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SURVIVING THE DEATH OF A SIBLING: A PHENOMENOLOGICAL STUDY
OF CHILDHOOD BEREAVEMENT

By

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B.S.W. Middle Tennessee State University, Murfreesboro, TN 2003
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A Dissertation
Submitted to the Faculty of the
Raymond A. Kent School of Social Work at University of Louisville
In Partial Fulfillment of the Requirements
For the degree of

Doctor of Philosophy

Social Work
University of Louisville
Louisville, Kentucky

December, 2014

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A Dissertation Approved on

November 21, 2014

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Brad Zebrack, Ph.D.

DEDICATION

This is dedicated to my sister, Angela whose untimely death at a young age inspired me to a career of helping others.

This is dedicated to my grandfather, Hilton Bonniwell who died in 2011, never doubting my ability to achieve my dreams, and always encouraging me to be a better person.

This is also dedicated to the children and parents who participated in this study and shared their stories.

ACKNOWLEDGEMENTS

This work would not have been possible without the generous support of the American Cancer Society Doctoral Training Grant in Social Work and support of faculty and staff at Monroe Carell Junior Children's Hospital at Vanderbilt and Alive Hospice in Nashville, TN. I especially want to thank Mary Murray, Dr. Mary Jo Gilmer and Dr. Terrah Foster for their collaboration, guidance, and ongoing support throughout this study. I want to thank Dr. Karen Nash for her insights, and moral support and collaboration with this study.

My eternal gratitude goes to Vern, Robin, Ryan, and Lucky Ledford, better known as my Louisville family for their warm and welcoming hospitality, and for the love, support, and generosity they showed me when I stayed with them while attending classes. Without them, this degree would not have been possible.

I thank my parents, John and Connie Crumb for their love, support, encouragement, and commitment to me. I have the utmost respect and appreciation for the great role models that they have been in my life. I would also like to acknowledge my husband, Daniel Gunter for his complete love, support, and encouragement through this process. He has graciously supported me during the countless hours it has taken to complete this work.

All the members of my dissertation committee are owed thanks beyond words for their unwavering commitment and dedication for helping me achieve my goals, and for sharing their expertise with me so that I could grow

professionally. Dr. Ruth Huber for whom I have the utmost respect, always believed in my project and took me under her wing. I am proud to call her mentor, colleague, and friend. I heartily thank Dr. Karla Washington for the countless hours she spent mentoring me as my biggest cheerleader and supporter through this process. When I was ready to give up, she was the voice of reason and encouragement. The unfailing kindness and encouragement of Dr. Sandra Ferreira throughout the dissertation process always challenged me to think critically to reach my fullest potential. Her expertise in qualitative research, bereavement, and children was an invaluable resource. Dr. Barbara Head was always there, supporting my vision, encouraging me to think expansively, and open my mind to new approaches. Dr. Ginny Sprang's expertise on children and guidance in shaping my dissertation, as well as her support and encouragement, were indispensable factors in the completion of this work, and I am grateful for her help. And lastly, Dr. Brad Zebrack was an invaluable consultant and inspirer of critical thinking. He continually challenged me to explore this rich material to its fullest potential.

Finally, I would especially like to thank the families that opened their hearts and shared their stories with me. My life will forever be changed as a result of that experience and I hope that this dissertation has really captured their stories.

ABSTRACT

SURVIVING THE DEATH OF A SIBLING: A PHENOMENOLOGICAL STUDY OF CHILDHOOD BEREAVEMENT

Edith Crumb Gunter

November 21, 2014

The loss of a sibling can be devastating to children, especially for children ages 7-12, who are at a critical juncture in their development. The loss can impede their development if their bereavement is not effectively addressed. For this reason, this dissertation evaluated four theoretical frameworks to provide a foundation for bereavement support for children: Assumptive World Theory, Dual Process Model, Meaning Reconstruction Theory, and Tasks of Mourning. Developmental theories and considerations were explored to gain knowledge of children's levels of understanding, processing, and coping.

Method: This study utilized a sample of five children ages 7-12 who had survived the death of a sibling; five parental participants. The study employed phenomenological and photo-elicitation methods to gain an in-depth understanding of the experiences these children during bereavement. To articulate the children's experiences, data were gathered from the children's and parents' perspectives. The participants provided a pictorial account of the children's experiences of their loss as well as a verbal account of their experiences.

Results: Data were transcribed and analyzed utilizing a 13-step process following protocols of phenomenological literature. Results identified 10 general and 3 unique themes. These themes identified areas that need additional attention from professionals when working with bereaved siblings. One finding is that current theoretical frameworks do not fully capture the bereaved experiences of these children. This study offers insight for future development, and urges that careful consideration should be given to bereaved siblings.

Conclusion: The approach provided a rich and in-depth account of a sensitive topic that allowed children's experiences to be better understood. The study revealed that children's experiences of surviving the death of a sibling produces strong expression of emotions, processing of grief reactions, commemoration of life, and reinvestment in life as part of their bereavement experiences. From these experiences, recommendations are made to better equip professionals to work with bereaved siblings. For example, these children identified the theme, *Expression of grief*, as a key element to their progress, and a recommendation was made to provide an outlet for children to effectively express their grief (e.g. support groups, counseling, art activities, or talking with parents).

TABLE OF CONTENTS

DEDICATION	iii
ACKNOWLEDGEMENTS.....	iv
ABSTRACT	vii
LIST OF FIGURES	xvi
LIST OF TABLES	xviii
CHAPTER I: PROBLEM STATEMENT	1
Problem Analysis	2
Factors that Influence How a Sibling Adjusts after a Loss.....	6
Consequences When Siblings' Needs are not Met	7
Study Rationale	9
CHAPTER II: THEORETICAL FRAMEWORK.....	11
General Grief Theories Informing the Dissertation.....	12
Assumptive World Theory	13
Constructs	15
Strengths	16
Limitations	16
Dual Process Model	17
Constructs	18
Strengths	19

Limitations	19
Meaning Reconstruction Theory	20
Constructs	21
Strengths	22
Limitations	22
Child-Specific Grief Theory Informing Dissertation	23
Fox’s Tasks of Mourning for Bereaved Children.....	23
Tasks of Mourning	23
Strengths	24
Limitations	24
Rationale for Selected Theories.....	24
Study Alignment.....	27
Child Development Considerations and Pertinent Theories.....	28
CHAPTER III: METHODOLOGY	35
Specific Aims of the Study	35
Research Question	37
Research Design	37
Phenomenology	38
Children and Phenomenology	40
Strengths and Limitations	41
Photo-Elicitation	42
Strengths	43
Limitations	44

Addressing Concerns about Scientific Rigor in Phenomenological	
Research	44
Randomness.....	45
Limited Number of Participants	46
Generalizability.....	47
Accuracy of Descriptions.....	47
Subjective Influence of the Researcher.....	48
Validity.....	49
Replicability	50
Absence of Control Groups.....	50
Absence of Hypotheses	51
Absence of Prediction	51
Absence of Interpretation and Comprehensive Theory	52
Qualitative Scientific Rigor	52
Triangulation	53
Trustworthiness.....	54
Strategies Used to Enhance Rigor	55
Ethical Concerns for Conducting Qualitative Research with Children.....	56
Informed Consent and Assent.....	57
Confidentiality.....	58
Power Relationship between Participants and Researcher.....	59
Appropriate Time and Way to Invite Potential Participants.....	60
Emotional Distress	60

Intrusion into One’s Privacy.....	61
Guiding Participants.....	62
Disclosure and Dissemination of Information	63
Conclusion	64
CHAPTER IV: METHODS: THE PHOTO-ELICITATION PROJECT	66
Participants	66
Institutional Review Board Approval.....	66
Participant Inclusion and Exclusion Criteria	67
Exclusion Criteria	67
Rationale for Age of Participants Chosen.....	68
Sampling Description	68
The Carter Family.....	69
The Lancaster Family	70
The Newsome Family.....	72
Rationale for the Phenomenological Sample Chosen	73
Study Procedures	74
Constructing the Minimally-Structured Interview	74
Recruitment Process.....	75
Initial Meeting	76
Data Collection.....	77
The Interviews.....	79
Data Analysis	80
Summary	95

CHAPTER V: FINDINGS	96
Background of the Study.....	96
General and Unique Theming Analysis.....	97
Presentation of General Themes	98
General Theme 1: Gaining Knowledge and Understanding	98
General Theme 2: Processing Grief	100
General Theme 3: Expressions of Grief	100
General Theme 4: Drawing on Faith.....	107
General Theme 5: Collective Experience	109
General Theme 6: Communication.....	111
General Theme 7: Adjusting to Changes.....	114
General Theme 8: Perceptual Differences	116
General Theme 9: Commemoration of Life	119
General Theme 10: Reinvesting in Life	121
Presentation of Unique Themes.....	126
Unique Theme 1: Life Exploration	126
Unique Theme 2: Shattered Expectations	127
Unique Theme 3: Protectorship.....	128
Summary	130
CHAPTER VI: DISCUSSION AND RECOMMENDATIONS.....	131
Discussion and Recommendations of General Themes	132
General Theme 1-R: Gaining Knowledge and Understanding	133

General Theme 2-R: Processing Grief	136
General Theme 3-R: Expressions of Grief	142
General Theme 4-R: Communication.....	145
General Theme 5-R: Drawing on Faith	149
General Theme 6-R: Adjusting to Changes.....	152
General Theme 7-R: Collective Experience	154
General Theme 8-R: Perceptual Differences	156
General Theme 9-R: Commemoration of Life	158
General Theme 10-R: Reinvesting in Life	160
Discussion and Recommendations of Unique Themes.....	164
Unique Theme 1: Life Exploration	164
Unique Theme 2: Shattered Expectations.....	166
Unique Theme 3: Protectorship	167
Congruencies between Findings and Theoretical Frameworks Informing the Study.....	170
Opportunities to Strengthen Existing Theoretical Frameworks based on Study Findings	176
Implications for Practice.....	179
Strengths and Limitations of the Study	181
Future Research	185
Summary	188
References.....	190
Appendix A: Summary of Grief Theories	212

¹ With Recommendations

Appendix B: Dissertation Timeline.....	213
Appendix C: Steps to Completing a Phenomenological Study	214
Appendix D: Letter to Families	216
Appendix E: Telephone Script	218
Appendix F: Informed Consent.....	219
Appendix G: Assent Form	223
Appendix H: Demographic Questionnaire	225
Appendix I: Minimally Structured Interview Questions	226
Appendix J: Photographic Reflection Sheet.....	227
Curriculum Vitae.....	229

LIST OF FIGURES

1. Interrelated Components of the Study	27
2. Steps in Interpretative Phenomenological Analysis	76
3. The General Themes from Clustered Units of Meaning	90
4. Unique Themes from Individual Interviews	92
5. Summary of Photo-Elicitation Project Steps of Analysis	94
6. Photo #1: The Lip	99
7. Photo #2: The Flower Pot.....	101
8. Photo #3: Worry Bowl	104
9. Photo #4: Grief	105
10. Photo #5: Camp Items	105
11. Photo #6: Painting of Brother's Tree, Fence, and Face in the Clouds	106
12. Photo #7: Bible and Blanket	108
13. Photo #8: The Mask	110
14. Photo #9: Camp Shirt	111
15. Photo #10: Red Tape on Mouth.....	112
16. Photo #11: Heart with an S.....	113
17. Photo #12: The Pumpkin	114
18. Photo #13: Christmas Tree.....	115
19. Photo #14: Ashes	117

20. Photo #15: Stain Glass	120
21. Photo #16: 5K Shirt Shadowbox	120
22. Photo #17: Steven's Sprint	121
23. Photo #18: The Top	122
24. Photo #19: Micah's Tree	123
25. Photo #20: The Sky	127
26. Photo #21: Trophies	127
27. Photo #22: A Warrior	128
28. Photo #23: Exhaustion	129

LIST OF TABLES

2.1. General Development Tasks for Ages 7-12.....	31
2.2. Conceptualizing a Loss.....	32
2.3. Typical Manifestations Children Experience Following a Loss	33
4.1. Sampling Description.....	69
4.2. Summary of Data Collection Procedures.....	80
4.3. Bracketing Bias and Phenomenological Reduction	83
4.4. General Units of Meaning	84
4.5. Units of Relevant Meaning.....	86
4.6. Eliminating Redundancies	87
4.7. Clustering Units of Meaning.....	88
4.8. Central Themes from Clustered Units of Meaning.....	89
4.9. Summary of Mason’s Interview.....	90
4.10. Contextualization of Themes	93
5.1. Emotional Symptoms.....	102
5.2. Physical Symptoms	102
5.3. Summary of General Themes, Definitions, and Examples	125
5.4. Summary of Unique Themes, Definitions, and Examples.....	129
6.1. Recommendations Informed by General Themes	163

CHAPTER I
PROBLEM STATEMENT

“For surviving children, the death of a sibling marks an end to what is expected to be one of the longest and sometimes most intimate relationships of a lifetime.”

(Robinson & Mahon, 1997, p. 477)

Limited research has been conducted on the experiences of children who are grieving the death of siblings; thus we are unaware what surviving siblings need during the bereavement process to better cope with the loss. Based on the literature, further information is needed regarding the needs of surviving siblings, the psychosocial manifestations that they experience, their coping strategies, and knowledge about death. Additional research is needed to clearly understand the experiences of siblings to better assess and support these children. Consistent with the body of literature on the topic, this researcher’s practice experience revealed the following: parents are often so focused on their own grief that they are not always able to recognize the needs of the bereaved child, the bereaved child may develop behavioral or emotional problems, which is when parents usually seek professional help, and children may not feel comfortable sharing their feelings or may not feel that their voices will be heard.

From this researcher’s practice experience, she has found that medical teams do not always provide adequate bereavement services to the families

following the death of a child. Most of the services provided to the family are while the patient is alive. Once the family is no longer in contact with the medical team, the parents and siblings are often on their own to pick up the pieces. Many parents perceive professionals as inactive in meeting the needs of siblings. This in itself can be detrimental and can be interpreted as professionals being unconcerned or worse, thinking that such help is not warranted (Ballard, 2004). Having done bereavement work for over six years, I definitely see areas where we as social workers, along with other health care professionals, could improve in helping families. These areas are addressed in the discussion section.

The focus of the next section is to describe the scope of the problem (numbers of dying children and bereaved siblings) and the impact of grief on bereaved siblings. This section will also focus on the risk and protective factors that influence the sibling bereavement experience. The section concludes with a discussion of the long-term consequences of losing a sibling as well as a rationale for this research study.

Problem Analysis

Most of the current literature on childhood bereavement has focused on the loss of a parent, which has been understood as a major loss for a child (Worden, 1996; Worden, Davies, & McCown, 1999). Less is known about the consequences of the death of a sibling in childhood. Childhood death is an *off time event* (Daaleman & Elder, 2007) meaning that it is statistically less common than death in adulthood (in the U.S., late adulthood). Therefore, experiencing the death of a significant loved one such as a sibling is an *off time event* during

childhood. It is estimated that 80% of children in the United States and Europe grow up with siblings (SuperSibs, 2008). When a sibling dies in childhood, existing systems (e.g., health care systems, education systems, social service systems) are often ill-equipped to help surviving siblings cope with the *off-time events*.

Roughly 45,000 children (defined as individuals between the ages of 0-19 years) die each year in the United States (Childdeathreview.org, 2012). Of these 45,000 deaths, the most common causes are unintentional injuries, homicide, and suicide. As will be described later, the three families who participated in this study were impacted by the death of a child due to Sudden Infant Death Syndrome (SIDS), a congenital anomaly, and cancer. In recent years, annual rates of childhood death due to these causes have equaled approximately 1910 (SIDS) and 6,296 (congenital anomalies) (CDC, 2012). In 2014, 15,780 children (0-19 years old) will be diagnosed with cancer, and 1960 of those will die from cancer (American Cancer Society, 2014). In 2013, over 400,000 people under the age of 25 lost a family member (National Mental Health Association, 2014). While we know the number of children who die each year from different causes, it is difficult to determine the exact number of children who are affected by the loss of a family member and specifically a sibling.

Sibling death has not been well studied and is often complicated. The loss of a sibling disrupts one's place in the family and purpose in life. Losing a sibling can have profound and long-term effects on surviving siblings (Davies, 1991)

"Don't forget about the brothers and sisters!" (Davies, 2006, p.4)

The deaths of siblings can be turning points in children's lives that can change the trajectories of their lives. Even at their worst, sibling relationships are significant and can negatively impact the life of a surviving sibling when the relationship is severed" (MADD Victim Services, 2004, p.1). A comprehensive review of the literature reveals limited research regarding the psychosocial needs of bereaved siblings (Mahon & Page, 1995; Nolbris & Hellstrom, 2005).

Bereavement is measured in terms of the emotional, physical, behavioral, social, and spiritual manifestations of people's experiences, their coping strategies, support systems, adjustments to new roles, and their ability to reinvest in life.

Little is known about the thoughts and feelings of children who are experiencing after effects from the death of a brother or sister (Martinson, Gilliss, Colaizzo, Freeman, & Bossert, 1990). The developmental and emotional needs of siblings are often disregarded during an illness or following a death. Research has shown that children aged 6-9 are more likely than their younger or older siblings to have emotional problems following the death of a sibling (Martinson, Gilliss, Colaizzo, Freeman, & Bossert). Further research is needed to understand the needs of this vulnerable population to help prevent them from having long-term emotional problems.

Most siblings develop very close bonds and attachments to one another that only a sibling may be able to understand. Often siblings protect each other, support one another, and play together. Due to the bond that siblings develop, the surviving sibling may have intense feelings and thoughts related to the death

of their sibling, which can affect their bereavement process and how they cope (National Child Traumatic Stress Network, 2009).

Following the death of a sibling, many children experience significant changes in their relationships with their parents due to intense fear, overwhelming grief, and guilt (Mandell, McAnulty, & Carlson, 1983). When communication between the child and the parents changes, the child is left vulnerable to the alterations in the family system. Parents may become protective or fear becoming too attached to the surviving sibling because they are afraid something will also happen to the surviving sibling.

Loneliness is an intense emotion that surviving siblings have expressed during the bereavement process. When a sibling dies, the surviving sibling is left without a close friend and companion (even if the fraternal relationship seemed contentious and competitive). The death leaves an emptiness in the surviving sibling's heart. Research suggests that this may be experienced more frequently by younger siblings than older siblings (Nolbris & Hellstrom (2005). Bereavement support groups or camps are one avenue to help children deal with the loneliness (Nolbris, Abrahamsson, Hellstrom, & Olofsson, 2010). Siblings are likely to develop unresolved grief if the loneliness or other grief symptoms are not addressed in a timely manner (Nolbris & Hellstrom, 2005).

Surviving siblings have indicated that the pain of losing a sibling can be intolerable, and children must find healthy outlets for this pain. Children who have suffered the death of a sibling may resort to daydreaming as a way to cope with the loss and to avoid intrusive thoughts and feelings (Di Ciacco, 2008). They may

find outlets such as video games, television, playing with friends, or sports as distractions to avoid dealing with the intense feelings associated with the loss. Some children write music, poems, or journal entries and blogs expressing their grief as a way to cope. Bereaved siblings need extra care and attention to cope with the loss, and parents, teachers, and other significant adults can be instrumental in supporting and helping them cope.

Siblings' reactions to death are unique based on the type of relationship the two siblings had, events surrounding the death, and length of the illness (Davies, 2006). Due to the significance of sibling loss, it can be devastating for children. Their expectations for the future had previously been embedded with their significant loved ones and when that loved one dies those expectations and dreams are shattered (Di Ciacco, 2008). Drastic changes occur in the child's daily life, when activities the children used to share such as playing games, going to school together, or sharing a room are no longer available.

