewer: Just knowing that others were praying for you. That was helpful?

Participant 3099: Yes, because really, there was nothing that anybody can do.

Participant 3490: I remember that people had to come over to make sure we had something to eat. Just sit with us and buy groceries or put toilet paper back on the roll. Whatever was supposed to happen. I couldn't do anything but just cry and yell and make these animal noises. Just listening. Not trying to fix anything. Just really... Especially if you didn't know. If you hadn't been a bereaved parent, not to say I know how you feel or just say I don't know how you feel. Just say I am sorry for your loss. I can't imagine how you are feeling.

Participant 3490: We found that we had two types of friends. One type of friend could sit with us in the living room and cry and the other type of friend had to go in the kitchen and clean. So we learned. We were ok with that.

We were like this is one person and this is this type of person, let them clean and this type of person let them sit here and cry with us and we'll throw Kleenex on the floor.

Participant 1254: Friends were the people who would do what they used to do and be sensitive to what they said and how they did things. Didn't push if we said no. We don't want to go there or no, we don't want company right now. What we didn't want to hear was that I feel sorry for you type of thing or people who were just overly gushing with sympathy or emotion and you know some of it just didn't seem sincere.

Hurtful comments. The participants expressed their dissatisfaction with comments from others that were not helpful. For the majority of respondents, unhelpful comments included clichés and expressing unrealistic expectations. Study participants noted that they were particularly sensitive to the comments made by others in their social circles.

Participant 262: God had a plan or God needs her as an angel in heaven.

Participant 262: You can't cry. Don't cry. <Deceased child's name> will be wandering in purgatory forever if you cry. You need to stop crying so that her soul can rest in peace.

Participant 3490: Yeah, I heard a lot of stupid shit. We put a list on the door of the top ten stupid things that people said to us. We said... Don't say these. It's like a manifesto on our front door. If you came in here, do not say any of these things that we could hear. Yeah, people say stuff like... I

have even had people say like... Oh, before <deceased child's name> was born, you and him had a contract that he would just for a short time. I said... What! Fuck! Are you kidding me? Let me just kill one of your kids right now and see how you like your contract.

Participant 9302: Yeah, I think they think they are supposed to say something. I didn't need that. To me, I felt like they felt they needed to say something and that's not always true.

Participant 9302: Sometimes, people when they don't know what to say, it's just clichés. I'm sorry. I don't know how you feel. I can only imagine. Everything happens for a reason. He's in a better place.

Participant 887: People told me all sorts of nonsense, typical things about God wanting another flower in his garden. Just a bunch of rubbish.

Participant 3826: I will never forget pastor <name> saying to me that <deceased child's name> is in a better place. I remember thinking, oh no he's not! He needs to be here with me.

Participant 3490: They say stupid things and they don't know what to do. They don't say anything or they ignore you and that's just how they are 'cause they can't deal with it.

Unrealistic expectations. Within the context of the participant's social experiences, how others responded included several emerging themes. There were messages received from friends and others who supported the uniqueness of individual grieving. For a minority of the respondents, they experienced family members who set

time limits or unrealistic expectations regarding the trajectory of their grief. While this was not true in early grief, this seemed to be significant as time went on.

Participant 249: You know how it is and everybody wants you to pull it together.

I got a lot of lectures from people saying you have to hold it together because you have other kids. They act like having other kids makes everything, you know, doable. In reality having other kids is just another job.

Participant 5122: My uncle, whenever I talk about her, would say like... I don't see how you can still talk about her? I'm like; really? She's my daughter and I'm fine talking about her.

Participant 249: I got a lot of lectures from people saying... You have to hold it together because you have other kids.

Participant 3490: People that cared about me attempted to adjust to the new me. I had other people say... Oh, you're different. Yeah, I'm frigging different. What do you think? This is in a mean way not a nice way. Like.... Oh, you're not the same person anymore. They say it in a judgmental way.

Interviewer: Like please come back to normal?

Participant 3490: Right.

Observance of holidays. How holidays are observed after the loss of their child, was another area of exploration included in this study. The majority of the participants voiced that there were changes related to how they observed holidays. This included

changes that caused family conflicts due to nonobservance or limited observance of holidays.

Participant 0875: Yeah. We... I guess we would normally... Thanksgiving and Christmas and we would have Christmas here with a tree and whatever.

We would travel to family and we haven't done any of that. Basically, we kind of skipped the first year and went on a cruise for Christmas. We had a reasonable good time and we did it again next year. It has turned into a new tradition, if you will.

Participant 1154: Early years or the first couple of years, they were really hard.

For the first Christmas, I made like a special candle with pictures all over it that we would take to Christmas dinner. I mean they saw it. I'd say like now, Mother's day is harder for me. His birthday is right near Mother's day and that was kind of a double whammy. I would say now, 16 years later, the holidays are good, normal, happy.

Participant 9302: I think it changes every year. Some years it's more present than others. This year, his birthday falls on Thanksgiving so I'm not really sure how this year is going to go.

Returning to work. Six participants who returned to work noted that their leave varied from one week to several years, while others never returned to work. For those who did return to work, it was important to have a very gradual and flexible work schedule. This allowed for adaptation and a gradual reentrance into the workplace.