Factors That Influence How a Sibling Adjusts After a Loss

Factors such as gender, age, family characteristics, parental stress, and social support can impact the adjustment of surviving siblings (Hastings, 2003). Studies have shown that higher socioeconomic status, less parental stress, better family cohesion, and the presence of consistent routines are contributing factors to positive adaption following the loss of a sibling (Williams, et al., 2002; Giallo & Gavidia-Payne, 2006). Davies (2006) reported that temperament, health status, and previous experience affect children's grief responses. Girls tend to internalize their emotions, which often leads to the development of depressive

behaviors, while boys tend to externalize their emotions, which often leads to hyperactivity and aggression (McCown & Davies, 1995).

Davies (1991) discusses situational factors that must also be considered: duration of illness, cause of death, where the death occurred, and whether the bereaved children were given a choice to be involved in the care. Children's ability to handle stress and cope with life's adversity is another factor that affects their ability to adjust to losses. Children are typically born with the ability to cope, strategize, and adapt to changes that the demands of life place on them, but some are better able to handle life's stressors based on their previous experiences and opportunities to build resilience. Children who are resilient are motivated to move forward, have the ability to connect with others, are willing to share their feelings, have a capacity for courage, and the willingness to ask for help (Goldman, 2009). Systems theory recognizes that while some of these factors are forerunners to others, (i.e. gender, race, and economic status to family cohesion, stress and resiliency), they can all be seen constantly interacting with each other at the ebb and flow of life.

Consequences if a Sibling's Needs Are Not Met

Those in middle childhood (ages 7-12) with unresolved loss are at risk of developing negative behaviors later in life because they have not developed internal knowledge or maturity to handle intense emotions for long periods of time (Di Ciacco, 2008). Studies have also shown that losing a sibling in childhood puts bereaved siblings at a higher risk for developing behavior problems compared to their non-bereaved peers (McCown & Pratt, 1985). As mentioned

earlier, behavior problems among bereaved siblings are not uncommon.

McCowan and Davies (1995) found that surviving children may use aggression and arguing to gain parental attention. Bereaved children may develop anxiety, depression, fears, and acting-out behaviors as a result of the death (McCowan & Davies). Though some children adjust well to the loss of a sibling, some parents reported that surviving siblings have unresolved feelings and symptoms up to three years after the death (Michael & Lansdown, 1986). Clearly, there exists an urgent need to better understand siblings' bereavement experiences.

Common manifestations of child grief include somatic symptoms such as nightmares, stomach aches, eating problems, and aches/pains. Other serious problems frequently experienced by surviving siblings include school difficulties, health fears, depression, guilt, antisocial behaviors, and anxiety (Fischhoff & O'Brien, 1976). Bereaved children sometimes experience a sense of spiritual abandonment when they are protected from the pain of grief, as often happens (Walters, 2008; Wolfelt, 2004).

Some of the potential long-term consequences of unmet children's needs are an increased likelihood of problems with the criminal justice system, mental illness, trouble forming relationships, substance abuse, and violence (Dowdney, et al., 1999; Salladay & Royal, 1981). Addressing these needs might lead to a decrease in mental illness, violence, substance abuse, and criminal activity, and may also avert surviving siblings' developing serious mental health issues such as post-traumatic stress disorder, adjustment disorder, depression, anxiety, and behavioral problems (Alderfer & Noll, 2006).

Study Rationale

While this dissertation focuses on child sibling loss, the researcher recognizes that humans suffer many other types of losses such as parents, children, relatives (grandparents, aunt, uncle, or cousin), friends, and pets. People grieve in their own ways and in their own time; no two people's expressions of grief are the same. While no two people grieve in the same way, there are many similarities in coping processes used during the bereavement process. The focus in this dissertation on sibling grief is occasioned by the uniqueness of the sibling relationship and the potential devastating nature of the loss to a child. "When a brother or sister dies, children can find it just as difficult as losing a parent, sometimes even more so" (American Academy of Pediatrics, 2003, p.2). Siblings are the peers not only closest in age, but also in shared life experiences, play routines, and close companionship. Siblings can build bonds that last a lifetime. The death of a sibling significantly impacts the surviving sibling and, thus, it is essential that we understand their bereavement needs to better serve them in the future.

Understanding children's needs or experiences of losing a sibling will make it more possible for us to develop appropriate interventions. It is extremely important to support children at this critical juncture in their lives because this life experience will shape the courses of their life trajectories. Children are often developmentally fragile at this time, and the sooner we can support them following a loss, the greater their chances of avoiding lifelong problems (psychological and physical). Thus, the goal of this dissertation was to learn from

bereaved children and their parents their thoughts, feelings, and experiences related to losing a sibling and to use this knowledge to better help future bereaved children.

CHAPTER II

THEORETICAL FRAMEWORK

“It is the theory which decides what can be observed.”

--Albert Einstein

Theory provides a contextual framework for examining a specific phenomenon through varying lenses. Theory can be defined as “a systematic set of interconnected statements, intended to describe some aspect of social life” (Rubin & Babbie, 2008, p. 46). As opposed to the aim of quantitative researcher, the goal of qualitative research is not to test established theories. Rather, existing theory can be used to provide a framework for the research design and other aspects of the study. Streubert and Rinaldi-Carpenter (2011) contended that, “In qualitative research the goal is to understand a phenomenon using already established theoretical principles to guide the structure of the design of the inquiry” (p.11). Theory can also be used in qualitative research to support or dispose of previous concepts or ideas during the process of analysis. “Qualitative researchers may simultaneously draw on several theoretical frameworks and concepts as *lenses* through which the study’s data and ideas are refracted” (Padgett, 2008, p. 13).

Theories are used in this dissertation to understand what is already known and to add to existing theoretical frameworks or leads to the development of a

new theoretical framework to explain sibling loss. Therefore, this chapter focuses on explaining the adult and child theories that inform the dissertation as well as aligning the theories with the methodology and data collection/data analysis strategies. This is followed by a discussion of the literature pertaining to adult grief theories and a more focused examination of child grief. Child development considerations as they pertain to conducting research will also be explored in this chapter. The chapter concludes with a summary.

General Grief Theories Informing the Dissertation

Bereavement is a life stressor that places demands on grieving individuals that can lead to overall negative health consequences (Stroebe, Schut, & Stroebe, 2007). The bereaved are at increased risk of developing a variety of mental and physical health problems that can last long after the loss has occurred if their grief is not properly addressed (Stroebe, Schut, & Stroebe, 2007). Most people adapt well to death losses without any professional intervention, although others develop symptoms of distress, thereby increasing their risk of chronic grief. It is important to understand how grief affects the bereaved, and many theories are useful in gaining this understanding. Scholars have postulated numerous theories in attempts to better understand and explain the grief process: works addressing the issue include, but are not limited to *Assumptive World Theory* (Parkes, 1972; Janoff-Bulman, 1989), *Dual Process Model* (Stroebe & Schut, 1999), *Meaning Reconstruction* (Neimeyer, 2000), and *Tasks of Mourning for Bereaved Children* (Fox, 1988). The theories in these works encompass observations, interviews, limitations the theorists found in

existing theories, and the writers' own personal experiences with death. The purpose of this section is to explain the main general grief theories that most closely align with this dissertation, and to identify the strengths and limitations of each. A summary table of these theories appears in Appendix A-1. A rationale for drawing from these theories over other famous bereavement theories closes this section.

Assumptive World Theory (Parkes, 1971; Janoff-Bulman, 1989)

The concept of the Assumptive World was originally brought to thanatology (description or study of death) by Colin Parkes in 1971. Parkes defined the assumptive world as the only way we know our world, which includes everything that we know or think we know about it. It includes our interpretation of the past and our expectations about the future. Assumptive World Theory (AWT) was later reintroduced by Ronnie Janoff-Bulman (1989). She defined the assumptive world in greater detail suggesting that the assumptive world is based on a set of assumptions that reflect and direct our interactions with the world and generally enable us to function successfully. Janoff-Bulman proposed three core assumptions: the world is benevolent and meaningful, and the self is worthy. AWT posits that in general, people believe the world around them is good and that life circumstances will result in a positive outcome. The basic concepts of benevolence, self-worth, and meaning present the illusion that these concepts are linked together and therefore would change together. Research has shown that, although these concepts are connected, over time they exist independently

of each other (Janoff-Bulman). The concepts of benevolence, self-worth, and meaning may all be questioned in the aftermath of trauma; one may change without affecting the others.

Fear and anxiety are often responses to overwhelming life events. Another psychological reaction is disillusionment, which often continues long after fear and anxiety have ended. Janoff-Bulman stated that “Victims’ inner worlds are shattered, and they see prior assumptions for what they are – illusions” (Janoff-Bulman, 1992, p. 70). Persons’ adjustments are determined by whether they experience profound disillusionment and despair, or minimal disillusionment and a return to hope. Survivors of trauma perceive their worlds as no longer safe, good, or protected. The illusion of invulnerability is no longer applicable as they realize that they are fragile beings. “The goal for survivors of traumatic events is to seek to arrive at a new, non-threatening assumptive world, one that acknowledges and integrates their negative experience and prior illusions” (Janoff-Bulman, 1992, p. 117). Another goal is to restore equilibrium following the traumatic event.

According to Kauffman (2002), AWT refers to the assumptions or beliefs that ground, secure, or orient people and give them a sense of reality, meaning, or purpose in life. AWT was originally developed as an adult grief theory, although Goldman (2009) described how children view their assumptive worlds when faced with traumatic events. Often children’s assumptive worlds consist of safety, protection, predictability, and trust (Goldman). AWT was developed to address how people deal and cope with traumatic events. AWT attempts to

bridge a gap between traumatology (study of trauma) and thanatology in creating a theory that encompasses both theoretical foundations. For children who experience traumatic deaths, it is important to distinguish between trauma and grief as it guides how we support grieving children (Levine & Kline, 2007).

This theory is most appropriate to explain children's experiences in a trauma and how their assumptive worlds are shattered and turned upside down. The world they once knew is no longer safe and secure. According to Goldman (2009), children need safe places that allow them to regain their assumptive world of benevolence, meaning, and worth to help them grow and develop socially, culturally, emotionally, intellectually, and spiritually, thus allowing them to reach their full potential. If the trauma is not addressed, children are not able to move through the grief process or get the help they need to rebuild their shattered assumptions or define new assumptions.

Constructs of Assumptive World Theory

1. ***Benevolence.*** In general people believe the world is a good place—that people are naturally good, kind, helpful, and caring. People believe they live in a safe and protected world.
2. ***Meaning.*** People believe events in the world have meaning and make sense. Assumptions about meaning include not only beliefs about why events happen in our world, but more specifically, why they happen to certain people. People want to understand the difference between good and bad.

- 3. Self-worth.** People perceive themselves as good, capable, and moral individuals. Self-worth includes the evaluation of one's essential goodness, decency, and morality. It also includes self-esteem and evaluation of one's wisdom and effectiveness of their actions.

Strengths

Parkes (1972) was heavily grounded in empirical/scientific research and it was from this research that he developed his ideas that later became a theory. AWT was the first to link the fields of trauma and grief into one theory. It also demonstrated how assumptions about the world change after a loss and how individuals adjust their assumptions based on that loss. It also introduced the concept of meaning-making in grief and the importance of making sense out of what has happened.

Limitations

AWT did not clearly define the conditions that distinguish a traumatic event from other stressful events. AWT proposed that most people who have not suffered from a traumatic event assume that their assumptive worlds are benevolent and meaningful, and they are worthy of such a world. Gilfus (1999) criticized this postulate as naïve and simplistic. This could be interpreted that traumatic events cause an individual's assumptions to become more negative owing to disappointment of the positive assumptions that the individual had already developed. Janoff-Bulman (1989) theorized that some of the contents of the assumptive world were often altered by trauma, although she stopped short of claiming that her list of domains was complete, stating "that the proposed

categories and the assumptions comprising those categories are unlikely to be exhaustive of vulnerability-related assumptions” (Janoff-Bulman, 1989, p.117).

The Dual Process Model (Stroebe & Schut, 1999)

An alternative conceptualization of grief was provided by Margaret Stroebe and Henk Schut (1999). Stroebe and Schut saw limitations in the other grief models and developed a more comprehensive model that encompasses how people cope with the loss of a loved one. Their Dual Process Model (DPM) was developed as a way to understand how people grieve. This is a bereavement-specific model of coping that is derived from psychoanalytic and attachment perspectives. DPM was originally developed to understand coping with the death of a partner. It has also been studied for parents who have lost a child; however, more research is needed to determine whether this model is applicable to other kinds of loss, such as that of a sibling.

DPM suggests that there are two types of grief-related stressors: loss-oriented and restoration-oriented stressors. Loss-oriented stressors require individuals to process their loss, performing tasks such as making meaning of the loss; trying to emotionally relocate the deceased due to their no longer being physically present, coping with separation; and examining the emotions associated with the loss. Restoration-oriented stressors direct the grieving person’s attention to the daily tasks of reintegrating into society after a loss. Restoration stressors include adjusting to new roles, learning new skills, and attending to life changes. This is not an exhaustive list of stressors as bereaved people experience many other stressors as they move through the grief process.

Oscillation, which is the bereaved individual's alternation between addressing loss-oriented and restoration-oriented stressors, is the regulatory process that distinguishes this model from other models. Stroebe and Schut (2002) acknowledged that the central force motivating people to complete the tasks in the loss-oriented and restoration-oriented phases is the search for meaning.

A loss in childhood can be devastating and can create additional challenges in trying to meet the demands of daily life, which can hinder achieving developmental milestones. Stroebe and Schut (1999) explained:

Children shift back and forth between grief and engagement-- a dual process of "loss orientation" dealing with and processing various aspects of the loss experience, and "restoration orientation" of adapting to the demanding changes triggered by the loss while trying to cope with the many activities of daily life. (p. 216)

If children do not effectively oscillate between the loss and restoration to adjust and cope with their grief, they may encounter problems. For example, a child who is solely focused on loss-oriented stressors may fail to re-engage in school, make friends, and take part in social activities.

Constructs of the Dual Process Model

1. ***Loss-oriented stressors.*** The focus is on dealing with the different aspects of processing the loss, such as making meaning of the loss, emotionally relocating the deceased, coping with separation distress, and examining the emotions associated with the loss.

2. ***Restoration-oriented stressors.*** The grieving person's attention is directed to the daily tasks of reintegrating into society such as adjusting to new roles, learning new skills, and attending to life changes.

Strengths

DPM was developed to address limitations of earlier bereavement models that presented grief as stages, phases, or tasks. This was the first model that explicitly included oscillation as a component, explaining that people move back and forth between coping with different types of grief-related stressors (some prior theorists speculated that people oscillate between tasks or phases, but failed to incorporate it into a cohesive theory of grief). Stroebe and Schut (1999) argued a need for a stressor-specific model of bereavement because death involves multiple stressors rather than a single stressor. DPM also addressed the concepts of chronic, complicated, delayed and traumatic grief. DPM has a strong non-linear focus and emphasizes a holistic approach. DPM has been used to examine concepts such as the tasks of mourning, meaning-making, and grief-focused interventions (Stroebe & Schut, 2002).

Limitations

DPM was originally developed to explain how people who have lost a spouse cope with the loss. However, DPM could possibly be applied to other forms of loss and other populations. Further testing of the model is needed to determine whether it can be applied to other losses and other populations such

as children. Comprehensive empirical evidence is not yet available, although some research has provided preliminary results (Stroebe, Schut, & Stroebe, 2005).

Meaning Reconstruction Theory (Neimeyer, 2000)

As meaning has been previously discussed in the theories above, the search for meaning plays an important role during the grieving process. Robert Neimeyer, a social constructivist, created a paradigm shift in his development of meaning reconstruction as a theory. Meaning Reconstruction Theory is based on the idea that individuals' worlds are dramatically altered when they experience the deaths of close friends or family members and, thus, there is a loss of meaning.

Neimeyer and Anderson (2002) extended the discussion of Meaning Reconstruction Theory by identifying three major activities in which people engage to reconstruct the meaning when they lose loved ones: sense making, benefit finding, and identity changes. Making sense of the loss is typically common in the first couple of weeks following the death to months after the loss. Grieving people attempt to pinpoint a cause or reason for the death in an attempt to understand the accident or illness that took their loved one's life. After this search for reason or cause dissipates, the bereaved begin to question larger worldviews such as *Why did this occur*, *Why did this happen to me?*, or *How do I make sense out of what happened?* Meaning Reconstruction Theory emphasizes that grief is interpersonal, yet should be viewed within the social context. In short, our cultural beliefs determine our views of meaning making. (Neimeyer, 2000).

Engaging in the search for meaning can intensify grieving individuals' distress. However, when people are able to find meaning, their distress decreases as well as their grief. Through meaning-making people are often able to find some benefit in the experience, either through personal growth, changed outlook on interpersonal relationships, or support from others (Gillies & Neimeyer, 2006).

In benefit finding, the bereaved seek to find a silver lining in the loss. Some suggest that the ability to find benefit is based on personality characteristics of the bereaved, such as their levels of optimism or pessimism (Davis & Nolen-Hoeksema, 2001). For example, a child whose personality is largely pessimistic may struggle to find benefits in significant losses.

Identity change occurs when the bereaved establish goals, and through those goals, they develop new identities. The loss of the relationship can lead individuals to question their own identities, as part of their identity may be wrapped up in the deceased. Further, the bereaved often take on new roles, which alter their identity. For example, a widow may have to take on the financial responsibilities for the household that were previously managed by her husband.

Constructs of Meaning Reconstruction Theory

1. ***Sense making.*** The bereaved search for meaning to make sense of the loss as well as question and seek answers about the loss as a way to make sense.
2. ***Benefit finding.*** This is the ability to find benefit in the grief experience. This involves finding benefits through the means of building new meaning

structures. Benefits are not always immediate and may arise months to years following the loss.

- 3. *Identity change.*** This is based on the premise that as people grieve they reconstruct meaning regarding the loss that leads the bereaved to reconstruct themselves.

Strengths

Meaning reconstruction requires the bereaved to engage in an active process (i.e., search for meaning) rather than a passive process. A major strength of this model is that it represents “a constructivist integration” of major works related to loss and grief (Gillies & Neimeyer, 2006, p.53). Therefore, it synthesizes major research findings and central tenets of multiple theories (including Assumptive World Theory and Dual Process Model) related to meaning-making during the bereavement process.

Limitations

Limited research has been conducted to measure the key constructs of the theory. More studies are needed to better understand the meaning-making activities of sense making, benefit finding, and identity change (Gillies & Neimeyer, 2006). The concept of “meaning-making” activities has not been effectively operationalized, which makes it difficult to draw conclusions about their functions (Gillies & Neimeyer). Meaning reconstruction of bereavement has typically been measured on an interpersonal level, but clearly it could be measured on a community or social level, especially since community affects how people grieve.

Child-Specific Grief Theory

Tasks of Mourning for Bereaved Children (Fox, 1988)

Fox (1988) recognized four key tasks of effective mourning in children that are similar to those proposed by Worden (1991) in his study of bereaved adults: to accept the reality of the loss, to process the pain of grief, to adjust to a world without the deceased, and to find a connection with the deceased. Although his work was primarily with grieving adults, Worden identified two factors that seem to influence children's conceptions of death—their developmental stages and their personal experiences (i.e. their environments, their ethnic, religious, and cultural backgrounds, and their personal ways of seeing things). Children's tasks of grief may shift over time in significance or focus throughout the grief process (Corr, Nabe, & Corr, 1996). It is important to recognize that bereavement has many dimensions and that children will attempt to find effective ways to deal with their grief.

Tasks of Mourning for Bereaved Children (Fox)

1. ***To understand and make sense out of what is happening or has happened.*** Children will seek information surrounding the events of the death, and find ways to understand and make meaning, or sense, of the death.
2. ***To express emotional and other strong responses to the present or anticipated loss.*** This involves recognizing, expressing, and validating

feelings or strong reactions to the loss, as well as finding appropriate ways to express those emotions and reactions.

3. ***To commemorate the loss through some formal or informal remembrance.*** This includes activities of memorializing or remembering the life of the person who died.
4. ***To learn how to go on with living and loving.*** Children find ways to go on with healthy lives after a significant loss and successfully integrating the loss into their lives.

Strengths

This model is similar to William Worden's (1991) tasks of grieving, which assumes an active process of grieving. Children may find it difficult to verbally express their feelings; thus, this model is helpful in understanding the various approaches and activities beyond verbal discussion in which children may engage to cope with the loss. A major strength of this model in terms of application to this dissertation is its exclusive focus on childhood grief.

Limitations

No published empirical research was found on Fox's Theory on Tasks of Mourning in Children. There is limited literature to explain this model in more detail. It does not take into account children's specific ages or cognitive development.

Rationale for Selected Theories

Freud, Lindemann, Kubler-Ross, and Bowlby have all brought a great deal to the forefront in expanding what we know about bereavement. Freud was first

to publish a bereavement theory in his work, *Mourning and Melancholia* (Freud, 1917). This was the beginning of his exploration of loss, grief, and bereavement. In this work, Freud observed that the process of mourning is painful. He also noticed that the pain diminished as the person moved through the mourning process.

Erich Lindemann (1963) was an influential psychoanalyst who studied the development of reactions to grief. He wrote a highly influential paper, *Symptomology and Management of Acute Grief* (Lindemann) and recognized that for the bereaved to be relieved of the pain of acute grief they must complete the mourning process and accept the implications of the loss. While a limitation of Freud's explanation of grief was that he did not elaborate on what happens when mourning is absent or incomplete, Lindemann explained that people are in danger of depression, withdrawal, loss of interest in life, and physical problems if the grief process is not completed.

Elisabeth Kubler-Ross (1969) developed the stages of grief model based on her interviews with dying patients. Kubler-Ross was a pioneer in the development of death and dying stage theory, and brought grief to the forefront of people's attention. Many people became attracted to her model because it was a neat and organized way to view grief. Thus, many began to apply it to people who were grieving the loss of a loved one. Some of her principles may well apply to those grieving the loss of a loved one. Even though some might interpret her theory to be linear in nature, she intended for people to move back and forth between stages and even concluded that some people might not experience all

of the stages. Although her theory intended people to move back and forth, theorists have further conceptualized the grief process and determined the process can be better understood as a non-linear process.

Worden's (1991) task theory was built upon the work of Freud (1917), Bowlby (1980), and Engel (1961). Worden concluded that people must complete specific tasks for homeostasis to be restored and the process of mourning to be completed. Tasks require effort that empowers the bereaved to regain control over their lives. The tasks, the accomplishment of which Worden believed completed the mourning process, are not necessarily addressed in any specific order, even though there is some suggestion of that in the definitions.

It is widely acknowledged that Freud, Lindemann, Kubler-Ross, and Worden were instrumental in expanding our knowledge of grief. However, their theories failed to address the meaning-making component that is the essential focus of this study given its phenomenological approach (described later in the dissertation). Neimeyer (2009) stated that, "A new generation of theorists has begun to question these generalizations, opening fresh possibilities for both research and practice" (p. 27).

The Assumptive World Theory, Dual Process Model, Meaning Reconstruction Theory, and Tasks of Mourning for Bereaved Children were determined to be the most appropriate theories to employ in guiding this study because all of these theories have a component that focuses on meaning-making during the bereavement process. A summary of the theoretical frameworks

informing the study are found in Appendix A-1. Figure 2.1 summarizes the foundations of each of these theories and details how each theory is aligned with various study components.

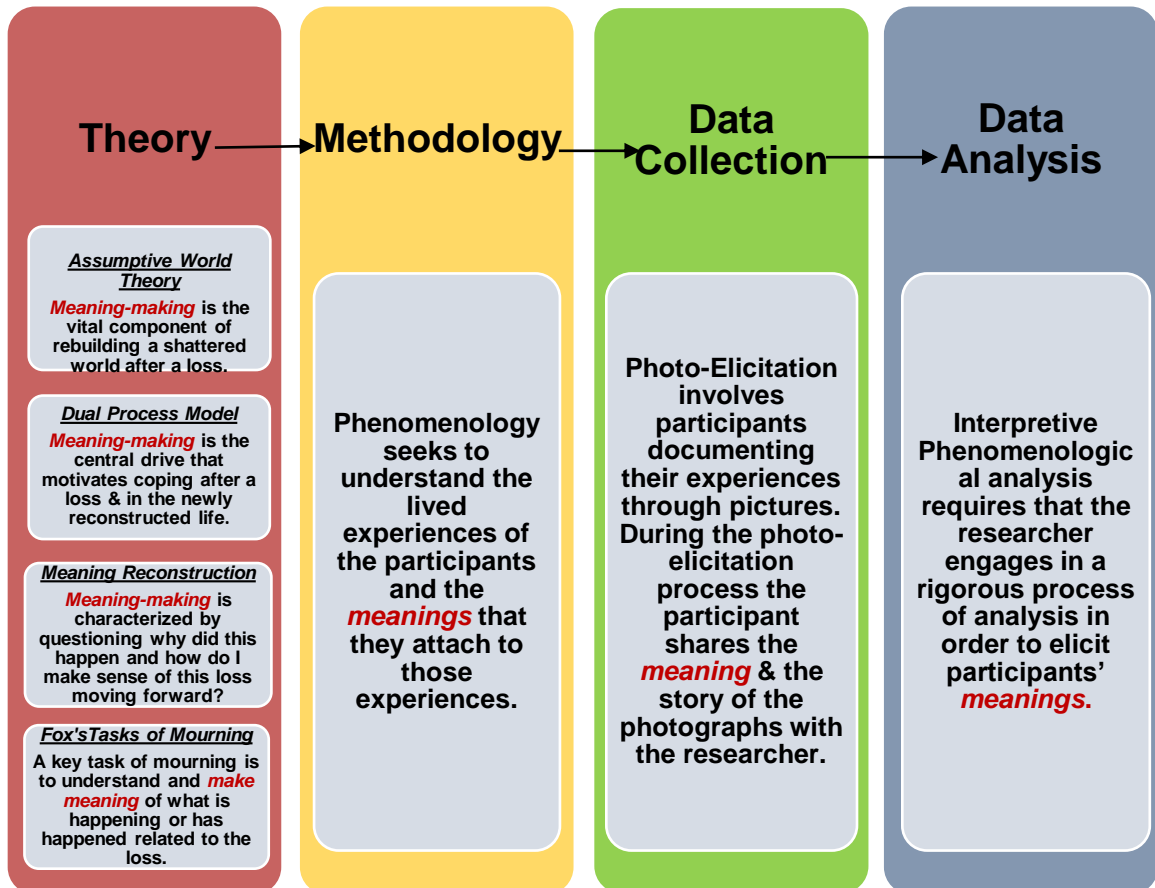


Figure 2.1. Interrelated components of the study.

Study Alignment

Phenomenological study ontologically assumes that “reality is multiple as seen through many views” (Creswell, 2010, p. 21) For example, during the data collection phase of the study, the researcher gathered data from the parents and the surviving sibling(s) of deceased children, allowing themes to emerge from each of their different perspectives. Further epistemological assumptions view

subjective evidence as best suited for knowledge building. Thus, the researcher sought to elicit and understand participants' accounts of their own lived experiences. These assumptions are highly consistent with the phenomenological approach employed in this study. In addition to aligning the philosophical assumptions with the study's methodology, it is also imperative that the theoretical foundation, data collection, and data analysis plan are in alignment as well. The interrelated components of the study are shown in Figure 2.1. Meaning-making is the central concept that drives the core of all methodological decisions made during the study.

Child Developmental Considerations and Pertinent Theory

Much of the development of the methodology for this dissertation was informed by theories of child development, specifically Piaget's Cognitive Theory of Development (1932) and Erikson's Psychosocial Theory (1956). According to Piaget, children 7-12 years old are developing the ability to think logically and consider the multiple aspects of a problem or situation. They are also developing their ability to use symbols to represent events in the real world. According to Erikson, children in this age range are grappling with developing a sense of industry or inferiority. As such, it is important that they experience a sense of mastery in their activities, and play is an important part of their lives. Taking these theories into consideration, the inclusion criteria of 7-12 years old was chosen for the methodology based on the need for child participants to be able to take pictures that represent their experiences upon losing their siblings (abstract thought, use of symbols) and discuss various aspects of their grief journeys.

Photo-elicitation (discussed more fully in Chapter III) was used as the primary data collection strategy with children, based on the need for developmentally appropriate play and to enhance the likelihood that their sense of mastery will enable them to supplement their verbal responses.

Children express grief differently than adults. Adults are typically better able to handle loss because they have had multiple lived experiences and from those experiences have developed coping mechanisms that have equipped them to handle stressful situations. According to Di Ciacco (2008), “Children lack the experience and brain development to handle a significant loss” (p. 27). Adults’ brains are more fully developed; thus they are able to process and reason abstractly regarding the loss and the events surrounding the loss. Children’s brains are still in the process of developing and, therefore, lack the experience to handle significant life events such as a trauma or death. “Their lack of experience with loss and undeveloped coping skills causes them to be more vulnerable in ways adults are not” (Di Ciacco, 2008, p.27). As a result of a loss many children may experience feelings of heightened separation anxiety, insecurity, mistrust, abandonment, alienation, and annihilation from the increased vulnerability that they may feel (Di Ciacco). These feelings can remain with them throughout their lives if they are not adequately dealt with during the grief process. Adults feel grief more intensely and are forced to grasp the finality of death, while children are often not cognitively able to understand death as adults do. “Thus, children

grieve without the same level of comprehension of what is happening to them, for they have not had the experience of the finality that accompanies someone's death" (Fitzgerald, 1992, p. 53).

If children face a loss early in childhood, they are left vulnerable to having to revisit the loss at each new developmental stage they enter. If they are not given the opportunity to grieve effectively, this lack can impact them negatively in their development and complicate their progress toward maturity (Di Ciacco). A death in childhood places additional challenges on children and places them at risk of falling behind in their normal developmental life demands and in jeopardy of getting "stuck" in their grief (Di Ciacco). It is important for children to remain developmentally on schedule even when faced with difficult life events. Thus, it is essential to provide children with support and interventions that help them lead healthy and stable lives. Children grieve at different times and often more sporadically than adults (Fitzgerald, 1992). Children may not grieve until many years after the loss has occurred. Children will often be confronted with their grief when anniversaries, birthdays, or major milestones (e.g. prom, wedding, graduation, etc.) occur, as these events will be reminders of what they have lost. These moments are memories that they would likely have wanted to share with their deceased loved ones (Fitzgerald, 1992).

Children's early years are critical for the healthy social, emotional, cognitive, and moral development that helps them form strong foundations from which to respond to life events and make reasonable choices. When children are faced with a loss during these early years, it is crucial for knowledgeable adults

to help them work through the long and difficult grief process. Unfortunately, not all children are developmentally or emotionally equipped to deal with the reality or finality of death. Thus, children are left vulnerable to developing internal fears, guilt, and anxiety (Salladay & Royal, 1981). Di Ciacco (2008) identified general developmental tasks that children ages 7-12 should be able to accomplish (Table 2.1), and further conceptualized loss for children ages 7-12 (Table 2.2). Finally, Table 2.3 lists the typical physical, emotional, behavioral, and spiritual manifestations that children ages 7-12 experience during the grieving process.

Table 2.1

General Developmental Tasks for Ages 7-12

<i>General Developmental Tasks for Ages 7-12</i>	
1.	Children are able to verbalize what they are thinking and feeling.
2.	Children’s cognitive abilities increase (i.e. see many point of views).
3.	Children want to be accepted by others, but especially their peers.
4.	Children realize actions lead to reactions.
5.	Children realize that personal experiences are not universal.
6.	Children begin comparing themselves to others (i.e. what they can do, who they are better than).
7.	Children are able to understand and grasp the notions of right and wrong.
8.	Children begin to develop abstract thinking and grasping the concept of conservation; meaning they understand a substance can be changed in one way (e.g. shape) while remaining the same in another way (e.g. amount).
9.	Prior to this stage, children were only able to think and follow something through in one direction. Now, they are able to understand that things can be reversed and ideas can be altered or changed.

Adapted from Di Ciacco, J. (2008). *The colors of grief: Understanding a child's journey through loss from birth to adulthood*. Philadelphia, PA: Jessica Kingsley Publishers.

Having a basic understanding of the general developmental tasks for this age group provided the researcher with knowledge on how to approach and work with this age group. At the same time, the researcher recognized that these tasks

are typical for this age, but that not all children mature and develop at the same pace. Some of these tasks may be challenging for some children in this age group based on their developmental understanding. This guided the researcher by helping her to develop age-appropriate questions and developmentally appropriate language to communicate effectively with the children.

Table 2.2

Conceptualizing a Loss

<i>Conceptualizing a Loss</i>
<ol style="list-style-type: none">1. Children began to grasp the finality and causality of death, but are literal and concrete thinkers. They began to understand that death cannot be reversed. Magical Thinking is still part of their thought process at this stage, but continues to decrease as time goes on (Di Ciacco, 2008).2. Children recognize that all living things have a beginning and an end and recognize the difference between the alive vs. dead.3. Death can be personified, such as a scary monster.4. Children view death as a punishment for a specific wrongdoing on their part or the part of their family member.

Adapted from Di Ciacco, J. (2008). *The colors of grief: Understanding a child's journey through loss from birth to adulthood*. Philadelphia, PA: Jessica Kingsley Publishers.

Having a general understanding of the developmental tasks for children ages 7-12 prepares the researcher to understand how children will understand, process, and conceptualize a death. Children conceptualize a loss based on meaning that they attach to the loss. When children perceive the loss as being manageable, their grief experiences following the loss will tend to result in more positive coping skills. However, if children perceive the loss as traumatic or feel the death was their fault, they may have a more difficult time coping. Having this knowledge helps the researcher anticipate challenges that may arise during the study and develop a plan for how best to work with grieving children.

Table 2.3

Typical Manifestations Children Experience Following a Loss

Behavioral	Emotional	Physical	Spiritual
Withdrawal	Depression	Stomach aches	Questioning one's own beliefs
Irritability	Anxiety	Difficulty sleeping	Turning away from their faith
Increased tantrums	Feeling helpless	Nightmares	Dreams of the deceased
Shorter attention span or difficulty concentrating	Anger	Hypochondria (manifest symptoms that sibling had)	Decreased ability to pray
Disobedience	Jealousy	Shortness of breath	Sense of presence of deceased
School problems	Frustration	Feeling of emptiness	Reaffirming one's spiritual or religious beliefs
Clinging to surviving family members	Isolation	Poor appetite	Anger at a higher power
Acting out	Loneliness	Headaches	Changing one's spiritual or religious beliefs

Adapted from Di Ciacco, J. (2008). *The colors of grief: Understanding a child's journey through loss from birth to adulthood*. Philadelphia, PA: Jessica Kingsley Publishers.

Adapted from Smith, S. (1999). *The forgotten mourners: Guidelines for working with bereaved children*. 2nd ed. Philadelphia, PA: Jessica Kingsley Publishers.

Grief produces physical, emotional, behavioral, and spiritual manifestations or symptoms. Children often present with these symptoms, but not necessarily realize that they correlate to losing a family member. Children who lose siblings will grieve differently; however, many will experience similar manifestations and reactions while grieving. Children may need to express their feelings relating to the death so that these manifestations do not have long-term consequences for

them. Having common knowledge of the typical manifestations enables the researcher to address these during the research process. Not only is the child's developmental level important to understanding children's grief experiences, it is also important for understanding how siblings are impacted by the loss.

The focus of this chapter has been to discuss the grief theories and the child development considerations informing the dissertation. The goal of this section was to provide a comprehensive overview of major theories related to sibling grief. The next chapter will discuss the research methodology that was utilized in this study.

“You have gone through enough theory, now it's time to take actions.”

— Amit Kalantri

CHAPTER III

METHODOLOGY

“Our duty is wakefulness, the fundamental condition of life itself. The unseen, the unheard, the untouchable is what weaves the fabric of our see-able universe together.”

(Robin Craig Clark, 2013)

This chapter describes the qualitative methodology used to understand the lived experiences of bereaved children who have lost a sibling to cancer, sudden infant death syndrome, and chromosomal anomalies. This chapter is organized into six sections: (a) specific aims, (b) research questions, (c) research design, (d) concerns in phenomenological research, (e) scientific rigor, and (f) ethical considerations. The specific steps used in analysis (*i.e.*, the research methods) will not be described here but, rather, will be presented in detail in Chapter IV.

Specific Aims

Parents are often overburdened when providing care to a sick child (Sloper, 2000) inadvertently leaving the needs of the child’s siblings unattended, which can lead to the development of a number of psychosocial problems. Studies have shown that siblings of ill children are at increased risk for developing social, emotional, behavioral, and adjustment problems (e.g. Alderfer & Noll, 2006; Massimo & Wiley, 2008; McCowan & Davies, 1995; Sloper, 2000).

These problems may continue after the patient dies and may be further complicated by the family's grief. Thus, the following aims have been identified to guide this study:

Aim 1A: To gain an in-depth understanding of the lived experience of children who have experienced the death of a sibling.

Aim 1B: To gain an in-depth understanding of the lived experience of children who have experienced the death of a sibling from the parents' perspective.

Aims 1A and B were accomplished using a phenomenological approach with interviews and photo-elicitation methods. The overarching methodology was phenomenological; photo-elicitation was used during data collection. A review of the literature revealed little is known about the experiences of bereaved children following the loss of a sibling; thus conducting a qualitative explorative study using a phenomenological approach was determined to be appropriate for data collection, owing to the richness, breadth, and depth of data that such studies are designed to provide. When working with children, it is essential to find data collection methods which interest and engage the children for this reason, the researcher used photo-elicitation methods to collect data from the children and their parent(s). Phenomenology and photo-elicitation are often used in conjunction with one another (Dennis, Gaulocher, Carpiano, & Brown, 2009; Harper, 2002).

Aims 1A and 1B included children and their parent(s) taking pictures of objects or things that represented the child's grief experiences.

Accomplishment of Aims 1A and 1B included 1-2 in-depth interviews with 5 children. It also included 1-2 in-depth interviews with at least one of their parents.

Aim 2: To generate evidence-informed recommendations to guide future implementation of new or existing programs that offer children's bereavement services.

To accomplish this aim, the researcher built upon study findings generated from Aim 1A & 1B to propose practice recommendations appropriate for such organizations as the American Cancer Society, the National Hospice and Palliative Care Organization, private practitioners, and others involved in bereavement care of children and families.

Research Question

To address identified gaps in literature, the following *research question* was posed:

What are the lived experiences of children who have experienced the death of a sibling?

Research Design

The purpose of this study was to provide an enhanced understanding of the lived experiences of bereaved siblings to enable social workers and other health care professionals to better support children and their families. Thus, a qualitative study was conducted using a phenomenological approach with

interviews and photo-elicitation methods. Phenomenology and photo-elicitation methods are often used in tandem in qualitative research studies (Dennis, Gaulocher, Carpiano, & Brown, 2009; Harper, 2002), are explained in greater detail below.

Phenomenology

Phenomenology, a philosophy and science dating back hundreds of years, has evolved through various phases of existence (French, German, Preparatory, and Sociological). For the purpose of this study, the researcher adopted the following tenets of phenomenology to guide research:

1. The task of phenomenology is to return to “taken for granted experiences” and to reexamine them in an intentional manner that brings to light the essence (meaning) of the human experience (Fochtman, 2008, p. 186).
2. Phenomenology demands that researchers seek to discover the world as it was experienced by those in it.
3. Theoretical underpinnings are rooted in Heideggerian and Hermeneutic traditions.
4. The goal of phenomenological research is to understand the meaning of lived experiences from the perspective of the individuals who experienced them.

Husserl (1857-1938) asserted that phenomenology should become a rigorous science and the foundation for all philosophy and science. He was concerned that the different disciplines had no methodology for forming basic concepts. He posited that experimental scientific research could not be used to

study all human phenomena, that it had become disconnected from human experience, and that it was blocking our understanding of ourselves (Roberts, 2013). His approach searched for meaning and essences of human experiences as told through participants and analyzed for meanings (Moustakas, 1994).