Participant 1254: I don't even know how long I was off work. I kind of said, I'll be back when I can. Weeks went by and I would go in for 1 hour or 2. I had a job that was high customer contact and I was just at the point where I couldn't. I just had a very hard time functioning and I remember that I was actually at our family physician's office for more of the checkup than anything. He just kind of said... We need to talk about everything because the path that you are on, you are not going to make it. You've got to do something and I think not working would be a good idea.

Participant 9302: My employer talked to me, asking me when I was going to come back and this was maybe a week after he passed away. When am I coming back? When am I coming back? You know... I just... I'm not coming back. I'm just not doing this.

Participant 7486: I didn't go back to work for 3 or 4 months.

Question 4: Balance and Adaptation

Trying to come to terms with the loss of their child included ways to regain a sense of balance or adapt to the new reality of their life. One specific theme that emerged from the data, included getting back into routines that existed prior to the death of their child. Two of the three male participants in this study, sought attempts to adapt through activities or doing things (see Table 11).

Table 11

How Parents Attempted to Adapt and Gain Balance

Attempts to adapt	Theme occurrences
Reestablish old Routines	5
Support group	3
Nothing	3
Professional Support	2
Giving to others	1

Note. $n = 14$

Interviewer: What did you do to try and adapt or gain a sense of balance?

Participant 0875: Well, I was involved socially in a men's church group that I attended for a year. I got pretty active in the church, doing different things. I think that really helped me. There were things to do and people to talk to. All those things helped me, especially since things were hard here. I needed something positive to do.

Within the same theme as adaptation, a subcategory emerged that included helping other bereaved parents. This was voiced as a desire to reach out to others. In part, this was due to what they would have liked to have had available for them.

Interviewer: It sounds like that very early on, it was important for you to be active in helping with something as well as getting support but you were also doing something that was an activity where you were giving back.

Participant 0875: Yeah, I think so. As a matter of fact, one of my catch phrases are helping is healing. I feel like a lot of people... Even when we suffer

and suffer who knows what... We are all going to... I just feel that even in that, I think if you take a break, and sometimes it's going to be all about you. I just don't think all the time. On top of that, the power of that help when you can reach out in the midst of your suffering and help somebody else, it's unbelievable the amount, just how far that goes.

Participant 3099: I will do things to try and help other parents or prevent another parent from going through the loss of a child.

Participant 5024: I certainly have a great degree of guilt over her death but I use it constructively. I don't wallow in it. I can't go back and change it now. All I can do is try and educate others to prevent what happened to her from happening to them.

Participant 5122: I have written a child's book called <book name>. Funny enough, it's due to be released next month, right around the time of her passing.

Interviewee: That's amazing.

Participant 5122: It's a blessing, yes, because then it will be a call for celebration and I see it as a time to celebrate and not be sad, not get depressed and thank God for who he is and what he has done for me. I'm throwing a book launch party!

Interviewer: Wonderful.

Participant 5122: Yes Tom, it will be a time to celebrate and of course to remember her and to share my message of hope and water safety and also share <deceased child's name> story.

Participant 3771: A lot of lobbying and I spoke at every news conference in the world. I spoke too, right in front of the Senate House Committee. TV interviews for every channel, radio interviews, and newspaper interviews. It was on TV all the time.

Seeking counseling. Exploring, seeking, and engaging in individual counseling became part of the respondent's experiences, as they attempted to adapt to their loss. Of significance regarding this theme, is what was most helpful when participating in individual grief counseling. Respondents who sought therapy did not acknowledge this as a way to adapt or find balance. The following quotes from the interview transcripts are representative of the experiences of participants who sought individual grief counseling (see table 12).

Table 12

Experiences of Parents in Grief Therapy

Most helpful experiences in counseling	Occurrence of theme
Receiving Information	4
Being heard or Validated	4
Receiving Permission to Grieve	3
Found it unhelpful	1

Note. $n = 7$

Interviewer: Was there something that was particularly helpful from the professional support that you received?

Participant 0875: Well, I just think he was a good listener. He hadn't been through child loss or anything but I think he was very supportive. He was... It was nice to have somebody who was looking out for me; if that makes sense? He didn't focus concern for my wife or my children or my relationship. He was concerned about me. In the end, I didn't have that many people who were.

Participant 5024: I think it's the validation that, what I was thinking and feeling, and experiencing was normal. The encouragement to seek support. That helped me. The person I went to was very holistic in her outlook and she said get a massage, get Reiki, get acupuncture. Go for a walk outside and

it's ok to lie down on her grave and connect that way. It's ok to look at pictures that you took. It's ok to do whatever you want. It's ok to think that you see her, you feel her, you talk to her. It's all ok. You are not broken you are grieving. That was really reassuring because there were times that I really thought I was very broken.

Participant 5122: Not to blame myself. Not to feel guilty. It's ok to grieve. They gave me the option, if you ever need someone to talk to.

The only identified discrepant cases were participants 1154 and 1254 who were at times, able to hear each other when their interviews were conducted. While this was not an issue identified during data collection, there was the potential for the presence of the other participant to influence the answers of the interviewee. No other cases were identified as discrepant during the interview. All interviews were successfully completed once they had begun.