Martin Heidegger (1889-1976) contributed interpretative phenomenology by focusing on human experiences rather than humans' perceptions of what they consciously know. His approach was known as hermeneutics and varied from Husserl's approach in that researchers bring their own experience and understanding of the phenomenon; whereas hermeneutics advocated for bracketing of bias defined as suspending one's own preconceptions or beliefs so that they do not influence the interpretation of participants' experiences (Walters, 1995). Heidegger (1978) challenged Husserl's idea that phenomenology was purely descriptive; Heidegger believed that the description of phenomenology lies in the interpretation.

Interpretative Phenomenology as a methodology involves a highly intensive and comprehensive analysis of the accounts (minimally-structured interviews, focus groups or diaries) produced by a small number of participants; analysis produces patterns of meaning that are reported in thematic form (Larkin, Watts, & Clifton, 2006). Interpretative Phenomenology is a qualitative method that offers a theoretical framework, and a detailed guide for analysis. Exploration of participants' experiences, understandings, perceptions, and views of their worlds is the focus of interpretative phenomenological research (Reid, Flowers, & Larkin, 2005). The researcher's aim is two-fold: to understand the participants'

world and describe it, then position the description in the social, cultural, and theoretical contexts (Larkin, Watts, & Clifton). Interpretative phenomenology allows the researcher to discover subjective experiences, helps the researcher describe and comprehend the participants' accounts of the processes by which the participants make sense of their experiences (Brocki & Wearden, 2006).

Interpretative phenomenological analysis (IPA) was developed by Jonathan Smith (1996) "argued for an approach that would enable researchers to capture the qualitative and experiential dimensions" (Shinebourne, 2011, p.17). J. Smith and colleagues viewed phenomenological research as systematic and attentively focused on everyday lived experiences. IPA was used to explore people's perceptions of an experience, but also considered the individual. It was originally developed to view health related issues, but has now spread to clinical, social, counseling, and educational disciplines. Through this procedure, the researcher seeks to understand what the experience means to the participants themselves, through a sense-making process (J. Smith & Osborn, 2003). The researcher is vital to this approach in the conduction of analysis and in attaching meaning to the experiences of the participants (J. Smith, 2004).

Children and Phenomenology

Phenomenology is a method that can be useful and beneficial when working with children. Merleau-Ponty (1964) suggested that children have nonverbal ways of describing experiences and grasping their meanings. Children's drawings, singing, playing, and movements can all be explored in

phenomenological studies. By exploring children's life worlds, researchers can better understand their experiences and what those experiences mean to the children.

Strengths and Limitations of Phenomenology as a Research Method

A phenomenological framework provides a guide for researchers to understand the experiences and behaviors of individuals. A phenomenological approach can lead to authentic accounts of complex phenomena and can tell an interesting story. Phenomenology provides a rigorous, critical, systematic investigation of a particular phenomenon (Streubert-Speziale & Rinaldi-Carpenter, 2007). The phenomenological approach yields a rich and complete description of human experiences and meanings. Findings are believed to emerge more directly from participants, rather than the investigators' agendas. Phenomenology seeks to understand the unique experiences of individuals. Conclusions depend on the particular participants chosen for the study and are not intended to reflect how the general population feels about the experience. In focusing on a rich description of an experience, however, the method may miss information about what led up to that experience, what its outcomes or consequences might be, and what factors are associated with the experience.

The focus of this section was to explain phenomenology as the methodology used for this study. As mentioned earlier, phenomenology and photo-elicitation methods are often used in conjunction. Thus the focus of the next section is on explaining photo-elicitation methods and reasons for using photo-elicitation with children.

Photo-Elicitation

Photo-elicitation is an approach in which photographs are introduced into the research process during in-depth interviews by either the researcher or the participants (Clark-Ibanez, 2007; Collier, 1967; Harper, 2002; Rasmussen, 2004). Photo-elicitation involves the participants taking pictures of the phenomenon being researched. A detailed description of the steps involved in implementing photo-elicitation techniques in this study is provided in Chapter IV.

The use of photography in qualitative research has been sporadic over the last century. Photo-elicitation was first named by photographer and researcher, John Collier, in 1957. It was a popular technique used by many anthropologists and sociologists until they were criticized because many felt that this type of work was “unscientific” and “unsystematic” (Hurworth, Clark, Martin, & Thomsen, 2005, p. 52). A thorough search of the literature found no evidence that anyone conducted research again using photography as a research tool until the mid-1970s when the works of Ruby (1976), Messaris & Gross (1977), Becker (1978), and Wagner (1978) appeared. During this time, photography became a popular research tool again, as many saw it as a powerful evaluation tool (Brown, Peterson, & Sanstead, 1980; Templin, 1978).

Visual tools such as photographs provide a more direct way to understand children’s lived experiences and their perceptions than typical data collection methods controlled solely by the researcher (Lorenz & Kolb, 2009). Photographs are especially useful in capturing people and events of the past, or in triggering memories. This leads to more in-depth discussions during the interview process. The photographs introduced during the photo-elicitation process are used to

reveal information that might have remained hidden in the verbal interviews, thus bridging the communication gap (Lorenz & Kolb). In this way, the interview itself, rather than the photographs, becomes the primary data source.

“Photo-elicitation approaches tend to emphasize images as a means of accumulating rich verbal data, which then tends to be prioritized over the visual photographs themselves” (Drew, Duncan, & Sawyer, 2010, p. 1678). It is important to note that participants’ photographs are not interpreted by the researcher. The participants themselves discuss their photographs, relaying the experiences, thoughts, and feelings associated with the photographs and the meaning behind them. As participants shared their pictures, they tell a story about the experience behind the picture.

Photo-elicitation has been found to be a useful tool when conducting research with children who are asked to recall and talk about past events (Hurworth, Clark, Martin, & Thomsen, 2005). Photo-elicitation has been used in many studies with children and adolescents to gain their perspectives on relevant topics, i.e. living with chronic illness, disease self-management and living in poverty (Aschermann, Danneburg, & Schulz, 1998; Close, 2007; Drew, Duncan, & Sawyer, 2010; Tucker & Dempsey 1991; Weiniger, 1998). Photo-elicitation helps children feel valued and part of the research process, and provides a forum for their voices (Clark, 2003).

Strengths of Photo-elicitation

This technique assists in establishing trust and rapport with participants and is a form of multi-method triangulation that provides a check for rigor and

trustworthiness of the research (Becker, 1975; Hurworth, Clark, Martin, & Thomsen, 2005; Lincoln & Guba, 1985). It provides pictorial evidence to support what participants communicated during interviews. Photo-elicitation encourages longer and more detailed interviews, compared with regular interviews (Collier, 1979; Hurworth, Clark, Martin, Thomsen, 2005).

Limitations

Consumers of research using photo-elicitation techniques may assign or inaccurately assume that they are to interpret the photographs (rather than referring to participants' discussion of the photographs), thereby introducing the possibility of misunderstanding (Dennis, 2004). Participants often take more photographs than time allows to discuss or integrate all of the images into the participants' narratives (Dennis, Gaulocher, Carpiano, & Brown, 2009). Thus, many researchers inform participants ahead of time that, while they can take as many pictures as they choose, there may be time to discuss a fixed number of pictures of their choosing during the interviews.

Addressing Concerns about Scientific Rigor in Phenomenological Research

The ever-changing landscape of qualitative research affirms that opinions about rigor will vary; although an area of consensus involves the rejection of traditional quantitative criteria (Altheide & Johnson, 1994; Whittemore, Chase, & Mandle, 2001). Some may erroneously apply quantitative criteria when evaluating the scientific rigor of qualitative studies. Below, are traditional criteria

for rigor in quantitative research and a discussion of the extent to which each was determined to be applicable to this qualitative phenomenological study.

Randomness

A concern that arises in qualitative research is that the sample is not always random. In experimental research, it is important that experimental and control groups be comparable and therefore, the researcher would develop a process of randomizing participants to increase the internal validity of the study (Rubin & Babbie, 2008). However, for qualitative studies, the sample is typically chosen based on participants' ability to address the specific phenomenon under investigation. The researcher employed this approach adopted for this dissertation. The sample under study employed a purposive criterion sample. Thus, as long as the participants met the established inclusion criteria, they were contacted to participate in the study.

Inclusion criteria required that participating children be age 7-12 and have experienced the death of a sibling within the prior 2 years. These criteria ensured that child participants were developmentally capable of participating in the study and had experienced the phenomenon under investigation (i.e. death of a sibling) recently enough to be reasonably able to reflect on their experiences across their grief trajectories. Participating adults were required to be the legal guardian of one or more of the child participants. No other inclusion criteria, beyond their willingness to consent to participate in the study, were established for participating adults.

Of the 18 families contacted, only 3 agreed to participate in the study. Actual participants included 3 mothers, 2 fathers, and 5 boys who had experienced the death of a sibling. No girls participated in the study and all of the families were Caucasian. Some of the families chose not to participate because their grief was still too raw or thought it would too emotionally difficult. Others did not return the researchers phone call to gather information about the study. For the purpose of conducting a phenomenological study, the researcher is seeking to understand the lived experience of the participants and not to generalize findings. Therefore, any participant who was unable to clearly articulate their experiences would have been excluded from the study; however, all participants were able to clearly articulate their experiences; thus, no one was excluded from the study.

Limited Number of Participants

In phenomenological research, generally only a limited number of participants is required due to the significant amount of data that emerges from each interview. Phenomenological research produces rich data from the participants explaining their experiences in great detail. The focus of phenomenological research is on the quality of data, not the quantity (Frankfort-Nachmais & Nachmais, 1996). Typically phenomenological researchers recommend keeping the number of participants at 2-25 to gain a more profound understanding of the lived experiences (Boyd, 2001; Creswell, 1998; Polkinghorne, 1989; Morse, 1994). As previously described, the final sample for

this study was comprised of 10 individuals, with equal numbers of children and adults representing three different families.

Generalizability

A concern that often arises in phenomenological research is whether the results may be generalized to other groups. Based on the lack of randomness and limited number of participants typically involved in phenomenological research, the results are not intended to be generalized to a broader population (Hycner, 1985). According to Rubin and Babbie (2008),

Qualitative researchers get a full and in-depth view of their subject and can reach an unusually comprehensive understanding of the subject. By its very comprehensiveness, however, this understanding is less generalizable than results based on rigorous sampling and standardized measurements (p. 430).

According to Hycner, through the process of investigating and seeking to understand the experience of each unique individual, the researcher learns about the phenomenology of a human being in general.

Accuracy of Descriptions

The descriptions the participants provide can lead one to question their accuracy. Hycner discussed two different criticisms, (confabulation and retrospective viewpoint), in relation to the accuracy of descriptions.

Confabulation, occurs when participants fill in gaps in their memory or as a way to please the interviewer. Although confabulation can introduce challenges into the research process, Hycner argued that confabulation can be valuable in

investigating the phenomenon since the goal of the researcher is to understand the phenomenon as the participants experienced it. Hycner's concerns about retrospective viewpoints address the timeliness of interviews: descriptions may be more accurate if the experience is being discussed while the experience is happening. If not, participants may forget key aspects of the experience with a lapse of time. According to Hycner, an advantage of shorter time lapses between the event and the interview is that fuller verbal descriptions of the phenomenon occur because participants reflect back immediately on the experience. For the purpose of this study, this researcher employed a retrospective perspective approach to understand children's experiences of losing a sibling; however, some parameters were introduced to address concerns about confabulation and retrospective viewpoints. In all cases, the interview occurred at least six months from the death, although in no case was the lapse longer than two years due to concern that participants' memories might lose accuracy with the passage of time.

Subjective Influence of Researcher

A concern when conducting phenomenological research is the researcher's ability to be subjective in the interview and analysis processes. Often qualitative researchers choose phenomena in which they have a vested interest; if the researcher is unable to remain aware of this subjective interest, the likelihood of the researcher producing objective and usable data is minimal. In phenomenological research, objectivity is even more important than in typical experimental research due to the comprehensiveness required in studying the

phenomena. Many researchers use bracketing (suspending judgment) to record and process potential bias, thereby enhancing their ability to remain objective through the entire study. According to Rubin and Babbie (2008), most researchers are able to sort out their own biases and points of view but, given the nature of science, their colleagues are also there to help them. This researcher used bracketing throughout her study to avoid any judgments or bias seeping through and met with dissertation committee members to discuss researcher's bias and maintaining objectivity.

Validity

When conducting scientific research, the following question is often raised: Are the data valid? In other words, do they accurately reflect the experience of the participants? In phenomenological research, there are multiple methods for validating data. The researcher met with many participants multiple times, thus the researcher was able to revisit the content of the interviews and clarify any uncertainties. The researcher conducted a process known as member checking, in which the researcher goes back to the participants to verify the findings to make sure that it accurately reflects their experiences (Padgett, 2008). This strategy was employed in the current study. The concept of validity is less applicable in qualitative studies than in quantitative studies wherein researchers are typically concerned with the trustworthiness of the data, described in detail later.

Replicability

Quantitative researchers may argue that a good scientific study should be able to be replicated by other researchers, with the possibility of producing the same results. In phenomenological research there will always be some degree of variability due to the nature of understanding the lived experiences. Simply put, no two people experience an event or phenomenon in precisely the same way; thus, replicability is not a central concern of phenomenological researchers. In addition, individual researchers may view data in slightly (or even dramatically different) ways.

Rather than focusing on replicability, qualitative researchers attempt to ensure the transparency of their methods. This can be accomplished in a variety of ways, including providing a detailed and explicit description of the methods used and by maintaining an audit trail. An audit trail is a thorough record of all aspects of the research, including any changes and major decisions that shaped the research process. While these efforts do not ensure that another researcher following the same steps would achieve identical results (this is highly unlikely), transparency allows for others to assess the appropriateness of the researcher's reasoning, decision-making, and procedures (Schwandt & Halpern, 1988).

Absence of Control Groups

Control groups are important components when conducting quantitative research as they help to establish validity. Researchers implement control groups to compare the extent to which the experimental and control groups differ on the dependent variable (Rubin & Babbie, 2008). Given that phenomenological

research is concerned with investigating the uniqueness of a person's experience, a researcher cannot logically control for a person's lived experience of a particular phenomenon (Hycner, 1985). In this phenomenological study, therefore, a control group was not used as the researcher was seeking to describe the unique experiences of each of the participants.

Absence of Hypotheses

Another important component of quantitative research involves the testing of hypotheses. However, this is not typically a primary aim of qualitative research. Padgett (2008) however, stated that, "While not ready to throw out hypothesis generation and testing entirely, I believe that expending too much effort in that direction betrays and undermines a unique strength of qualitative methods" (p.48). Thus, in conducting phenomenological research, the researcher approaches the study from the standpoint of exploring a certain phenomenon without restricting the study's perspective by placing the phenomenon within a structured series of hypothesis testing.

Absence of Prediction

Many quantitative researchers seek to explain or predict relationships in scientific research. Quantitative researchers often try to predict relationships between two variables when testing hypotheses or attempting to explain the influence one variable has over another (Rubin & Babbie, 2008). The goal of phenomenological research is to provide an in-depth and comprehensive description of a specific phenomenon. According to Hycner (1985), phenomenologists believe the most meaningful aspect of human experiences

cannot be predicted, and that which can be predicted is insignificant in phenomenological research. This researcher did not seek to predict the outcome of the data, but rather to understand the participants' lived experience.

Absence of Interpretation and Comprehensive Theory

It is the practice of phenomenologists to seek to understand a certain phenomenon and to be careful not to interpret a phenomenon according to an already developed theory. Hycner (1985) stated,

At the core of phenomenology is the very deep respect for the uniqueness of the human experience and that this ever-present uniqueness will always make the attempt to develop a totally comprehensive theory of human experience an ultimately futile one. (p. 300)

As mentioned earlier, Rubin and Babbie (2008) explained that the goal of qualitative research is to gather a full and in-depth view of a phenomenon for the purpose of reaching a comprehensive understanding of individuals' experiences. The goal is not to interpret theory. In this study, the researcher reviewed theories related to the phenomenon being studied not as a way to interpret the data through the lens of an already developed theory, but rather to develop a foundation for her study. As stated above, the phenomenologist seeks to develop a comprehensive experience of the phenomenon and thus unpredictability is inevitable.

Qualitative Scientific Rigor

Establishing scientific rigor is essential in all forms of empirical research (Padgett, 2008). Therefore, qualitative researchers should seek to develop

rigorous studies that are legitimate, valid, and trustworthy. Strategies for developing rigor in qualitative studies include triangulation, trustworthiness, and rigor will be discussed in more detail below along with an outline describing how the strategies were used in enhancing the rigor of this study.

Triangulation

Triangulation is a research strategy of collecting the same information from at least two sources (e.g. respondent testimony and case files) or, as in this case, photographs and interviews from parents and children. Triangulation is often used to confirm findings (Miles & Huberman, 1989; Patton, 1983; Risjord, Dunbar, & Maloney, 2002). Confirmation occurs when the researcher verifies information from different sources or vantage points, thereby adding both depth and breadth to the results (Denzin & Lincoln, 1994). Data, methodological, investigator, environmental, and theoretical are types of triangulation used in qualitative research. For this study, the researcher employed methodological and data triangulation.

Methodological triangulation comprises the use of multiple qualitative methods to study the phenomenon. Information gathered from interviews and photographs were triangulated in this study. The information from the interviews provided the researcher with a richer description of the participants' grief experiences and validated the meanings of the pictures. Using multiple data collection methods provides a more holistic and enhanced understanding of the phenomenon under study (Streubert & Rinaldi-Carpenter, 2011). If the results from each of the methods are the same, then validity is established.

Denzin described three types of data triangulation: time, space, person. When using person triangulation, researchers collect data from more than one level of data, such as a person, a set of individuals or groups (families or dyads), and collectives (communities, organizations, or societies) (Denzin, 1989). Person triangulation can add to the rigor of a qualitative study when it is carried out responsibly. Both children and their parents participated in the study which included taking pictures and being interviewed by the researcher. Data were analyzed to find any similarities or differences between the testimony of children and that of their parent(s). The researcher did not use space or environmental triangulation in her study.

Trustworthiness

Trustworthiness in qualitative research is similar to reliability and validity in quantitative research (Padgett, 1998). Padgett identified three threats to trustworthiness: (a) reactivity, defined as the distorting effects of the researcher's presence in the field, (b) researcher's bias, or preconceived notions or opinions that the researcher brings to the study, possibly even recruiting participants who agree with these preconceived opinions and using data that support these biases, and (c) participants' biases, e.g., purposefully withholding information to protect their privacy or avoiding revealing unpleasant truths. A study that is carried out fairly and ethically and in which the findings represent as closely as possible the experiences of the participants is considered trustworthy (Steinmetz, 1991).

This researcher recognized these potential issues and identified several ways to avoid these threats to increase the integrity of her study. A primary threat to trustworthiness of a study is, of course, researcher bias. This researcher discussed her own bias regarding sibling grief prior to beginning the study with committee members. This researcher overcame a second threat to trustworthiness by the method of prolonged engagement, in other words, by extending time spent in the field and becoming accepted by participants. Prolonged engagement was achieved through multiple visits and interviews with participants for long periods of time. Interviews typically lasted 1.5-2.5 hours. The effects of this were to reduce reactivity and participant bias. As a result of having multiple interviews with the participants and interviews with multiple members of the same family, the researcher was able to revisit and clarify content.

Strategies Used to Enhance Rigor

“Rigor in qualitative research is demonstrated through the researcher’s attention to and confirmation of information discovery” (Streubert-Speziale & Rinaldi-Carpenter, 2007, p. 49). In the end, this researcher followed the strategies recommended by Padgett (1998) to enhance rigor and accurately represent participants’ experiences. The strategies included (a) prolonged engagement, or extended periods of time in the field and becoming accepted by participants, (b) peer debriefing and support, or a means to renew researcher’s view of data collection and guard against biases, (c) member checking; gaining the participants’ perspectives to ensure the accuracy of the resulting data, and

(d) openness to documenting and recording each step in data collection and analysis. Each of these strategies is described in greater detail below.

Prolonged engagement occurred throughout the research process via the researcher conducting multiple interviews with participants lasting 1.5-2.5 hours. The researcher also made several phone calls to participants throughout the study to make sure the process was going as planned. The researcher also used member checking during the analysis process to verify the findings. The researcher captured direct quotes from the participants to achieve a richer description of the data, met with faculty members and clinical experts to gain their perspectives on working with children and appropriate ways to ask questions. The researcher met with dissertation committee members to debrief after meeting with families and discuss the events of the meeting.

Ethical Concerns for Conducting Qualitative Research with Children

Children are a vulnerable population and do not always have the developmental understanding of the personal impact of participating in research. Ethical concerns can arise when children participate in research. The Institute of Medicine (2004) identified three concerns that researchers should consider when conducting research with children: (a) because children are a vulnerable population, they need additional protection beyond that which is provided to adults; (b) systems protecting children involved in research should not unreasonably impede research that may benefit them; and (c) researchers who work with children need to be aware of the special ethical concerns that are relevant when conducting research with this vulnerable population. The

researcher has meticulously respected these ethical concerns, has obtained informed consent and assent, has respected confidentiality, has been mindful of the power relationship between participant and researcher, has considered the appropriate time and way to ask participants to participate in research, has respected emotional distress and avoided intrusion into participant's privacy, has guided participants in the use of technology, and has received written consent for disclosure and dissemination of information. These concerns are discussed in detail below, as the steps taken to overcome such concerns are explained.

Informed Consent and Assent

Assent is an agreement by individuals not legally competent to give valid informed consent to participate in research. When going over assent forms with children, age-appropriate language and methods must be used so that children understand the purpose, expectations, and overall risks and benefits of participation. Children should be given opportunities to ask questions regarding their participation. Researchers should discuss assent procedures with the children away from parents or others who may influence their decisions to participate. Children should be given a copy of the assent form they have signed. The researcher analyzed the informed consent and assent documents for reading ease to make sure the documents were on appropriate grade level and easy to understand for this population. The documents were put into a computer software program that the Institutional Review Board recommended for reading ease. The documents were then revised until the documents were appropriate for the populations being studied.

The Committee on Bioethics (1995) mandates that legal permission be obtained from a child's legal guardian and assent be obtained from children over age seven prior to their participation in research. The committee indicated that age, maturity, and psychological state should be considered in determining whether children are capable of assenting to participate in research (Committee on Bioethics). Children's participation in the assent process has many potential benefits such as increasing their self-worth, giving them a sense of control providing them with the opportunity to exert their autonomy in decision-making, and reinforcing the possibility of better communication with their parents.

Informed consent is a person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research. Adequate information, voluntariness, and capacity to understand information are the main elements of the informed consent process (National Institute of Health, 2008). When conducting research with children, researchers must obtain informed consent from the parent(s). In this study, parental consent as well as child assent were obtained prior to research activities. Consent and Assent Forms are presented in Appendix F-1 and G-1.

Confidentiality

Confidentiality is a multifaceted issue when conducting research with children, some have voiced concerns about actual or potential breaches of confidentiality to other researchers (Triseliotis, Borland, Hill, & Lambert, 1995; Westcott & Davies, 1996). The children who participated in this study did not voice any concerns regarding confidentiality. Confidentiality issues can be

addressed by clearly outlining the conditions of participation in which confidentiality can be maintained; however, safety and protection of life override the commitment to confidentiality (e.g. if there is an indication that the respondent is a danger to themselves or others, breaching confidentiality is likely appropriate) (Freeman & Mathison, 2009). Using visual methods requires the researcher to focus special attention on anonymity and confidentiality when pictures become part of a study (Freeman & Mathison; Levin, 1995).

This researcher used a research pseudonym to identify participants instead of their names or initials. All information that was discussed remained confidential. Participants signed consent and assent forms, which discussed the conditions of confidentiality. This researcher went over both forms with the participants in great detail and clarified any questions.

Power Relationship between Participants and Researcher

Adults usually have authority and power over children, which can make it challenging for children to disagree or dissent, fearing it may be unacceptable. Children may not be accustomed to being asked to give their opinions, or may feel disregarded by key adults in their lives (Cloke, 1995). Children are a vulnerable population, susceptible to persuasion, and easily influenced by persons of power putting them in positions of potential harm. To empower children, research began with the children (rather than parents) in order to first gain their perspectives and keep them engaged throughout. This researcher

engaged children by using informal language, sitting on children's level, and playing with the children to minimize the perceived level of authority of the researcher.

Appropriate time and way to invite potential participants

An issue that arises when working with this population is determining the right time to ask them to participate in the study. Not only do researchers have to know the right time to approach a participant, but also the boundaries of intruding on their private spaces. The researcher did not approach participants to participate in the study until at least six months after the death in order to be sensitive to the participants need to initially grieve their loss. For all participants, the death was one to two years past at the time of participation. The researcher was sensitive to families' emotional needs, recognizing that certain times of the year--the anniversary of the death, birthday, or specific holidays would be difficult for the family. The researcher offered to reschedule or postpone any meetings scheduled during these times if the family found the topic too emotionally difficult.

Emotional Distress

Bereaved children are at increased risk of experiencing emotional pain and distress when participating in research. When children agree to participate in research, they may not necessarily understand the repercussions of their decisions. When asked to re-experience the events surrounding the deaths of their loved ones, children often display behaviors such as crying, anger, shaking, or shortness of breath when discussing the loss of a loved one (Balk, 1983; Cook, 1995). If a child becomes upset as a result of discussing the death of a

sibling, researchers may provide immediate comfort and show compassion, but should not provide long-term counseling even if they are also trained counselors (Green & Hogan, 2005).

Foreseeing the possibility of emotional reactions during the course of the study, this researcher encouraged children and parents to report their concerns immediately to the researcher and discuss whether they should continue with the study or withdraw. If the researcher or family felt the need of additional support or resources, the researcher was in a position to make an appropriate referral from a list of community resources such as Alive Hospice Grief Support Services, Gilda's Club, Lifecare Family Services, Guidance Center, Centerstone, and Compassionate Friends. The researcher agreed that if any adverse reactions or complications occurred as a result of the study she would report them verbally within 24 hours to the Chair of the Institutional Review Board (IRB) with written notification of any adverse event to be provided to the IRB within a week.

A few participants cried during the interviews. The researcher immediately provided support to them and after a few minutes the participants felt ready to continue with the interviews. None of the participants felt the need for a referral to community resources for additional support.

Intrusion in One's Privacy

In the last decade, "a resurgence of attention has been given to visual methods" (Wiles, 2008). Children often have a hard time expressing their feelings through words and may be better able to express themselves through expressive arts such as sand therapy, phototherapy, or play therapy. Researchers often

invade the lives of research participants, and this can create ethical challenges. The process of informed consent and consent to publish pictures addresses this difficulty. Wang and Redwood-Jones (2001) found that most participants are pleased to give permission to researchers to publish pictures as this gains public attention for the issues being researched. Wang and Redwood-Jones provided a number of best practices for research with photographs including the following that were used in this study: (a) provide and review consent forms with participants, (b) train participants in the use of cameras, (c) provide written material about the project, (d) provide participants with prints, (e) provide and review consent forms with participants regarding permission to publish photographs, and (f) mentor research staff and participants on ethical principles.

Guiding Participants

Researchers may struggle with giving directions to participants about the content of their photographs (Wang & Redwood-Jones, 2001). The ethical struggle arises when the researcher wants to suggest photo content to the participants, but fears that it will influence the results of the study; on the other hand, participants may not feel that they have a clear idea of the purpose of the study and feel they need more suggestions.

This researcher encouraged participants to think of their own ideas and allowed participants to discuss those ideas with her. The researcher gave participants one example to avoid swaying the participants. For example, the researcher suggested that if participants identified anger during their bereavement then they could take a picture of toy that looks angry. When

participants were discussing their pictures, the researcher would listen carefully and intently, trying not to interrupt or interject her opinion. The researcher clarified points the participant did not understand.

Disclosure and Dissemination of Information

When reporting results of a study that involves visual images, researchers understandably want to use those images that convey the strong feelings and are associated with the meaning and experiences pertaining to the phenomenon being studied. Researchers should discuss with participants that confidentiality cannot be ensured, or provide guidelines for how confidentiality will be maintained during the informed consent and assent process (Freeman & Mathison, 2009). One way to maintain confidentiality is to show photographs that have no identifying information. Children and parents were asked to sign a consent form to publish photographs which allows the researcher to publish pictures in journals, books, or presentations at conferences. This researcher has only published pictures that have no identifying information thereby maintaining confidentiality.

Researchers who use visual methods often want to include photographs in the dissemination of research. However, issues related to consent and copyright develop when photographs are included in the results. The researcher negotiated with the participants to turn copyright over to the researcher and sign consent for researcher to publish pictures. Photographs involving objects or places can create issues of breach of anonymity or confidentiality. Photographs and

descriptions can make it easy to identify or make a guess about where the photograph was taken and possibly be linked back to participants (Clark, 2006).

Photographs may be disseminated, as in the case of the research presented in this dissertation, in many different ways such as media (DVDs or internet), presentations at conferences, journal or book publications, and/or memory books. The researcher provided memory books to the participants with their pictures. Other ways may be used by the researcher at a later date to disseminate the findings of this study. Researchers need to be aware and respectful of the broader issues of confidentiality particularly when using public formats to display visual research methods (Wiles, 2008). Participants may consent to pictures being published at the time of the study, but feel differently as their circumstances change in the future (Barrett, 2004). It is often difficult or impossible for the researcher to remove the photographs once the photographs have entered the public arena (Banks, 2001). Researchers can listen to the participants' concerns and try to help them remove those photos from the public arena, but participants need to realize that it may be impossible. All participants agreed to have their pictures published as part of the study.

Conclusion

This chapter has focused on explaining the research methodology that guided the study and various concerns that arise when conducting phenomenological research, ways to ensure scientific rigor, and ethical concerns that arise in conducting bereavement research with children were discussed. Going forward, Chapter IV describes *the photo-elicitation project* in detail, the

findings appear in Chapter V, and a discussion of the findings and implications for practice are in Chapter VI. Also, proposed guidelines or recommendations for implementation in new or existing programs appear in Chapter VI.

CHAPTER IV

METHODS: THE PHOTO-ELICITATION PROJECT

“The thrill found in a photograph comes from the onrush of memory.”

(John Berger, 1992, p.192)

The purpose of Chapter IV is to explain the photo-elicitation project and the process used in conducting the study. Through explaining the steps used in this project, the researcher’s hope is that other professionals in the field can replicate the steps in their own phenomenological/photo-elicitation project. In this chapter, aspects of the project are discussed: (a) participants, (b) procedure, (c) data collection, and (d) analysis.

Participants

Institutional Review Board Approval

The researcher developed a collaborative relationship with nursing researchers and social workers at Monroe Carrel Jr. Children’s Hospital at Vanderbilt. Ethical approval for this study was granted in November, 2011 from Vanderbilt University Medical Center Institutional Review Board (IRB), and because this researcher was a Ph.D candidate at the University of Louisville, the study also received approval by the

University of Louisville's IRB, in March 2012. When Alive Hospice was added as an additional recruitment site, the IRB application was updated and approved in February 2013.

Participant Inclusion and Exclusion Criteria

Purposive criterion sampling (Patton, 1990) was used to select subjects that met the following specific criteria:

1. Participants must have experienced the death of a sibling.
2. Participants must be aged 7-12.
3. Participants must have a parent or parents who were willing to participate in the study with them.
4. Participants must be fluent in English and have a parent or parents who are fluent in English.
5. Participants must live within 100 miles of Nashville, TN.
6. Participants must have been bereaved for at least six months, but no longer than two years since the death. ***Rationale for Time Frame:*** At least six months allows participants time to process their initial feelings about their loss, and spares researchers from being too intrusive with families in early grief. On the other hand, after two years, participants are likely to have forgotten aspects of their grief experienced earlier.

Exclusion Criteria

The researcher did not exclude any race or gender, but excluded children who did not meet the above criteria. Children of age six or younger were excluded from the study even though the literature revealed that they also

suffered emotional problems. The reasons children younger than seven were not chosen are (a) they are not able to grasp the finality and causality of death, (b) they think that death can be reversed, and (c) magical thinking is still part of their thought processes (Di Ciacco, 2008).

Rationale for Age of Participants Chosen

Martinson and colleagues (1990) found that younger school-aged children were more likely than their younger or older siblings to have emotional problems following the death of a sibling. Children aged 6-9 were more likely than their younger or older siblings to have emotional problems following the death of siblings (Alderfer et al., 2010). Children aged 7-12 years old manifested poorer physical quality of life than those older and younger (Alderfer et al., 2010). Meaning that these children developed more physical symptoms following the death of a sibling.

Sampling Description

As you may recall, the goal of the study was to interview participants about experiencing the death of a sibling. This section provides information about the sample and background of the siblings' illnesses leading up to the death. Three families were selected to participate in the study. Five children and 5 parents (3 mothers and 2 fathers) participated in the study. Two families each had 1 child participate and 1 family had 3 children participate. For this study, all participants happened to be biological siblings and parents, although a biological relationship between siblings was not required as an initial inclusion criterion (e.g. step-siblings who, per parent report, had spent a significant amount of time

together would have been eligible). Pseudonyms identifying the families and individual participant ages, and pseudonyms of the deceased and cause of death are presented in Table 4.1 below. Following the table is a brief description of each family and their loss and well as information about each of the diagnoses that ultimately led to the children’s deaths.

Table 4.1

Sampling Description

Name of the Family*	Name of Deceased Child*	Cause of Death*	Parental Participants*	Child Participants*
Carter	Steven (6 mo.)	Sudden Infant Death Syndrome	Tiffany (30) Henry (31)	Jason (7)
Lancaster	Mitchell (11 yrs.)	Brain Cancer	Kelly (40)	Ricky (8)
Newsome	Micah (17 hrs.)	Trisomy 13	Kristen (36) Mark (38)	Miles (12) Mason (10) Maddox(7)

**Pseudonyms*

The Carter Family

The Carter family consists of both parents and three children. Both parents (Tiffany and Henry) and one child (Jason) participated in the study. The other two children were too young to participate. Jason lost his brother, Steven, to Sudden Infant Death Syndrome (SIDS). Steven was the product of a twin birth.

His sister, Sarah, was a healthy baby and is still alive today. Jason always wanted a brother because he already had a sister. He was very excited when he found out that Steven was a boy after he was born.

Mrs. Carter put Steven down for a nap and later went back to check on him. Mrs. Carter found Steven was not breathing. She began CPR and called 911. Steven was rushed to a local hospital before being airlifted to a trauma center. Steven remained alive on machines for three days until the family decided to withdraw support due to the extensive injuries that Steven endured from lack of oxygen and CPR. Steven was six months old when he died on Halloween.

SIDS is the leading cause of death among infants from 1 month to 1 year old. Approximately 2,500 children die each year from SIDS in the United States (KidsHealth.org, 2014). Boys die more often from SIDS than girls (KidsHealth.org, 2014). Most of these deaths happen while the child is sleeping and they often show no signs of distress. SIDS is diagnosed after all other causes of death have been ruled out.

The Lancaster Family

The Lancaster family consists of both parents and three children. Only the mother (Kelly) and one child (Ricky) participated in the study; the other children were older than the inclusion criteria. During her interview, Kelly reported the following things regarding Mitchell's illness. Mitchell succumbed to brain cancer in April, 2011 after he had turned eleven years old. He was diagnosed with brain

cancer in November, 2009. The tumor was technically benign, but effectively malignant because of its location in the brain stem. Most likely, Mitchell was born with the tumor; many of his flukes or quirks started to make sense when the family received the diagnosis, which came out of the blue when he was taken to the doctor for what was thought to be a sinus infection. The doctor noticed nystagmus (involuntary eye movements caused by abnormal function in the areas of the brain that control eye movements). From the time of the diagnosis to the time of his death in April, 2011, about 17 months passed. He died unexpectedly when pneumonia set in. He went from laughing on the couch, to a fever, to admission to the hospital, to death by 7:00 PM, when he simply stopped breathing. The ultimate cause of death was respiratory failure and herniation caused by the brain tumor.

Cancer is the leading cause of death from disease and the second leading cause of death overall of children ages 1-14 in the United States. In 2011, approximately 15,780 children in the U.S. were diagnosed with cancer and 1,960 died as a result of the disease (American Cancer Society, 2014). According to the Danis Foundation (2011), 35% of childhood deaths are caused by cancer and 46 children are diagnosed with cancer every day in the United States. In 2005, 2.9 of every 100,000 children, birth to age 19, were found to have brain or central nervous system cancer, and .7 per 100,000 died from it. This type of cancer is found most often in children between 1-4 years old, but most deaths occurred between 5-9 years of age (CDC, 2011).

The Newsome Family

The following members of the Newsome family participated in the study: both parents (Kristen and Mark) and their three children (Miles, Mason, and Maddox). They have one younger child who was not old enough to participate. The children lost their sibling, Micah, to trisomy 13. The family learned of the diagnosis at the 18-week ultrasound. It was further confirmed after Mrs. Newsome had an amniocentesis. The family was informed that Micah had a life-limiting diagnosis, which meant they would not know how much time they would get to spend with him after his birth. The family learned of the diagnosis in December 2010. Micah was born at 35 weeks in April, 2011 and died April, 2011 after living only 17 hours. The children spent time with Micah in the hospital and then again at home. Each child was able to express love to Micah and say goodbye. The family had a memorial service a week after he died.

Mrs. Newsome had a tubal pregnancy one year prior to her pregnancy with Micah, and at the time of her first contact with the researcher she was 32 weeks pregnant with another boy. At the time this dissertation was written, Mrs. Newsome had delivered a healthy baby boy and reported that the family was enjoying their time with their new child and brother.

“Trisomy 13 is a rare chromosomal disorder in which all or a portion of chromosome 13 appears three times rather than twice in cells of the body” (NIH, 2013). Trisomy 13 affects one in 16,000 newborns (NIH, 2013). Trisomy ranges in severity of abnormalities and may depend on the specific location of the

duplicated chromosome. Infants with Trisomy 13 often have heart defects, brain abnormalities, respiratory issues, a cleft lip and/or a cleft palate, and weak muscle tone. Given the severity of medical problems these children face, many babies with Trisomy 13 die within a few days to weeks. According to NIH (2013), only about 10% of children with Trisomy 13 live past their first year.

Rationale for the Phenomenological Sample Chosen

The aim of qualitative research is to explore the quality of data, not the quantity (Frankfort-Nachmais & Nachmais, 1996). Thus, the size of a sample is less precisely prescribed in qualitative research than in quantitative research. In the absence of strict calculations for sample size, however, a number of general recommendations for qualitative research in general, and for phenomenological research more specifically, have been provided. Boyd (2001) recommended a sample size of 2 to 10 participants in phenomenological research. Similarly, Creswell (1998) recommended long interviews with up to 10 participants for a phenomenological study. Polkinghorne (1989) recommended 5 to 25 participants for phenomenological studies while Morse (1994) called for at least six participants. Lee, Woo, and MacKenzie (2002) suggested that studies that use more than one method require fewer participants, as do studies that use multiple (or very in-depth) interviews with the same participant (e.g. longitudinal or panel studies). Based on the above references, a phenomenological sample of 5 children and 5 parents was selected to participate for this study.

Study Procedure

In planning a scientific study, it is essential for the researcher to explain the procedures delineating how the study will be implemented. These procedures include construction of interview questions, recruitment, initial meeting with family, data collection, and data analysis. A timeline of the study and steps of the study are in Appendix B-1.