Evidence of Trustworthiness

As described in Chapter 3, the credibility of this research is grounded in the specific methods used to ensure the accuracy of the recorded data. One such method described by Creswell (2012), is peer consultation. This process was completed with Dr. Sandra Owens from the University of Nevada, Las Vegas. Dr. Owens is a seasoned researcher and is well versed in both qualitative and quantitative methods. This consultation was approved by Walden University IRB allowing Dr. Owens to have access to the data and participant related information, as necessary. The meeting consisted of a

review of the data collection, coding, and the identification of themes. Dr. Owens's did not voice any concerns related to the analysis of the data or the coding procedures.

In addition to the peer consultation, participants were provided a copy of the completed transcripts for review with an invitation to provide feedback on any contents. Providing the transcripts to the participants allowed for the verification of accuracy and meaning that was conveyed during the interview. At the time of the writing of this content, only one participant had a question related to meaning that required a review of the interview recording. Other comments included typographical errors made by the transcriptionist or dissatisfaction with the way they interviewed, such as rambling, use of nonlexical utterances, and not being succinct in their responses.

I reported in Chapter 3 that this study and the outcome results may not transfer to other age groups of deceased children, or other types of loss such as found in cancer-related studies. No change has been made to directly influence the transferability of this study. This study was designed to address a gap in the current research that was not captured in more generalized studies exploring parental bereavement.

In Chapter 3, I provided a description of procedures that were put into place to address issues related to dependability. These procedures and practices included the use of a single coder and interviewer. In addition, a professional transcriptionist was used to transcribe the interview recordings. There were no changes to the aforementioned procedures or practices that might affect the dependability of the study.

Confirmability or replication, as described in Chapter 3, included the documentation of the interview process, coding, and peer consultation. These processes

were documented and then put in place during the interview and analysis phase of this study. The change in interview venue that included phone versus face-to-face interviews, does not pose a threat to the ability to replicate the study. No other changes were made related to confirmability.

Results

Research Questions

What were the initial experiences of parents who lost their child? The interviewees for this study reported their initial experiences and responses to their child's death, such as shock, disbelief, and feelings of fatigue. Their experiences were representative of both psychological and physiological states in response to their loss. A sense of not being present in the reality of their loss was also noted. Of the 13 participants who made reference to physical feelings, there were a total of 38 references made to the physical manifestations of grieving.

The physical manifestations, as reported by the participants, included feelings of having a heart attack, including tightness in the chest. There were also issues related to difficulty breathing or shortness of breath. The most prominent of the physical feelings reported by the respondents included insomnia, anxiety, and feelings that centered on the heart.

Another aspect of initial and early grieving included a shift in spiritual beliefs. Respondents who identified their spiritual beliefs as a strength, were able to deepen their faith. This was also noted to be a source of support for the bereaved. The other extreme included participants finding their beliefs too restrictive or no longer applicable. The

result was an abandonment of their original beliefs or a reevaluation and reinterpretation of their beliefs. Only one of the participants interviewed reported that there was no change in their belief system. As a result, 92% of the participant noted a change or shift in their spiritual beliefs.

Along with a shift in spiritual beliefs, the majority of the participants responded that they experienced a change in their world view. This included feelings of cynicism and a general distrust of others. At least one participant noted that she felt hardened by her experiences. It was also related that over time, there was a desire to give back to others.

What are the familial experiences of bereaved parents selected for this study? Uncovering the familial experiences of the respondents began with themes that related to the differences in how partners grieved. Each of the participants described their perceptions of how their partners grieved and the noted the differences. The majority of the respondents, 93%, expressed that their grieving experiences were different, causing a shutting down of communications between them. There is a theme of grieving alone that is noted in the interview transcripts.

The majority of participants noted that their families did not voice any expectations regarding how they should grieve. Of the 12 respondents to this question, 10 reported that there were not subjected to unrealistic expectations. The remainder of the participants related that family felt they were making rash decisions or were waiting for them to return to normal. In general, the majority of the participants noted that they felt supported by their families.

What are the social experiences of bereaved parents selected for this study?

For the purposes of this study, the social experiences of the participants included their friendships, work colleagues, and general social interactions. The majority of the participants noted a significant change in their friendships. Out of 13 respondents to this question, nine participants indicated a loss of friends or reported that others avoided them, due to the loss of their child.

When asked about what was most helpful to them, 13 of the respondents related that others doing things without being asked, followed by being allowed to talk about their child, was most helpful. Doing things without being asked included the delivery of meals and basic needs for the family. In addition, respondents indicated that speaking with other bereaved parents and those who would just listen, was helpful.

One of the most hurtful experiences described by the respondents regarding the expectations of others, included the use of clichés, such as God needed another angel. Another common theme included others, who would tell the bereaved that they had to get past the event due to their responsibilities in taking care of other children. It was generally acknowledged by the respondents, that their social contacts did not want to hurt them and that they just did not know what to say. Some of the participants related this to those who were waiting for them to return to normal. These issues have the potential to increase isolation for the bereaved and exacerbate their grief.

Respondents, who eventually returned to work, did so as early as one week after the death of their child. One participant experienced a secondary loss after he was told that he no longer had a job and could reapply when he was well enough to return. For

those who did return to work, it was a gradual transition requiring a flexible work schedule. Of the respondents who returned to work, the majority reported that their coworkers were sensitive and supportive.

How did parents respond to their loss in an attempt to adapt to a new reality? When asked about how the participants had attempted to adapt to the reality of their loss, the most frequent response included engaging in old routines. This may have been something as simple as paying bills or going shopping for groceries. Support groups were also noted to be a resource sought by parents, with the most helpful groups being homogeneous and exclusively made up of bereaved parents. The majority of the participants were able to identify specific things that they did to try and reestablish balance or adapt to a life that was forever changed.

Summary

The scope of this study included the subjective, individual, familial, and social experiences of 15 bereaved parents, whose children, between the ages of 2 and 12, suddenly died. In addition, through this research, I uncovered how the bereaved attempted to adapt to the reality of their loss. The methodology utilized included a interpretive phenomenological analysis (IPA). This complex phenomenon was described by the participants in the form of themes that emerged from the interview data.

Identified within this study, are themes of dissociative experiences due to shock and disbelief, leaving many of the participants unable to function. Within this context, the value of others stepping in to provide basic needs and lend support was a significant

theme. This was identified in the transcripts as being particularly helpful to the respondents in their early grief.

As part of their grieving experiences, respondents noted both psychological and physical or somatic experiences that need to be addressed as part of the grieving process. The physical manifestations of grieving, were described by the respondents as causing insomnia, heart pains, and anxiety. A total of 13 out of the 15 participants related having physical issues that were associated with the death of their child.

In addition to emotional and physical effects, the potential for a shift in spiritual beliefs was also noted by a majority of the participants. This change in spiritual beliefs was identified as both a strength and secondary loss. Other shifts included changes in the participants' assumptive worldview to include the bereaved individual's sense of safety and security.

Within the family system, the importance of not expressing expectations regarding how grieving will occur, was also noted as an important theme. This was also an indicator of how families acknowledged and validated the dynamics of grieving, its variable trajectory and what is most helpful to the bereaved. Also within the family system, is the potential for the distancing of couples, in part, due to not understanding the differences in grieving styles. For the respondents in this study, this included not understanding the variability, intensity, and duration of early grieving.

The social experiences of bereaved parents in this study, as reported by the participants, reflected the loss of friendship as a secondary loss. As related within the identified themes, the majority of respondents experienced avoidance by friends. In a

number of instances, the interviewees expressed that their friends were not equipped with the knowledge and understanding of what to do, further exacerbating avoidance.

Finally, attempts to adapt to their loss included a significant theme of returning to previously established routines. These routines could be as simple as paying bills, doing dishes, or reengaging in activities outside of the home. This also included the creating of new rituals to cope with holidays and special occasions.

In Chapter 5, I revisited the purpose of this study, based upon the need to expand existing knowledge. The findings, based on the individual interviews of the bereaved parents, are compared to the existing body of literature. This included the most current research consistent with the focus of this study. Implications for social change, within the boundaries of this study, was also explored. Finally, recommendations related to informing practice and expand understanding of sudden child loss within the limits of this study, are identified.

Chapter 5

Introduction

The purpose of this interpretive phenomenological qualitative study was to explore the lived experiences of a subpopulation of bereaved parents who are not traditionally the focus of the current literature. I explored the narratives of bereaved parents who experienced the death of a child who was between the ages of 2 and 12 years. The research questions included:

1. What were the initial experiences of parents who lost their child?
2. What are the familial experiences of bereaved parents selected for this study?
3. What are the social experiences of bereaved parents selected for this study?
4. How did parents respond to their loss in an attempt to adapt to a new reality?

I performed my analysis using an interpretive phenomenological methodology to uncover emerging themes within the data. All participants resided within the continental United States and had experienced the sudden loss of a child between the ages of 2 and 12 years at the time of death. The prevailing themes identified in this analysis, included the attempts of the respondents to come to terms with their shattered reality.

Superordinate themes reflected the research questions that framed this study. These included early grieving or initial experiences, familial experiences, social

experiences, and adaptation to loss. These themes were representative of the lived experiences of the participants and included the following:

1. The psychological and physical manifestations of grief.
2. The inability to function and remain active in life.
3. Grieving with their partners and grieving differences.
4. Support provided by partners and provided to partners.
5. Shifts or changes in spiritual beliefs.
6. Changes in assumptive world view.
7. Familial experiences.
8. Social experiences and friendships.
9. Attempts to adapt to the reality of the death of their child.

Interpretation of the Findings

Early Grieving Experiences

Several themes and subcategories embodied the data related to the early grieving experiences of the respondents. This included the participants expressing that they felt absent and unable to function. This sometimes prolonged state of shock resulted in difficulties performing everyday tasks. As a result, a number of the participants reported being unable to effectively parent surviving children. For several of the participants, this created an estrangement from their children, with other people stepping in to provide care. Harper et al. (2011) described that surviving children provided a focus or reason to continue living. In this study, the participants echoed this phenomenon. However, several of the respondents noted needing someone to initially take on the role of a

surrogate parent during their early grief. In the participant transcripts, the presence of what seemed to be significant impairment related to caring for surviving children, is worthy of additional research. Providing a temporary source of surrogate or supportive care for surviving children, may also be an area of intervention for bereaved parents. This may be particularly valuable in their early grief. In a study by Barrera et al. (2012), the authors explored the experiences of bereaved parents who were between 6 and 18 months postloss of a child, due to cancer. The participant base was made of 20 respondents and 87% had surviving children. In their study, the presence of surviving children was noted as a strength in coping with early grief. Further research may lead to information related to variables related to grief and the presence of surviving children.