Constructing the Minimally Structured Interview

Upon review of the literature, the researcher determined it was best to develop a set of interview questions to guide participants. By developing a list of minimally structured questions, the researcher ensured that relevant data would be collected but that participants would largely be able to guide the interviews. Preparing interview questions ahead of time allowed the researcher to word the questions sensitively (Smith, 1995). The researcher also was able to think through areas that might be covered during the interview process. The process of developing the interview questions is described:

1. The researcher determined that the experience of bereaved siblings was to be investigated through the interview process.
2. The researcher identified questions that were appropriate to address the experiences of bereaved siblings.
3. The researcher reviewed the literature on the development of photo-elicitation interview questions as well as of the literature on child grief.
4. The researcher developed an appropriate, logical sequence of the interview questions.

5. The researcher submitted a draft of questions to dissertation committee members and to a panel of experts (i.e. colleagues in pediatric health care and/or children's bereavement) for review and final approval.

Recruitment Process

The participants were recruited from Monroe Carrel Jr. Children's Hospital at Vanderbilt and Alive Hospice in Nashville, TN. Family members of children who were treated at the study institutions and ultimately died were identified as potentially eligible for participation. Social workers provided the researcher with a list of names of children who matched the criteria for the study. Once the potential participants were identified, they were mailed an informational letter (Appendix D-1 & D-2) outlining details of the study. The letter informed participants that they would be contacted by the researcher in three weeks. They were able to opt out of receiving a phone call by calling a confidential 1-800 number. When the researcher contacted the families by phone, she provided the parents with information regarding the study purpose and procedures involved in the study. If they agreed to participate, the researcher set a time to meet the participants. To avoid inconveniencing the participants, the researcher went to the participants' homes. The participants decided on a time for the initial meeting that was convenient for them and ensured that the participants would not be distracted. A copy of the telephone script the researcher used is provided in Appendix E-1.

Initial Meeting

The meetings with the participants in their homes included explaining the study in greater detail, a discussion of the consent and assent forms (Appendix F-1 and G-1), and completion of the demographic questionnaire (Appendix H-1). As part of the consent and assent process, participants were reminded that they were free to withdraw from the study at any time and would not be penalized in any way for doing so. Participants were reminded that the goal was to learn about their experience of losing a sibling, and that the researcher was not looking for any particular answer. The participants were informed that the interviews would be recorded and transcribed, but that their information would remain confidential to the extent possible. Participants were informed that certain people may need access to their information such IRB staff, funders, etc.). To ensure confidentiality the data were de-identified. During the initial meeting phase, the researcher met with four families. Only three families consented to participate in the study. The fourth family declined to participate due to the emotional distress that might result from discussing their loss.

The researcher also educated the children and their parents to use the camera that was provided. The participants were given instructions on taking their pictures. The researcher informed participants that they could take pictures of objects or things that represented their experiences of losing a sibling, provided an example of a picture (e.g. if anger was identified as a feeling, the

participant could take a picture of toy such as a monster or action figure that looked angry) that could be taken to describe their grief experiences, then answered any questions.

After the consent and assent forms were signed, the researcher explained the process of data collection to the children and their parents. The researcher requested that the parents take pictures first, so that if they needed to assist the children with using the camera while taking their pictures, they would not be influenced by the children's pictures. The children were not privy to seeing the parents' photos. The researcher asked the parents to complete the Photograph Reflection Sheet to help guide the interviews (Appendix J-1). If a second parent was in the family, they were also asked to participate in the study. If they chose to participate, they signed consent forms and the study materials were explained to them. The researcher asked that the camera then be given to parent #2 to complete their pictures, and the above procedure was repeated. Finally, the children were asked to take pictures depicting their experiences of losing a sibling.

Data Collection

Before beginning the data collection process the researcher attempted to establish rapport and allow the children to become more comfortable with the process. In an attempt to build rapport, the researcher asked the children questions to learn their interests and to engage them in something they enjoyed. The researcher also got down on their level (sat or otherwise put herself on the same physical level) to avoid any perception of a power differential. The

researcher asked to see some of their favorite toys, thus allowing the children to feel comfortable conducting the interview without their parents being present. The children were all given a choice as to whether they would like their parents present during their interviews. This was discussed during the assent process.

Data were collected through photography and in-depth interviews. Participants were given cameras and the bereaved children took pictures of objects or events that represented their experiences of losing a sibling. The parents also took pictures separately representing their children's experiences of losing a sibling. Permitting children to take pictures of their everyday lives allowed them to make choices about which pictures to include, thereby controlling the images to be analyzed (Smith & Barker, 2000). Participants were allowed to take an unlimited number of pictures during the three weeks they were allotted to take pictures. However, they then had to select only 10 for inclusion in the research. Each participant discussed his or her photos during the interview process. Most participants took 11 pictures and some took less than 10. For the participants who took 11 pictures, the researcher chose to include all 11. Children gave their own interpretations of their pictures and the parents interpreted their pictures. After the participants had taken all of their pictures, the pictures were printed and the participants contacted the researcher to arrange a time to meet individually to discuss their pictures.

The Interviews

During the interview process, the participants were provided a list of the following minimally structured interview questions: (also in Appendix I-1).

1. What is the picture?
2. What is the story or experience behind the picture?
3. What does this picture mean to you?
4. What have you learned by participating in the study?
5. Are there things you have learned that you think would be helpful for other children to help them as they grieve?

The researcher also asked additional questions to clarify a statement or gain more information about a particular topic. Parents were interviewed separately, although the children had the option of having the parents sit in on their interviews. The researcher was aware that this could influence how the children would respond to the pictures that they took. For example, the children might not give information as freely, withhold information, or lean on their parents to interpret their pictures. However, this choice was ultimately included to enhance the children's comfort level. The three youngest children chose to have their parents sit in on the interviews. Parents were respectful and only interjected when children asked for clarifying information from them. Interviewees were allowed to take as many breaks as they needed during the interview process.

Once the interviews were completed, the data (interviews) were transcribed. The data were coded and common themes were identified. Parents were mailed copies of their interviews and asked to make sure the researcher

had captured everything the parents wanted to say about their experiences (otherwise known as member checking) (Padgett, 2008). The researcher discussed the transcripts with participants by phone. Once all of the interviews and photos for the participants were completed, the researcher made a photobook for each family, including their pictures and parts of their interviews. The photobook was mailed to the participants, unless families requested that the photobook be hand-delivered to them. Table 4.2 summarizes these procedures.

Table 4.2

Summary of Data Collection Procedures

Activity	Frequency	Duration	Timing
Letter mailed to family	X1		When it is determined that criteria are met
Phone calls to participants	X1	15-30 minutes	3 weeks after mailing participants the letter
Entrance Meeting (Informed Consent/Demographic Questionnaire/Specifics of Study)	X1	45 minutes	Completed at first home visit
Individual Interviews with parents	X1-2 per participant	1-2 hours	Completed after pictures are taken
Interviews with children	X 1-2	1 hour	Completed after pictures are taken
Telephone calls to discuss the interviews (member checking)	X1	30-45 minutes	Calls were made after all interviews were completed and interviews had been transcribed and analyzed

Data Analysis

The researcher organized the data by reviewing the transcribed data and studying the material through methods of interpretative phenomenological analysis, “a process of reading, reflecting, writing, and rewriting that enables a researcher to transform the lived experiences into a textual expression of its

essence” (Van Manen, 1990, p. 10). The figure 4.1 shows the steps for analyzing data using Interpretative Phenomenological Analysis.

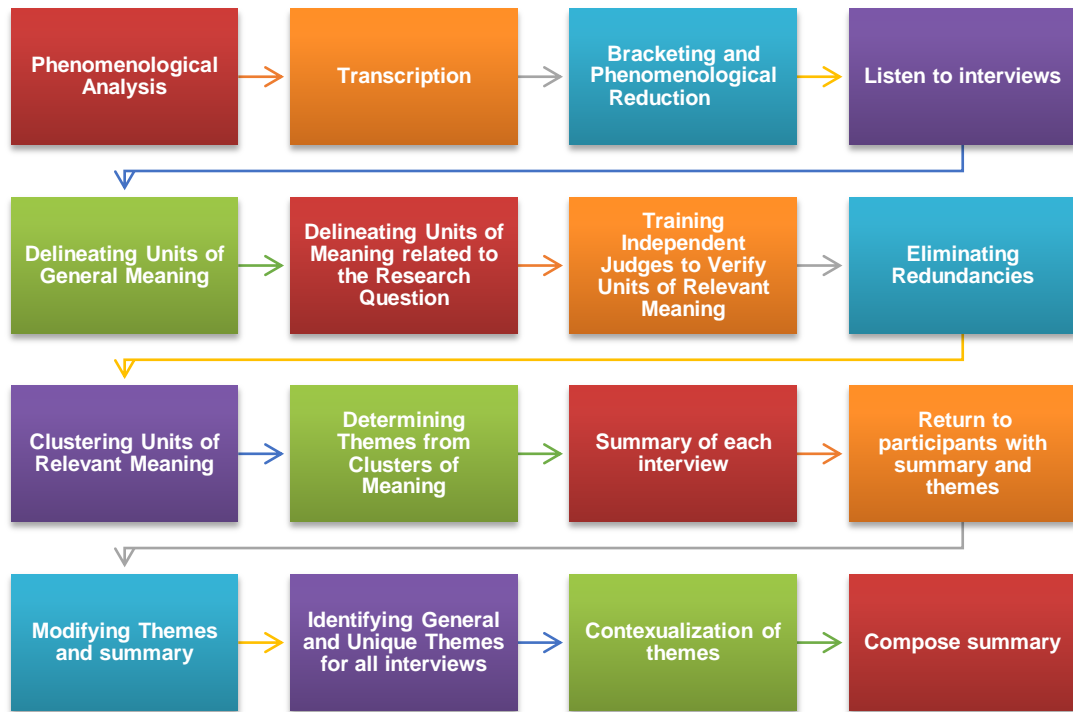


Figure 4.1. Steps in Interpretative Phenomenological Analysis

In accordance with Hycner (1985), the researcher began the analysis by transcribing each of the interviews verbatim. The interviews were transcribed using Microsoft word in a table format. After the researcher transcribed all of the interviews, the researcher carefully considered and documented her own personal experiences and discussed with dissertation committee members how the researcher’s experience was connected to the topic being researched before she began analyzing the data (better known as bracketing the researcher’s own biases) (Van Manen, 1990). This process allowed the researcher to approach the data with openness to meanings that emerged throughout the analysis (Hycner). Bracketing offered the researcher the opportunity to suspend her own

interpretations and focus on the uniqueness of the person being interviewed. Through this, the researcher was able to understand the meaning of what the person was saying rather than what the researcher expected the person to say (Hycner). As part of this step, the researcher also elicited the units of general meaning through a process called phenomenological reduction. This process is an effort to open oneself to the phenomenon as a phenomenon and to see it as phenomenon with its own meaning and structure (Keen, 1975). To claim pure objectivity during the process of phenomenological reduction would be a fallacy, as it is impossible to reach complete absolute phenomenological reduction (Merleau-Ponty, 1964).

Phenomenological analysis involved the investigator approaching the text with an open mind seeking to learn from the meanings and expressions that developed (Rossman & Raliis, 1998). The process of Interpretative phenomenological analysis involved the researcher bracketing her own personal bias, thereby making interpretations as objective as possible and grounded in the data. Thus, the researcher outlined and recognized her personal bias prior to beginning and revisited these biases throughout the study to make sure she remained as objective as she could, thus maintaining a rigorous qualitative study. The researcher's biases are outlined in Table 4.3.

Table 4.3

Bracketing Bias

My sister died when I was 18 years old. She was brutally murdered by her ex-husband. It happened in a small town in Georgia at the Holiday Inn where my sister worked. He walked in and shot her and then turned the gun on himself. My sister and I were extremely close. It has been the hardest loss I have ever had to face in my life. Not a moment goes by that I don't think of her or wish that she was still here. She missed some of the most important milestones in my life (graduation, prom, getting married) and will continue to miss many more. It is from this experience that I learned to deal with my grief. I tried to educate myself about grief and how to deal with it on my own. At that time, counseling was not that widely known or as accepted as it is now. I spent many days crying in the bathroom by myself. Ten years after her death, I learned that I had been able to grieve the loss of my sister, but I had never been able to reconcile how she died. I entered counseling and through counseling have finally reconciled the trauma of how she died.

Through educating myself, I learned to deal with my grief. I also learned that I did not want others to go through the pain that I went through alone. I wanted to be able to help others. Thus, I became a hospice social worker. I worked for Alive Hospice in Nashville, TN, for five years as grief counselor so that I could help others deal with their grief. I especially wanted to help children, but also worked with adults. My work at Alive Hospice allowed me to be a camp counselor at their children's bereavement camps and facilitator for their support groups, in addition to individual counseling. I also recently volunteered for American Cancer Society's Siblings Camp.

In my work at Vanderbilt, I have encountered many parents who have faced sudden or expected deaths of their children. No family is ever ready to lose a child, but as a social worker I was able to be a supportive influence during a very difficult time. I remember working with a child who lost her two-year-old sister and provided emotional support to her after she pulled her sister out of the swimming pool. It was incredibly difficult to see the pain that she was feeling and carrying, knowing how much she was going to miss her sister. I remember sitting with her in the hallway as she reminisced about how she had always wanted a sister and she did not know what she was going to do without her sister. They held such a close bond that only siblings could have.

Through my work at Alive Hospice, I worked with one child who lost his brother suddenly and unexpectedly. He was very young, but very much knew the pain of losing a sibling. Developmentally, he was mature beyond his years and it was difficult to see how much pain he was feeling. With my help and that of his parents, he was able to move forward in healing from his grief. From my own experience and this experience, I came to the realization that siblings have a bond that is unique and different from any other relationship with anyone else.

My dissertation research was formulated from my personal experience of losing my sister as well as my experience working with grieving children and adults. From my work with grieving children, I gained an appreciation for how siblings can develop a close bond at such a young age. Siblings have bonds that are very different than any other bond with any other family member. Many studies have been conducted on children who have lost a parent, or parents who have lost a child, but less research has been conducted on sibling grief. From my own experience of losing a sibling at a young age, I felt compelled to learn from others who had lost a sibling.

I really want to learn from other children who have lost a sibling. I want their experiences to be heard and understood. Thus, I am stepping back from my own experiences and what I have learned about grief so that I can truly understand the participants' experiences of surviving the loss of a sibling.

Next, the researcher listened to the interviews for a sense of wholeness. The researcher read the transcripts several times as a basis for development of specific units of meaning. The next step involves delineating units of general meaning (Hycner). During this step, the researcher began the rigorous process of going through every word, phrase, and sentence to elicit the participants' meanings. This is done with as much openness as possible and does not yet answer the research question (Hycner). The purpose of this step is to get at the essence of the meaning expressed through words, phrases, or sentences. An example of this step is given below in Table 4.4. It is difficult to express the entire context in this brief example which demonstrates the purpose of the general units of meaning.

Table 4.4

General Units of Meaning

Transcription	General Units of Meaning
<ol style="list-style-type: none"> 1. This actually represents my oldest son. 2. He is very much like me and 3. He will talk your ear off. 4. He just always has been. 5. We got Micah's diagnosis and slowly he stopped talking. 6. Not that he didn't talk and didn't share stories but that he was the type of child as soon as he was verbal. 7. I would say what are you thinking and I would listen for an hour or two. 8. I would hear all sorts of stuff things some would be about his imagination, some would be his feelings, some would be things 	<ol style="list-style-type: none"> 1. Actually represents my oldest son. 2. Very much like me. 3. Will talk your ear off, 4. Just always has been. 5. Got M's diagnosis and slowly he stopped talking. 6. Not that he didn't talk and didn't share stories, but was the child as soon as he was verbal. 7. What are you thinking and listen for an hour or two. 8. Hear all sorts of stuff about his imagination, feelings, and things going on in the neighborhood.

<p>going on in the neighborhood or whatever it happened to be.</p> <p>9. I didn't realize, he was still communicative enough and I was enough into my own stuff that I didn't really realize what was going on for him.</p> <p>10. I don't remember exactly when in the pregnancy it was.</p> <p>11. He just seemed off somehow.</p> <p>12. It was at that point that I realized he wasn't talking like he used to.</p> <p>13. He didn't come down and give me a hug and tell me about his dream right away which was something that we had always done.</p> <p>14. I didn't realize that had been going on for weeks and weeks and weeks.</p>	<p>9. He was still communicative and I was enough into my own stuff I didn't realize what was going on with him.</p> <p>10. Don't remember exactly when in the pregnancy it was.</p> <p>11. Just seemed off somehow.</p> <p>12. At that point, I realized he wasn't talking.</p> <p>13. Didn't come down and give me a hug and tell me about his dreams, which was something we had always done.</p> <p>14. Didn't realize that had gone on for weeks.</p>
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The context of this example is the mother describing her oldest son's experience of losing his sibling. She shared a picture with red tape over a person's lips to represent her son's silence during the grief process.

The next step involves extrapolating data from the units of general meaning to answer the research question. If what the participant has said appears to answer the research question, it is noted as a unit of relevant meaning. This is a crucial step in the process as it is the basis for the rest of the analysis. Statements that are not pertinent to the research question are not included in this step. If there is any uncertainty as to whether the statement answers the research question then it should be included. As the researcher engrosses herself in the data, it should become clear whether the statement is pertinent. According to Hycner (1985),

This requires some kind of *judgment call* on the part of the researcher, though if the researcher has done a good job of bracketing presuppositions, is very open to the data, and yet utilizes a rigorous approach, it would seem that the danger of inappropriate subjective judgments is minimal. (p. 284)

Table 4.5 demonstrates how units of relevant meaning are extrapolated from units of general meaning using the previous example. The researcher erred on the side of caution when determining the units of relevant meaning. The researcher then trained independent judges to verify units of relevant meaning. Members of the researcher’s dissertation committee reviewed the analysis to verify the findings. Multiple conversations were held to discuss the analysis and any minor differences that may have emerged. This is also useful in establishing the rigor of the study. According to Hycner (1985), “If there is a significant agreement between the researcher and the judges, then this indicates that the researcher has bracketed her presuppositions and has been rigorous in her approach in explicating the data” (p. 286).

Table 4.5

Units of Relevant Meaning

Units of Relevant Meaning
<ul style="list-style-type: none"> • Actually represents my oldest son. • Will talk your ear off. • Got Micah’s diagnosis and slowly he stopped talking. • Not that he didn’t talk and didn’t share stories, but as soon as he was verbal he never stopped talking. • What are you thinking and listening to for an hour or two. • Hear all sorts of stuff about his imagination, feelings, things going on in the neighborhood. • He was still communicative and I was enough into my own stuff I didn’t realize what was going on with him.

Table 4.5 *Continued Units of Relevant Meaning*

- Don't remember exactly when in the pregnancy it was.
- Just seemed off somehow.
- At that point, I realized he wasn't talking.
- Didn't come down and give me a hug and tell me about his dreams, which was something we had always done.
- Didn't realize that had been gone for weeks.

Once the above steps were completed, the researcher eliminated any redundancies from the list. In this phase, the researcher looked not only at the literal meaning, but also the number of times a meaning was used. During this step, the researcher noted the number of times a unit of relevant meaning was listed as this could indicate significance for the participants. Table 4.6 represents the process of eliminating redundancies.

Table 4.6

Eliminating Redundancies from Jason's Interview

Counselor from school/counseling. (3)
Squirrel (4) (note: "squirrel" was the deceased child's nickname)
Grief (13)
Tears (5)
Anger (5)

The next step involved clustering units of relevant meaning, which included the researcher looking for relevant meanings to see if any of them would naturally cluster together. In other words, does there appear to be a common theme that united the units? The researcher rigorously examined each of the relevant meanings as a way to elicit the essence of that unit of meaning within the

context. This step involved a constant process of going back and forth between the units of relevant meaning and clustering units of relevant meaning. Table 4.7 shows an example of clustering units of meaning. A danger of this step is that the researcher exercises her judgment more than in the other steps, which could lead to the researcher's presuppositions to hinder the analysis. This issue was addressed by having committee members verify the clustering units of meaning results and discussing any differences that emerge.