The majority of the participants described their grief as physical in nature. The physical manifestations of grief included feelings of having a heart attack, including tightness in the chest. The top three complaints noted by those participants included heart pain, anxiety, and difficulty sleeping. Other physical complaints included low energy and generally feeling sick. There were also issues related to difficulty breathing or shortness of breath. The most prominent of the physical feelings reported by the respondents included insomnia, anxiety, and feelings that centered on the heart. This is consistent with the work of Cacciatore et al. (2013), who in a broader study, explored the experiences of bereaved parents as physical in nature. In the study by Dr. Cacciatore et al., a minority of the participants did not note any decline in overall health and reported that the health of some of their participants, improved. This may indicate the need for

additional studies that focus on this population of bereaved parents and the somatic experiences and health consequences related to grieving.

A shift in spirituality was also noted in the participant narratives. Only one of the respondents denied a change in his established beliefs. The majority of the participants reported that their established beliefs were abandoned or reevaluated. The rationale for the change in beliefs may be a direct result of the disruption of the participant's assumptive world. This is consistent with the work of Parkes (1988) and psychosocial transition theory. As such, the individual is left with having to come to terms with a world that does not make sense. A small number of the respondents expressed an increase or renewal of their established spiritual beliefs. This is in contrast with the findings by Alam et al. (2012) and their study exploring the experiences of bereaved parents. Based upon the study results, the majority of their participants in the Alam et al. study continued to maintain a strong religious connection. The majority of the participants in this study, approximately 93%, experienced a shift in their previously established beliefs. Included in this shift is a complete abandonment of their previously established beliefs by 29% of the respondents. The significance of spirituality as a way of coping with the devastation of loss, was also noted by Sharpe et al. (2013). In their study of death due to homicide and suicide bereavement in African Americans, spirituality was helpful in coping with death due to homicide, but not necessarily suicide. This may identify an area for further study related to this subpopulation of bereaved parents.

In this study, I identified that the majority of participants experienced a shift in their beliefs about the world they live in. This shift was noted by the participants as a change in their assumptive world view and was not necessarily a direct result of how the death occurred. This phenomenon was one of the potential factors that increased isolation and poor support for the bereaved parents included in this study. While this phenomenon may not be a direct result of how the loss occurred, it may be due to how parents perceive their ability to ensure the safety of their children. In addition, this may also relate to the parents sense of responsibility for keeping their children safe. The increased isolation may be a direct result in social stigmatization, as others make assumptions or judgments regarding the death of the child within this age group.

Familial and Partner Experiences

Related to the respondent's familial experiences, I identified a subtheme that respondents found it difficult to support each other in their grief. More specifically, participants frequently found it difficult to express their feelings to one another. This resulted in feelings of isolation and in some cases, was noted to precede a separation or divorce. Essakow and Miller (2013) identified that in the reality of child loss, each of the marital partners has forever changed, requiring an adaption to a new reality. However, the study by Cacciatore et al. (2013) did not confirm this phenomenon. The majority of the respondents in their study reported an improvement in postloss partner relationships. This current study was consistent with Thompson et al. (2011), and their finding that differences in the way partners grieved may be misunderstood by their significant other, causing relationship difficulties. In a study by Barrera et al. (2012) of parental

bereavement due to death as a result of childhood cancer, the authors identified gender differences in grieving. Men were described as more private and stoic in their early grief responses while women expressed their grief more openly and intensely. One respondent identified the belief and observation that women weep and men get angry. In contrast, a study by Alam et al. (2011) explored the gender differences in coping with child death due to cancer. Included in their findings, are the differences in the bond related to parenting. This may be representative of who assumes the role as the primary caregiver and the trajectory of grieving.

The majority of the respondents noted that their families were supportive during their early grieving experiences. This included the absence of any specific expectations regarding the trajectory of grieving. The lack of expectations was particularly noted in the first year of grieving but this was not necessarily true as grieving continued. This represents an honoring of grief as an individually unique experience. The majority of participants in this study did not identify the loss of other children in their family history. One participant noted that a relative who experienced the loss of a child was least helpful in providing support. His own expectation is that she would be a greater source of information and support.

Social Experiences

The majority of the participants identified a subtheme of changes in their established friendships. The respondents were able to identify this phenomenon as a secondary loss. Umphrey and Cacciatore (2011) identified the significance of support groups in helping to establish a network of caring and understanding friends. This

phenomenon was also reported by Ghesquiere (2014) in their qualitative study of bereaved parents related to complicated grief. The authors, through their collected data, related the experiences of the participants regarding sudden estrangement from family and friends shortly after the death of their child. The absence of expected support was identified as an experience that exacerbated grief.

For friends and supportive others, there were specific things that the participants found helpful. The majority of participants identified that others who did things without being asked, was most helpful. This included making meals, stepping in to help with children and doing things around the house as simple as changing the toilet paper. Tasks that are often considered mundane and simple were found to be difficult to complete, especially during early grieving.

In addition, allowing parents to talk about their deceased children was also noted as a helping theme. This was in contrast to what some of the participants labeled as avoidance by those who would attempt to change the subject. Avoidance in social interactions had the potential to increase isolation for those who are suffering the loss of their child. Hunt and Greeff (2011) identified this sharing of memories as one way for bereaved parents to maintain a connection with their deceased children. In the absence of knowing what to say, the majority of the respondents noted that the use of cliches were extremely hurtful and also exacerbated grief while increasing the likelihood of isolation for the bereaved. This was identified by a number of the participants who expressed being very sensitive to comments made by others even though they recognized that their intentions were not to be hurtful or disrespectful.

How the observance of holidays had changed since the death of their child, was reflected in several themes. The majority of participants noted that their holidays had significantly changed in contrast to preloss years. This included minimal to complete avoidance of holiday and family celebrations. One participant reported going on a cruise to escape the holiday festivities. This phenomenon is also representative of how the bereaved attempt to adapt to the reality of their loss. Cacciatore and Flint (2012) reported that part of the rituals observed by bereaved parents included acts of altruism. This included the purchasing of gifts for other children during the holidays. The use of rituals was an important aspect of maintaining the continuing bond with their child. Another example of how parents attempt to adapt to their new reality and the holidays, is included in Umphrey and Cacciatore (2011). The authors explored the narrative themes within a grief support group. Participants in their study openly shared stories to assist in coping with the holiday season. Parker and Dunn (2011) also identified that adaptation included new traditions, which were created to honor the deceased child while maintaining some of the old traditions that were not as painful. The results of the aforementioned studies appear to be consistent with the findings included in this current research.

Of the 15 participants who participated in this study, six returned to work. Themes associated with adapting to the workplace and receiving support from coworkers were identified. The length of time absent from work varied from one week to several years. The importance of having a flexible work schedule was identified in the respondent transcripts. For the majority of the respondents who returned to work, they found coworkers to be understanding and work to be a distraction from their grief. In the

Gipson et al. (2010) study (described previously) bereaved parents who returned to work expressed a number of concerns that included how they or others would respond to discussions related to their loss. Several of the participants in this study avoided social interaction to mitigate their feelings of guilt, anxiety, or being judged by their colleagues. As related in the participant transcripts, this did not seem to be as big a concern for participants in this current study, who experienced compassion and support from their colleagues. Breen and O'Connor (2011), in their study of family and social networks for the bereaved, reported that a significant source of support included colleagues. They found that coworkers were reported to be compassionate and understanding though the duration of this was sometimes short lived.

Adaptation to Loss

Attempts to adapt to the reality of their loss included reestablishing old routines and seeking out support, including professional support. In addition, a subcategory included giving back to other bereaved parents by sharing their own grief experiences. This was inclusive of being part of something bigger and meaning making associated with their loss. While support groups were identified as helpful, this was dependent upon the type of group, with homogeneous groups identified as being most helpful. Dyregrov et al. (2013) explored the recommendations from grief support group members related to what was most helpful and how to improve grief groups. The participants identified that having information prior to entering the support group was very helpful. This included being informed if the groups were heterogeneous or homogeneous in nature. It was also identified that homogeneous group increased overall group cohesiveness for the

members. The findings included in Dyregrov et al. (2013) were relevant to this current research in that homogeneous groups were preferable, for those who sought out support groups. Homogeneous groups were an absolute requirement for those participants who investigated this type of support. For several of the bereaved parents, their dissatisfaction related to this type of support, was the absence of groups inclusive of participants who had experienced the loss of a child. They did not want to be grouped with those who had experienced other types of losses. In this current study, this was also a reason that some of the participants sought out individual grief work versus seeking out a support group.

Professional support was sought out by five of the participants. What was most helpful, as reported by the respondents, was normalizing their grief. Being told that their experiences were normal, was a helpful part of adapting to their loss. Two of the participants noted interacting with therapists who either invalidated their feelings or were not able to handle the emotional aspect of child death. More frequently, the respondents were apt to attend grief support groups. In general, groups were noted to be safe places where respondents could openly share their grief with others who had some insight into what they were going through. Hunt and Greeff (2011) conducted a study of central themes of bereavement for 22 bereaved parents. Their respondents reported disappointing interactions with mental health professionals due to a fundamental lack of experience and mistiming of interventions by the therapist. Giannini (2011) also explored the narratives of five bereaved parents. Two of the participants sought out professional support and one couple was terminated from services after two or three sessions, when they were told they were ok.

Limitations of the Study

To participate in this study, participants must have experienced the sudden loss of a child who was between the ages of 2 and 12 years at the time of death. I identified the appropriateness for each of the participants based on their responses to the prequalifying survey. When possible, this was also verified through public records, verifying the length to time since the child died and the cause of death. In addition, the study results may not generalize to other types of losses or groups of bereaved parents due to the small sample size. This includes a potential study limitation due to the absence of other types of losses, such as suicides and homicides. There may also be homogeneity for the grieving experiences of parents whose children have died and are consistent with the parameters of this study.

Issues of trustworthiness were also mitigated through member checking. All of the respondents received a copy of the interview transcripts and were requested to comment if there were issues related to accuracy that affected the meaning of what was recorded. Only two of the respondents responded with corrections that were a result of typographical errors made by the transcriptionist. One respondent provided feedback that could have resulted in an issue related to the meaning of what was said and this was reviewed against the original recording for accuracy. In addition, each of the participants was provided with a copy of a theme summary. This included the themes that were uncovered for their specific interview. The participants were instructed to contact me if there were inconsistencies with the identified themes. Only one participant wrote back to express that the themes were extremely accurate.