Table 4.7

Clustering Units of Relevant Meaning

Communication
<ul style="list-style-type: none"> • Will talk your ear off. • Got M.'s diagnosis and slowly he stopped talking. • Not that he didn't talk and didn't share stories, but was the child as soon as he was verbal, what are you thinking and listen for an hour or two. • He was still communicative and I was enough into my own stuff I didn't realize what was going on with him. • At that point, I realized he wasn't talking. • Didn't come down and give me a hug and tell me about his dreams, which was something we had always done. • He wanted to talk about his own stuff. • He is older he processes things with his friends and he will talk to his father. • Had mentioned when we were talking that he kept a lot inside of him in the beginning. • Didn't feel like he could talk to anyone. • If they want to talk about him or look at his pictures or they wanted to do something then we are going to. • Sometimes they would talk about something not necessarily M. but they would want to talk about something that was going on.

Once the researcher finished clustering units of meaning, the researcher identified one or more dominant themes expressed as essences of the cluster.

The researcher matched the similar clusters of meaning together. Then once all

similar clusters of meaning were matched, the researcher ruminated over the clusters to identify a central theme. An example of a theme that emerged from the clustered units of meaning is presented in Table 4.8 below. Figure 4.2 shows the themes from all the clustered units of meaning.

Table 4.8

Central Themes from Clustered Units of Meaning

Commemoration of Life
<ul style="list-style-type: none">• Legacy• Ritual• Reminder of the Loss• Mementos• Memorializing• Remembrance• Making an Impact• Holding on to the loss• Symbol• Prized Possessions• Fulfilling his wishes• Honoring your loved one• Life Purpose• Life story• Meaning• Memorial Service• Still a part of us• Memories• Memorial Object• Special Memories



Figure 4.2

The General Themes from Clustered Units of Meaning

Next the researcher wrote a summary of each individual interview incorporating the themes that emerged from the data. The summary provided a holistic view of what the participants were trying to convey about their experiences. The goal of the researcher was to reconstruct the inner world experiences of the participants and how they were understood in relation to others (Ellenberger, 1958). An example of the summary from Mason’s Interview is shown in Table 4.9.

Table 4.9

Summary of Mason’s Interview

Mason began the interview describing his brother’s diagnosis and what he learned about the diagnosis. He remembers spending time with his brother before he died and describes it as very emotional. He feels family members grieved differently and feels his mother was “freaking out” more than others. He explained that he was not as free with his emotions. Mason shared that he *gained knowledge and understanding* of his brother’s diagnosis. Mason explained that he did not really know much about Trisomy 13. He knew it was something that would cause his brother’s brain to send messages to stop breathing. *Expression of grief*- He expressed anger and regret after his brother died. He explained that when his brother came home that he was really tired

Table 4.9 Continue Summary of Mason's Interview

because they had gone to the hospital in the middle of night so he fell asleep when they came home. He shared that he felt guilty because he should have been awake because when he woke up his brother died 10 minutes later. The theme, *commemoration of life* emerged from Mason when he described the stained glass window his family made. He explained that each family member and friends decorated a square to represent Micah. He described each of the squares that his family completed. He shared that this serves as a reminder that Micah will never be forgotten and will always be loved. They did this as a way to remember him and keep his memory alive. *Reinvesting in life*- He found through his experience that you have to try to look on the bright side and keep your chin up. He shared that you cannot quit and that you have to keep going and talk eventually. *Collective experience* was another theme that emerged as Mason described his grief experience. Mason described his experience at camp. He remembers being around people who had experienced a loss. He found just being around people who lost a sibling or somebody was helpful. He shared that they became friends and have each other's back.

The researcher returned to the participants with the summary and themes to verify that the information was accurate. This was an important step as it validated that the participant and the researcher were in an agreement with the findings. This is known as member checking (Padgett, 2008). This is also a crucial step because judgment calls come into play when clustering and identifying themes. This step either validates the findings or identifies the need to conduct more interviews with participants or to review the data again. This researcher provided copies of the interviews to the participants and had them read the interviews to ensure accuracy. The researcher also engaged in dialogue with the participants when clusters of meaning and themes were identified. The researcher discussed any discrepancies and asked questions to further clarify the discrepancies. This researcher also reviewed the interview in its entirety

again to understand the context of the interview as a whole. Throughout the process the researcher continually modified the themes as she further immersed herself in the data.

All of the above steps were repeated for each participant. The researcher identified common themes for all of the interviews as well as individual variations. This procedure acknowledges differences among participants as well as the phenomenological viewpoint of emerging essences (Hycner, 1985). The researcher noted that all themes were unique to a single interview. Committee members verified the results, which provided further rigor. The unique themes identified are listed in Figure 4.3.

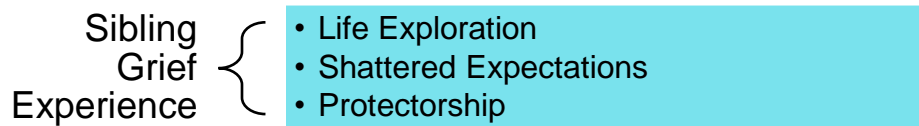


Figure 4.3.

Unique Themes from Individual Interviews

After the general and unique themes have been identified, the researcher positioned the themes back within the original framework of the interviews. This is done to understand the phenomenon and the role it plays within the framework of the original interviews. This step is known as contextualization of themes. An example is provided in Table 4.10.

Table 4.10

Contextualization of Theme

<i>Contextualization of Theme</i>
Commemoration of Life. The findings suggest that it is important to find ways for children to commemorate their loved one's life. This theme emerged from all of the participants' interviews. Each person describes their experience of how their family chose to commemorate their sibling's life. Examples included participating in a 5K run, donating Legos to hospitals, making a stained glass window, and raising money to donate to local organizations. This is something that each family chose and wanted to do. They felt it was a way to honor their sibling and keep their memory alive. Participants also described memory items that they have of their loved ones. These items were stored in the children's room and could be looked at whenever they wanted. These items included things such as a memory box, pictures, blankets, and clothing. All of these items carried special meaning for each of the participants. These items served as a reminder of the love that they had for brothers.

The final step involved completing a composite summary of all the interviews to capture the essence of the phenomenon. The summary described the phenomenon as it was experienced by the participants. Given the length of a summary for all the interviews, an example will not be provided. An example of an individual interview was provided in Table 4.9 and this example can be further incorporated into the composite summary.



Figure 4.4

Summary of Photo-Elicitation Project Steps of Analysis

Summary

The focus of this chapter was to explain the methods and procedures for the photo-elicitation project. In this chapter, information regarding participants, data collection, and analysis were explained. The chapter outlined the steps in the analysis process and provided the reader with an example for each step. The findings of the study will be presented in Chapter V. The themes that emerged from the interviews will be presented throughout the findings.

CHAPTER V

FINDINGS

*“If tears could build a stairway and memories a lane, I would walk right up
to heaven and bring you home again.”*

-Author Unknown

This chapter presents the findings of children’s experiences of losing a sibling told from the children’s and parents’ perspectives. Their experiences were detailed through photographs taken by the participants and then discussed with the researcher during the interview process. This chapter discusses the background of the study, general and unique themes, and a summary of the findings.

Background

Recall the aim of the study was to gain an in-depth understanding of children’s lived experience of losing a sibling. The aim of the study was accomplished using a combination of photo-elicitation and phenomenological methods. To get at the lived experience of bereaved siblings, the researcher interviewed surviving children and their parents. The parents were interviewed about the children from the parents’ perspective. The researcher analyzed the data using interpretative phenomenological analysis, and the findings are discussed in greater detail below.

To protect the identity of the participants who participated in the research study, pseudonyms have been used throughout this dissertation. Some of the pictures were altered to avoid identifying any of the participants in the study. For example, the name was changed on one of the pictures to the pseudonym.

Any alterations to the quotes have occurred only when it is necessary to clarify the participant's experience. To truly capture the participants' lived experiences and provide an important context necessary to understand the essence of participants' experiences, some quotes are lengthy. This is consistent with some previously published guidelines, i.e. that quotes or extracts should be used to support interpretations and explanations as well as be presented in a manner that reflects the conversation as accurately as possible (Kirklees, 2014). Morrow (2005) stated that, "Just as numbers contribute to the persuasive *power* of a quantitative investigation, the actual words of participants are essential to persuade the reader that the interpretations of the researcher are in fact grounded in the lived experiences of the participants" (p. 256). Although this is a departure from other published guidelines, Ritchie and Lewis (2014) claim that it is better to use short quotations with multiple pieces of evidence in the narrative.

General and Unique Theming Analysis

Ten general themes emerged from the qualitative data: (a) gaining knowledge and understanding, (b) processing grief, (c) expressions of grief, (d) drawing on faith, (e) collective experience, (f) communication, (g) adjusting to changes, (h) perceptual differences, (i) commemoration of life, and (j) reinvesting

in life. While the general themes were consistent across most of the interviews, a few unique themes were identified among participants: (a) life exploration; (b) protectorship; and (c) shattered expectations. Each of the general and unique themes are discussed throughout the findings of the study.

Presentation of General Themes

The process of phenomenological analysis is to identify general and unique themes for all the interviews. As part of the process, the first step is to recognize themes common among most or all participants. If there are themes from individual interviews then the themes are clustered together as a general theme. The researcher reviewed each of the general themes with her dissertation committee to verify the findings. The general themes are identified and further explained in greater detail below.

General Theme #1: Gaining Knowledge and Understanding

Study participants, particularly parents, frequently commented on how difficult it can be for children to comprehend information related to a sibling's illness or death. Many indicated that their child(ren) had not previously experienced a loss of similar magnitude and, thus, did not initially possess the coping skills necessary to respond to the loss. For those children, understanding the death and questioning why the death occurred became important. They engaged in *gaining knowledge and understanding*.

Maddox learned that his future brother would be born with Trisomy 13. This picture shows someone pinching his lips with two fingers. Kristen describes

Maddox's experience of trying to understand exactly what the diagnosis meant and how his future brother would be affected by the illness. Maddox was trying to process the information based on his developmental understanding.

Photo #1: The Lip



It is called the lip. It is basically my two fingers pinching my upper lip in an upward motion. If you have ever seen a picture of our son, Micah, he had a bilateral cleft palate. We had an ultrasound. They had given us 3D images of it. The boys had seen that. Developmentally, thankfully, one of the best things the palliative care team had done was give us a folder of various things. You look at some of it and go I am not going to look at any of that, but you have to look at it a few weeks later because that is where you are. But it is there. Working with your children dealing not just with the grief process but also dealing with the tragedy or bad news knowing that you are going to have an imminent loss. It talked about some of the different developmental

stages (concrete and so forth)... At the time, he was seven. I was putting them to bed. My youngest said, "Is Micah going to die." And I said, "Yes, Micah is going to die." My third son said, "Am I going to die." I said, "Yes, everybody dies sometime but you are not going to die anytime soon." Oh, okay. Well at least I don't look like this. He pinched his lip and pushed it up towards his nose...He wasn't trying to be mean. That is exactly where he was. I have to realize he wasn't trying to be mean. It wasn't an intent to insult his brother. He had seen this picture that made no sense to him. I hadn't shown them pictures of other kids with Trisomy 13 because honestly I had no clue what their own brother was going to look like...But that said, He didn't look like everybody else. He wasn't normal. My third son needed to figure that out. He didn't know what it meant... I had to allow myself to realize where he was developmentally." (Kristen, 36)

While to most it might have seemed offensive for Maddox to pinch his lip as if he was making fun of his future brother that is where he was in his understanding of

the situation. Having that knowledge before Micah was born prepared Maddox for what his new brother would look like. Through learning about Trisomy 13, he knew that any time he had with his brother would be limited.

This picture portrays Maddox's experience of trying to *gain knowledge and understanding* of his brother's diagnosis and using that knowledge to process his grief. This is a theme that resonated with all of the participants. Kim described Ricky's experience trying to understand Mitchell's brain cancer:

"We used to come back from the doctor and Ricky would say did they get the bump out of your head?"...Mitchell says, "No buddy." Ricky would say, "Stupid doctors"... "He got it by the ball hitting him in the head. It was when he fell playing football"... "He hit his head about 6 months before he was diagnosed. But for a long time we found it through the school teacher that he thought that is where it came from. Even at recess he was scared to play so we had to explain that it was something that he was born with."

General Themes #2: Processing Grief and #3: Expressions of Grief

Through conducting the interviews with participants, it became evident that each one of the children went through a recovery period where they processed different aspects of their loss and the grief that followed. This period was a time of reflecting on their loved one's life, feelings surrounding the losses, and identifying things that helped them to deal with the loss. *Processing grief* is defined as a process of children working through their grief and identifying things that are helpful/unhelpful in moving toward healing. *Expression of grief* can be defined as children identifying and expressing different feelings and symptoms that represented their grief.

As Maddox was processing grief, he identified sadness of losing his brother. The picture below was taken of a flowerpot that was made while he was

at a camp for bereaved children. He explained that his counselor broke the flower pots beforehand and he had to put it back together. He shared that the flowerpot represented the hard work he had to do during the grief process. As part of the process of putting the flower pot back together, he explained that he was able to move from sadness to being happy again.

Photo #2: The Flower Pot



*“It was a flower pot that was broken and I had to rebuild it. The broken pot was sadness and I had to put it back together...I got it from camp. You can go there if you have lost a brother or something. It tries to help you be happy again. It means my hard work with it trying to be happy again.”
(Maddox, 7)*

The flower pot represents his process toward healing and his desire to be happy again. This picture represents Maddox *processing his grief* as well as *expressing his grief*. Other participants also shared their experiences *processing grief* and making *expressions of grief*. All adult participants discuss how their children processed grief except for one adult. All of the children discussed how they processed their grief after losing their sibling. Other examples of this theme are presented in Table 5.1. Expressions of Grief in relation to this picture are discussed in the next section.

Many children throughout the interview process identified different feelings or physical symptoms and behaviors that they experienced throughout the grief process. The broken flower pot symbolizes Maddox’s grief process and represents his sadness and the process of putting it back together to make him happy. Other feelings that were identified from participants were guilt/regret,

anger, worry, fear, boredom, and confusion. Physical expressions of grief, as identified by a few participants, are in Table 5.2.

Table 5.1

Emotional Symptoms

Confusion

“It was really confusing.” (Miles, 12)

Guilt

“I felt guilty.” (Mason, 10)

Denial

“In a way, I was expecting him not to be here. So when he was, I had been ignoring it before, but there wasn’t really a good way to ignore it now.” (Miles, 12)

Anger

“That week he was so full of anger.” (Kristen, 36)

Worry

“One of the things that he really struggled with was anxiety.” (Tiffany, 30)

Boredom

“I was bored because I had no one to play with.” (Ricky, 8)

Fear

“He is afraid that he isn’t going to wake up.” (Tiffany, 30)

Table 5.2

Physical Symptoms

Difficulty sleeping

“In this moment, this is currently what he is dealing with. He is having a hard time staying asleep. He wakes up in a panic.” (Tiffany, 30)

Crying

“I felt like crying a lot.” (Mason, 10)

Exhaustion

“It signified to me not that the grief is never over, but just how tired you feel from feeling so much. Sometimes, I felt that he was just exhausted.” (Henry, 31)

Clinging more to surviving family

“He probably slept in a room a week or so after Mitchell died...Ricky and his older brother, Michael went back into Michael’s room. Ricky slept in there with Michael for several nights.” (Kelly, 40)

As mentioned above, many expressed strong emotions regarding their loss. Many of the children had worked with parents or counselors to identify healthy ways to express those emotions regarding their loss. Some of the children were not as forthcoming with sharing their emotions, as they tended to internalize their feelings. For example Mason stated,

“I was kind of more back with my grief. Of course, when he died I was like ah (makes crying sound), but later on I was trying to take it good. I was not taking it better than my brothers just trying not to show it as much.”

Some emotions were not expressed until there was something that triggered a particular feeling. For example, a trigger for Mason (10) was seeing his brother’s ashes, and it made him angry that he felt his brother’s life had been reduced to ashes. Kristen states,

“He kept getting meaner and meaner throughout the week. He was mean. More so than just a fly off the handle. It was all this stuff bearing down on him. We didn’t know what had caused it. Finally found out a week later that it was seeing his ashes that triggered it. That week, he was so full of anger.”

Anxiety was also another common emotion identified by many participants. The picture below represents Jason’s (7) *anxiety* and how he processed that anxiety during a counseling session and continued throughout his grief journey. He identified things that caused him to worry. He wrote those things on rocks and put them in the worry bowl. The worry bowl represented taking those worries away from him so that he was no longer burdened from carrying all of those worries. His mom, Tiffany, pointed out that another way to address the worry was talking about their worries and anxieties.

Photo #3 Worry Bowl



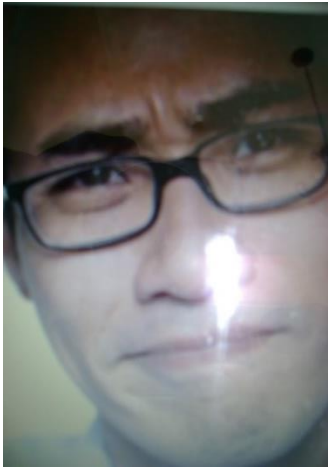
"The worry bowl. One of the things that he really struggled with was anxiety. One of the things that I felt really trickled down. Then, he was so young that it was hard for him to really verbalize that this makes me anxious. I think a lot of it was just his personality. He is a lot like me-high strung, edgy, extremely deep thinker. I think a lot of it was his personality, but then obviously other life situations tend to play into it. We will continue to add to it. We

are really trying to work through that. We are having a lot of anxiety about things. We try to talk and not let it fester and build." (Tiffany, 30)

Each participant described numerous emotional and physical symptoms and behaviors that the surviving siblings experienced as they grieved. The examples above represent three child participants and how they expressed different emotions during the grief process. Two other child participants expressed emotional and physical symptoms. All five of the parental participants discussed the emotional and physical symptoms that their children experienced during the grief journey.

Henry described his son, Jason's, experience *processing grief*. He also discussed some of the emotions that he noticed Jason experience. To him, this picture was the closest thing he could find to represent grief. Henry explained that he believed Jason was feeling a lot of the same things they were feeling but on a child's level. Henry identified several emotions (pain, anguish, sadness, and anger) and describes a look of confusion on Jason's face as he tried to process the different feelings.

Photo #4: Grief



"This one to me was as close to grief that I could find in a picture. It was the expression of grief on the face. Just the anguish and pain that goes along with that. When I was searching for some things that was one of the images that I found, and I guess it struck a chord with me because I felt like in his own way obviously he was going through grief. He was feeling a lot of the same things that we were feeling only on a young child's level...To me it was just confusion, like just a look of I don't know how to react because of all the sadness, the anger, and grief...There all these different phases of grief yet some of them come back." (Henry, 31)

Many children who participated in the study, identified things that helped them process their grief. The picture below contains items that represent projects that Jason (7) created at a bereavement camp, including a feeling mask, memory box, and the name tag that he wore at camp. He reported that these items helped him better cope and deal with the loss of his brother.

Photo #5: Camp Items



"These are some of the things that I made at Camp that helped me to deal with the loss of my brother." (Jason, 7)

According to Tiffany another thing that he found helpful was participating in individual counseling. She stated, *"I think with the counseling and acknowledging*

his grief was really a turning point for him.” In addition to Jason, Maddox and Mason indicated that they found bereavement camps and/or counseling to be helpful.

For many children, *processing grief* was often accomplished in the company of other people. Maddox (7) stated, *“It is good to find someone that you can talk to about your brother or sister.”* Mason (10) found watching his dad paint a picture of his brother’s tree, fence, and his face in the clouds helped him to process his grief.

Photo #6: Painting of Brother’s Tree, Fence, and Face in the Clouds



Mason (10) also identified talking to people as helpful. Mason stated, *“I think talking it out is helpful and something people should do.”* Miles (12) found support from a church friend who helped him process his grief. *“Even though I didn’t really know him at the time that well, he was kind of one of the few people that understood.”*

“Even though I didn’t really see him that often. He would sort of know what he was talking about.” He would say, “Oh hey, how have you been doing since your brother died?” “That was one of things that kind of helped in the long run but obviously not at the exact moment.”