In one telephone interview, the discussion was interrupted by another incoming call, which resulted in a brief interruption in the flow of the interview. In addition, members of one couple were in proximity of each other at different times during the interview. This could have influenced the responses provided by the two participants.

Recommendations

The results of this study included the early individual, familial, and social experiences of the bereaved who are representative of the respondents. In addition, their attempts to adapt to the reality of their loss were also included in the data. Themes included the respondents' memories of an event that significantly changed their life. What was made clear by the participants, is the need for social dialogue related to their experiences. This includes educating service providers on how to support and respond to those who are grieving the loss of their child, in addition to not assuming that all grieving experiences are the same and that all losses are dealt with in the same way. As many of the respondents noted, being in the company of other bereaved parents was particularly helpful because they seemed to understand the experience due to their own journey.

In addition, continued research related to the trajectory of grief and complicated grief for participants in this subpopulation of bereaved parents, is needed. Future research, specific to this identified group of bereaved parents, may include the exploration of the themes that emerged from this study. Also significant in the study data includes the general inability to function as noted by many of the respondents. This is also an area of potential future research related to this subpopulation of bereaved parents. The implications of this phenomenon include the need for more focused and task oriented

support in early grieving. While this type of support may be available in the early grieving experiences, the participants noted the withdrawal of this type of support, too early in their grieving process.

Implications

The implications for social change associated with this study include the advancement of our understanding of the lived experiences of this subpopulation of bereaved parents. This insight includes understanding grief as a result of child loss for this population of bereaved parents, as both an emotional and physical experience. Within the context of this phenomenon, the needs of the bereaved and how to best meet these specific needs, must be addressed. This may include the care of surviving children and addressing everyday life demands that may be beyond the ability of the bereaved. Interventions to address these issues must be considered within the context of a tendency towards isolation for the bereaved due to, in part, a shift in their worldview.

As I described in Chapter 2, bereaved parents may be subjected to various stereotypes and beliefs regarding how they should grieve (Breen & O'Connor, 2011; Cacciatore et al., 2013). These expectations may be unrealistic due to a lack of information related to the length of time and the process in which grief occurs. Through the completion of this study, I have been able to add to the existing body of knowledge as it relates to the variability of grieving and how the bereaved attempt to adapt to the reality of their loss.

As identified by the study participants, a lack of services or inadequate understanding of what is helpful to those who have experienced this type of loss, was

captured within this study. Informing practice includes the importance of creating programs that allow the bereaved to openly express their feelings and memories of their cherished children. The importance of this may explain the tendency of participants to engage in grief support groups, rather than individual grief therapy.

There are also implications for continued support and intervention beyond the first year of loss. While the majority of the respondents expressed that their families were very supportive, beliefs related to how grief should progress may set unrealistic expectations regarding the need for continued support. Consistent with the work of Parkes (1998) and psychosocial transition theory, shifts in the individual's belief system and assumptive world view may further exacerbate grief and increase social isolation. This phenomenon can represent a specific point of intervention that can aid parents in finding meaning in a life that has forever changed. It is also significant that the support needed in early grieving may vary greatly from the support needed after a period of early grieving. Furthermore, support may include helping couples to do grief work independent from one another with an understanding that they may be unable to express their feelings to each other.

Conclusions

I achieved the study objective of exploring a gap in the current parental bereavement literature. The themes within the participant narratives challenge the generalization that the loss of a child, regardless of the age of the child at the time of death, is a homogeneous experience for the bereaved. As such, while the study was not focused on specific types of losses, such as cancer, the goal was to explore bereavement

due to child death at a very specific age range, that was prior to an age when individuation occurs. I described, not only the devastating aspects of child loss, but the challenges associated with access to supportive services and navigating their loss, within the context of the participant narratives included in this study. These challenges represent multiple domains that include the individual, familial, and social experiences of bereaved parents. In addition, these experiences and sense of support provide a foundation for how the participants attempted to adapt to their new reality. While families are representative of the first line defenses for the bereaved in this study, this support may not have been long term due to expectations and families as they were jointly coping with their own grief.

The goal of this research was to gain a better understanding of the lived experiences for a specific subpopulation of bereaved parents. I explored the complexity of parental bereavement for the participants through the analysis of the data and themes. The courage and desire of the participants to share their individual experiences is reflective of their desire to advance social understanding of this type of loss.

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Appendix A: Prequalifying Survey

No.	Questions:
1	Name:
2	Gender:
3	Email Address:
4	Telephone Number:
5	Are you 18 years or older?
6	Do you live in Las Vegas?
7	Do you have any prior relationship with the researcher Thomas Fulbrook?
8	Are you able to communicate in English?
9	How long ago did your child die?
10	What was the cause of your child's death?
11	How old was your child at the time of death?
10	How would you like to be contacted? A) Telephone : B) Email:

Appendix B: Letter of Interest

My name is Thomas Fulbrook and I am a doctoral student at Walden University. As part of the requirements for the completion of my Ph.D. in Health Psychology, I am conducting a research project. My topic is titled “A phenomenological study of bereaved parents who have experienced the sudden loss of a child”. My interest is in exploring the grief experiences of parents whose child, between the ages of 2 and 12 years of age, suddenly died. Approximately 10 to 15 participants will be interviewed regarding their bereavement experiences. Participants must be 18 years or older and must meet the criteria for participation based upon the type of loss. In addition, the loss must have taken place at least two years ago. Participants will be requested to provide input and make corrections to the written descriptions of their experiences.

Please do not hesitate to contact me directly if you are interested in this study.

Thomas Fulbrook

Ph.D. Health Psychology Study

Walden University

(702) 245-4755

childlossstudy@gmail.com

Appendix C: Community Resources

Organization	Contact Name	Address	Telephone
GriefShare	Daphne Jordan	6200 W. Lone Mountain Road Las Vegas, Nevada	702 658-2722
Compassionate Friends		Nevada State College Room 103 Henderson, Nevada	702 289-8300
Nathan Adelson Hospice		4141 Swenson St. Las Vegas, NV 89169	702 796-3167
Faith Lutheran Church		2700 S. Town Center Las Vegas, NV	702 921-2700
Jewish Family Services		4794 Eastern Ave – Suite C Las Vegas, NV	(702) 732-0304
St. Joseph – Husband of Mary		7260 W. Sahara Las Vegas, NV	(702) 363-1902
Bereaved Parents		Nevada Power – Tory Pines and Jones. 3 rd Floor 2 nd Tuesday 7:00pm	(702) 383-1810
Bereaved Parents		Community Lutheran Church 3720 E. Tropicana 4 th Tuesday – 7:00pm	(702) 383-1810
St Rose Hospital Bereavement Support	Ellie Fears	St. Rose Professional Center 2 nd & 4 th Wednesdays 6 – 7:30pm	(702) 616-6560

Appendix D: Detailed Interview Questions

No.	Questions:
	Subjective Experiences
1	How were you informed of your child's death?
2	Can you tell me about your early grieving experiences?
3	Did your experiences change your spiritual beliefs? If so, how?
4	Did your experiences change your beliefs regarding the world in general?
5	How did you feel in those early days?
6	What do you recall regarding how you felt physically?
	Partner support
7	What do you recall regarding your partner's early grieving experiences?
8	Tell me about how you supported your partner?
9	What was most helpful regarding how your partner supported you in your grief?
10	Did your experiences change your relationship with your partner? If yes, how?
11	Were you able to openly express your feelings with your partner?
12	What do you remember about the differences regarding how you and your partner grieved?
	Social Contexts
13	Have your experiences changed your relationships with friends? If so, how?
14	How did others respond to you in your grief?
15	Did you feel that you were able to openly express your feelings to others?
16	What was most helpful regarding the support you received from others?
17	Have others changed the way they relate to you?
18	If you returned to work, how did coworkers respond to your loss?
19	If you returned to work, in what way were others helpful in aiding your return?
	Familial Experiences
20	Who was the first family member to contact you after the loss?
21	Can you tell me how your family responded to your loss?
22	What do you remember most about how your family supported you?
23	Who in your family was closest to you in your grief?
24	Did your family voice expectations regarding how you would be expected to grieve?
25	In general, did you feel supported by your family?
26	If there were other children in the home, how did your relationship with them change due to your loss?

No.	Questions:
27	Has there been a change in the way holidays are observed since your loss? If so, how has this changed?
28	Had other family members experienced the loss of a child?
	Attempts to Adapt
29	What did you do to attempt to gain a sense of balance after the death of your child?
30	What did you do to take care of yourself during this time?
31	What professional support, if any, did you explore?
32	If you took advantage of professional support, what was most helpful?

Appendix E: Participant Recruitment Letter

Date: 12/14/15

«Title»«FirstName» «LastName»

«Address1»

«City»«State» «PostalCode»

Re: *Parental Bereavement Study – Thomas Fulbrook Doctoral Candidate*

Dear «Title» «LastName»

First, I would like to express my sincere condolences for the loss of your child. While I cannot know how you feel, I am also a bereaved parent and I have some understanding of the devastation resulting in such a loss.

My name is Thomas Fulbrook and I am a doctoral student completing my dissertation in fulfillment of my Ph.D., through Walden University. I am writing to let you know about an opportunity to participate in a research study about parental bereavement. This study explores the experiences of bereaved parents whose child, between the ages of 2 and 12 years old, suddenly died.

This study will explore a group of bereaved parents who are not specifically represented in the academic literature. The goal of this research is to address this gap in the literature and advance social understanding of this type of loss in hopes of creating more meaningful support for grieving parents.

I would ask that you consider participating in a telephone interview focusing on your experiences or pass this information on to anyone who may be interested in participating in the study. The study is open to anyone in the United States and I will personally conduct telephone interviews with the participants. In order to participate, the parent must be at least 2 years beyond the date of their loss.

Once again, I appreciate your time. If you are interested and would like to know more about the study, please visit <https://www.youtube.com/watch?v=K5zjyW-XpUo> or search “Thomas Fulbrook” on YouTube. Please also feel free to contact me at chidlossstudy@gmail.com. Contact with the researcher does not imply acceptance or any obligation to consent to participation.

Thank you for your time and consideration.

Thomas Fulbrook
childlossstudy@gmail.com

Public Information Disclosure:

*Your contact information was obtained from the following public record(s):
«Source1», «Source2»*

_____. *If no
response is received, no further action is necessary and you will not be contacted again
regarding this study.*