Each child participant identified and described things that they found helpful in dealing with the loss of their sibling. As described above, they may not have been able to identify all of those things in the moment the support was offered, but looking back and reflecting on their experience they were able to identify things that helped them along the way.

General Theme #4: Drawing on Faith

Drawing on faith was a theme that resonated with three of the child participants. Three adult participants also described *drawing on faith* as a way their children coped with the loss. This theme was defined as relying on faith for strength, answers, and for healing during the loss of a loved one. The child participants indicated that their deceased sibling was “in a better place” and “they are no longer suffering.”

“Micah is in heaven, and he is still with us. Helps me to remember that he is somewhere better and my family will never forget him.” (Mason, 10)

In the picture below, Mark described his understanding of God’s plan and how God’s plan does not always align with humans’ plans. This picture demonstrated the comfort that this family got from relying on God and scripture to help them deal with the loss of Micah. Mark described the comfort of a warm blanket and the comfort of the scripture as a way to share love through their experience. Through this experience, they always wanted Micah’s story to be told and encouraged their children to share his story. They also wanted Micah’s life to

have meaning. Mark explained his belief that, even though the loss was a terrible thing, God's plan is always so much better in the end.

Photo #7: Bible and Blanket



“Romans 5:8. It is a myriad of but God statements. But god demonstrates his own love towards us and while we were yet sinners Christ died for us. It is a huge summary revealing that God’s perspective is so much different than ours. Our expectations of a new baby, kids having a new brother or sister, totally different perspective and blessing than what God had planned. One of the biggest words is God’s perspective on life and His plan is so much different than we ever expect. The comfort of the scripture and the comfort of a warm blanket. Being able to cuddle up in a warm blanket is always comforting and being able to share love through that experience... There was the agony of the grief of it all... One of our biggest prayers for his life is that it would have meaning and that God’s perspective would be told through his story. Of course, it is not comfortable. Well here this is and it is going to be a terrible experience, but it is going to work out greater in the end than we expect... I think we have always encouraged them to share his story.” (Mark, 38 years old)

Miles (12) described how the loss of Micah changed his view of his own spirituality. Through the loss of Micah, Miles clung to his faith and made him live and act upon what he had believed.

Before, I had been acting at church if that makes sense. I would sit there and go. Yes I have heard this 3 thousand times and I could probably quote it. I didn’t actually do anything with it. I knew I was a Christian, but I never really thought about it. I wasn’t living it. I wasn’t feeling it. I guess obviously Micah’s why was not just about me and my philosophical problems. Personally, I think his life helped me think and feel more if that makes sense. I actually lived what I said I lived. I wasn’t as fake anymore. (Miles, 12)

Ricky drew upon his faith as a way to cope with the death of his brother, Mitchell. Ricky (8) described Mitchell in heaven finally getting to play football

because he is no longer sick. When he thought of Mitchell in heaven playing he got excited because he knows the next time he sees Mitchell; he will be able to play with him.

Each of these children drew upon their faith to help them process the deaths of their siblings. For many of the children it gave them comfort knowing that their siblings were in heaven with God and were no longer sick. For others, relying on their faith drew them closer to God and intensified their relationship with God.

General Theme #5: Collective Experience

Three of the children in the study identified collective experience as a central theme. *Collective experience* involves being around other children who have experienced a loss similar to theirs' and feeling supported by each other. The three child participants spoke about having the shared experience of being around other children who had also experienced the death of a sibling. For them, it made them feel like they were not the only child who has lost a sibling. They felt like they could relate and understand what each other was going through. The children met other children through camps and support groups. Mason (10) stated, "*Being around other people who have had a loss...We became friends, we got this, we got each other's back.*" Maddox goes on to further corroborate the *collective experience* as he describes his experience at camp.

When I made the memory box at camp, I had to bring stuff that reminded me of my brother. I was happy to show and tell my friends about it...Everybody was telling about the people they lost so I thought I could too. (Maddox, 7)

A few examples described Jason's experience of being around other children who experienced the loss of a brother. His experience is told from his perspective as well as his parents' perspective as they described his *collective experience* with others.

Photo #8: Mask



"A picture of the mask from camp. Camp was a good memory because I could have fun with people that knew how I felt about losing my brother." (Jason, 7)

"The mask from camp. I felt like some of the cycle of grief was starting to get better because he had learned some tools on how to talk and express himself. He was getting older and getting a little more mature. One of the things that I felt like was a huge benefit for him was being in a place around other kids having that shared experience even though their losses may have been different, but just having that shared experience. I felt like he found some comfort in knowing he wasn't the only one going through this." (Henry, 31)

Henry and Jason both described a picture of the mask that Jason painted at camp. Jason described the experience as having fun with people who knew how he felt about losing a brother. Henry described Jason's experience as comforting, knowing that he was not alone and could have a shared experience of being with other kids who had experienced a loss.

The picture below was a camp shirt. For Jason, camp was a good thing because he realized he was not the only one who lost a sibling. Camp and support groups was an opportunity for him to make friends with other children who knew what he was going through. It was an opportunity for them to support one another in their grief.

Photo #9: Camp Shirt



“This was a picture of camp. It was the greatest thing ever. Just being around other kids and having a social environment to talk about things. Even though, I know it was so heavy in the things that they were all doing there. We left at the end of camp and went to Gatlinburg. He just seemed so free. I think a big first for him. It’s not fair. I am the only one. I am the only one of my friends who has lost a brother. I don’t know anyone else whose family member has died. In support groups and at camp is where you may keep friendships. He realized there were other kids whose brothers had died.” (Tiffany, 30)

These parents provided the opportunity for their children to be around other siblings who had experienced a loss. For these children, it provided an outlet for them to see they were not alone. It was also an opportunity for them to process their grief, but also realize they could have fun at the same time.

General Theme #6: Communication

Some parents in the study reported difficulties engaging their children in communication. In the midst of his own grief, Mark (38) realized the importance of communicating with children when they have experienced a loss. He reported that, without good communication, things could go poorly for his children. Thus, he continually tried to find ways to engage his children in conversation regarding their brother or their grief experience.

“Always have that communication going. Without communication I think things can go bad. Continually talk to the children because they are experiencing loss different.” (Mark, 38)

As mentioned above, some children choose silence as form of communicating. Kristen (36) described an experience she had with her oldest son, Miles (12) who had stopped communicating with her. Prior to learning about

his brother's diagnosis, Miles shared many aspects of his life with his mom on a daily basis. For Miles, the silence continued for a while. Kristen realized that she had to sit down and talk with Miles about the change in his behavior. As she discusses in the quotation below, Kristen believed that Miles chose silence as a way to demonstrate his love to her.

Photo #10: Red Tape on Mouth



"This actually represents my oldest son. He is very much like me and he will talk your ear off. He just always has been. We got Micah's diagnosis and slowly he stopped talking. Not that he didn't talk and didn't share stories but that he was the type of child as soon as he was verbal. I would say, "What are you thinking?" and I would listen for an hour or two. I would hear all sorts of stuff about

his imagination. Some would be his feelings, some would be things going on in the neighborhood or whatever it happened to be. I didn't realize, he was still communicative enough and I was enough into my own stuff that I didn't really realize what was going on for him. He just seemed off somehow. It was at that point that I realized he wasn't talking like he used to. He didn't come down and give me a hug and tell me about his dream right away, which was something that we had always done. I didn't realize that had been gone for weeks and weeks and weeks. There was a real disconnect between what I was going through and what he was going through. He is also a very observant child so he could see very distinctly that there was a difference in how I was behaving. His life was continuing. He went through a couple of really difficult situations with friends at school. He didn't share any of that stuff with me. In the past he would have...Finally, the lord put it on my heart that I had to sit him down...He admitted he didn't want to talk about it because he didn't want to burden me with anything else. He had chosen silence not as a coping mechanism and not as selfish endeavor but as a way to love me so that is why the tape is red." (Kristen, 36)

The next picture represents Jason's experience with communication.

Jason's father, Henry, explains that this was the first time that Jason went somewhere to talk about his grief with someone other than with them. This

experience provided an outlet for Jason to talk about his grief with someone he felt comfortable with and trusted.

Photo #11: Heart with an S



“This is a heart with an S on it. That represents what my counselor from school gave to me.” (Jason, 7) “That was the first time you had really went anywhere to talk to somebody else besides me and mom.” (Henry, 31)

Kelly (40) talked about their experience with communication as a family. She recognized that it is important to talk about their loss. As time has gone by, she realized that they spend less time talking about Mitchell than they did in the beginning. The times that he does come up, they spend time talking about him. It may only be for a brief moment. For example, as they are watching TV and the actor reminded them of something Mitchell did. According to Kelly, it is important to keep his memory alive through talking and sharing memories.

He still does talk about it and sometimes the most random things will come out of him...It is important to talk about them...As much as we have talked this hour, we have not all sat down and talked this much in a long time...He still comes up in conversation all the time. (Kelly, 40).

From these examples, each child communicates differently and for different reasons. For one, it was a way to protect and love his mother. For another, he spoke with a school counselor about his grief and could help him

process his grief through talking and completing activities. Lastly, study participants reported that talking and sharing memories about siblings is another important way to remember them.

General Theme #7: Adapting to Changes

The theme, *Adjusting to change* emerged during analysis of participants' interviews. *Adjusting to change* is defined as the recognition and adaptation to changes that occur as a result of a loss. Participants shared many examples of ways in which they were challenged to adjust to a new way of life after their losses.

Jason's brother died on Halloween. In the past, Jason (8) could look forward to going trick or treating for Halloween. After his brother died, the holiday was not the same for him. This picture represents his struggle with whether he wanted to go trick or treating. The second Halloween after his brother's death, he decided that he did not want to go trick or treating. In the end, he changed his mind. This was a decision that weighed on him.

Photo #12: The Pumpkin



"The first Halloween...wasn't as hard for Jason because I think he was so young...He was so caught up in it...Even still, it's Halloween. Kids are supposed to be excited and running around. The second Halloween was last year. About two weeks before Halloween, he came to me and said, "I don't want to dress up and I don't want to go trick or treating." I said, "That is fine because I don't either. If you decide not to go, we will stay home. If you change your mind, we will go, but that is totally up to you."

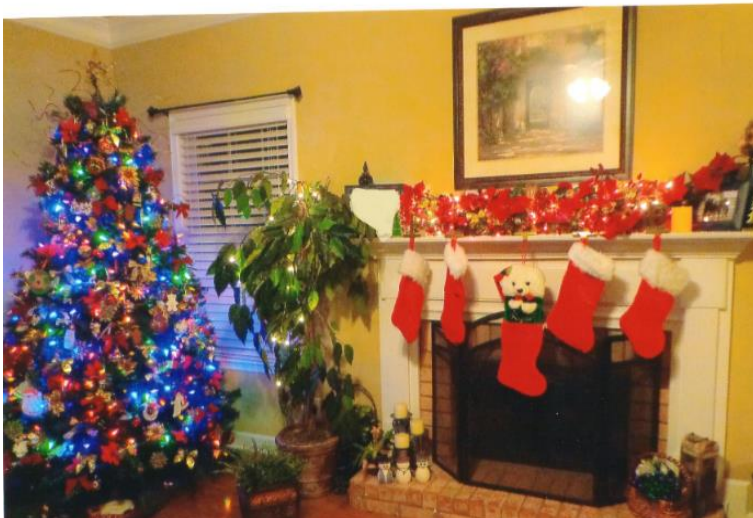
Halloween rolled around. "He did decide to go trick or treating which I thought was huge for him. Knowing the grieving process and being able to think about it and being able to sort out those feelings. I realized how far he had come at that

point. How comfortable he was and how he had matured. Not just for celebration and everything that goes along with it. And that day came. He wasn't even thinking about it. The anticipation and the dread is so much worse than the actual day. Most of the time, we know in our mind that we shouldn't worry about so much in advance. For him, it was good to not only realize that emotion, but to share it with me and Henry." (Tiffany, 30)

According to Tiffany, Jason was able to realize that was going to be a difficult time beforehand. He was able to think through what he wanted that day to look like and process the emotions that go along with that day. He was able to share his emotions with his parents.

This next picture is also an example of adjusting to change. In this picture, Kelly (40) described the family's experience of changing traditions. This family chose to change the way they celebrated Christmas. They had always celebrated Christmas with extended family and had a big celebration. After Mitchell died, the family chose to keep it more intimate. They reported that they really like the change in tradition and have continued to keep that same tradition.

Photo #13: Christmas Tree



"So, this being the second Christmas without him, I guess bitter sweet. You know definitely feeling a little bit. I don't know if feel is the right word. A little more functional this past Christmas than the first one. The first one everything just seemed so weird. So weird. Normally, we would travel for holidays. Grandparents have always come over early in the morning to

watch the children open gifts. So the first Christmas after Matt passed away we just decided that we wanted it to be the five of us that morning. Get up and do our thing...So the first Christmas we did that. We got through our gifts. We had breakfast and showered and cleaned up. We got dressed. We went to family's

home. Well actually a friend of Matt's was in the hospital, so we went to see her. We went to mom and dad's house and had lunch. We went to the movies and went out to the dinner and literally came home exhausted. This year was similar. We did our own thing that morning. The family came down here, and we went to the movies. We didn't do the big turkey dinner and all that. For now, I think we are going to kind of stick with it. It is something that we have enjoyed the last two Christmases- just having the five of us and not having to explain the emotion. His picture always sits there." (Kelly, 40)

General Theme #8 Perceptual Difference

Analysis of participant interviews revealed the extent to which individual children each perceived and experienced their losses in unique ways. Thus, the theme *perceptual differences* were identified. *Perceptual differences* can be explained as a recognition that the lived grief experience differs for each individual child. While common patterns emerge, each loss and each child's response to that loss are unique.

Four of the parental participants provided data that informed this theme. The next few examples are an account of one parents' perspective. Kristen (36) explained the disconnection between her grief and her son's grief. She was able to see that her son was aware there was a difference in how she was behaving as compared to him. She had to be tuned into her children's grief even though she recognized a definite disconnect between how she and her children grieved.

There was a real disconnect between what I was going through and what he was going through. He is also a very observant child, so he could see very distinctly that there was a difference in how I was behaving...It is important to recognize each child is different and you have to be in tune to their needs and what they are going through." (Kristen, 36)

Kristen's picture prompted her to describe how Mason processed the loss of his brother differently than his siblings. For Mason, seeing his brother's ashes made him face the reality that his brother, Micah was dead. Kristen noted that

this event is something that seemed to only bother Mason. His brothers, Miles and Maddox, did not seem to be affected by seeing the ashes.

Photo #14: Ashes



“This is ashes on a baby blue background. They represent something that Mason went through. He and I haven’t spoken about it except very briefly one time since it happened. It was completely different from all of his other siblings. The picture represents loss. It is not just the loss of Micah to Trisomy 13 but

the loss of Mason when he had to come face to face with the realities of life. We had Micah’s body cremated. When my husband was unloading the van the next morning after the memorial service, it was my Mom, me, Mason, and my husband in the front room. He brought in a blue velvet bag and he opened it up. There were so few ashes from a 3 lbs. 11 oz. baby. There is just nothing there. Mason made mention of it and said there aren’t very many ashes there...He kept getting meaner and meaner throughout the week...More so than just a “fly off the handle and move on.” It was all this stuff bearing down. I didn’t know what had caused it. We finally found out a week later that it was seeing his ashes that triggered it...He didn’t know how to process the whole idea of the reality of the fact his brother was reduced to this little amount of ashes. But at the same time, he didn’t know how to continue to love all of the rest of us through that.” (Kristen, 36)

This example demonstrated the differences between the parents’ grief and their child’s grief. Tiffany discussed how she and her husband were so focused on their own grief that they did not realize what Jason was experiencing. Once she realized how strongly he was affected, they sought counseling for him to process his grief. Through that process, they realized that he had a lot of needs that were going unmet.

I think it was right after the anniversary (of the death). Until then, Henry and I were so focused on our own grief that we didn’t realize how deep Jason was into his own grief. Even though we would try to talk about it; we were just trying to get through the day. He’s got a lot he is dealing with. It has affected him and everything. I think, with the counseling, just acknowledging his grief was really a turning point for him. He realized we

wanted to help him deal with his grief. It was not about me and Henry, it was about dealing with his pain...I thought we were doing everything that we were supposed to be doing at this time, but I just realized that he had a lot of needs that were going unmet at that time. I really feel like having somebody out of the family that was unbiased (was helpful). (Tiffany, 30)

Tiffany recognized that her son's grief affected him differently than her grief affects her. She also explained that different things affect each of them differently. *"It doesn't do to me what it does to him. And different things affect me and him in different ways."* (Tiffany, 30)

Miles was the only child who talked about *perceptual differences*. Miles explained how his parents and his brother grieve differently than him. He recognized that while his brothers' grief is similar to his, there are still differences among them. He described Mason and Maddox being really sad for long time. He also shared that Mason would cry and talk to their mom about his feelings. He felt that his parents' grief should be different from his and discussed how his mother had a deeper connection with his brother, Micah. He described his mom as being angrier and more distant for a while after the loss.

My brothers were more similar to me but my parents were different in how they reacted...I tried to process the fact that I had to talk to people and stuff whose loss was equal to or greater than mine especially in the case of my mom. She knew him better than the rest of us did if that makes sense...I purposefully put it off. I don't think it really sunk in to them. My brothers, Mason and Maddox, were really sad for a long time. Mason (10) especially would cry at night and talk about it to mom. I guess I don't know so much about my dad, but my mom seemed a little bit more distant for about a month or so. She seemed a little bit angrier. It was the difference between losing somebody that you created and losing somebody you had no control over and somebody you never really knew. Even though it was hard for me, I expected it to be a lot harder for Mom and Dad. (Miles, 12)

These quotations illustrate how their different connections with the deceased affect their grieving processes. Mason's mother described his struggle with facing the reality of seeing his brother reduced to ashes and him being the only one of his brothers affected by this. Miles felt his parents' grief- especially his mom's grief- was and should be different from his because she had a deeper connection than he did. Jason's mother reported that she and her husband were so focused on their own grief that they were unable to recognize how affected Jason was with his own grief.

General Theme #9: Commemoration of Life

The siblings who participated in this study valued honoring the legacy of their deceased siblings. Every child and parental participant identified and discussed different aspects of *commemoration of life*. This concept includes maintaining a connection and honoring a deceased family member via developing and participating in rituals, memorializing, and meaning-making. The next section describes ways in which two of the child participants chose to commemorate their brothers' lives.

Mason took a picture of a beautiful stained glass window. He explained that the stained glass was made from drawings that family and friends created at Micah's memorial service. For Mason, the stained glass window is a reminder of Micah's life and that Micah will never be forgotten. It also symbolizes that his family surrounded Micah when he was alive and are still surrounding and loving Micah now.

Photo #15: Stained Glass



“It is part of the stained glass window. The ones that our family made and others are more the ones friends made. It is showing the ones that our family made. It helps me to remember that he is somewhere better and my family will never forget him. We were around him then and we are around him now... For me what does the picture mean? I just put love. Our family is loving him and still loves him.” (Mason, 10)

For the purpose of confidentiality, the researcher was unable to show the squares that his family made because they surrounded a picture of Micah. Thus, the squares that are shown are friends’ drawings etched in the glass.

The next picture represents a 5K race the Lancaster family participated in following the death of Mitchell. They chose to participate in the race because it was something Mitchell wanted to do before he died, but he died before the race took place. The family knew how much this race meant to him so they wanted to fulfill his wishes.

Photo #16: 5K Shirt Shadowbox



“We completed a 5k after Mitchell died because it was important to Mitchell. It was something that he wanted to do so you wanted to fulfill that. We decided that we wanted to do it for him.” (Ricky, 8)

The next picture represents a family’s desire to give meaning to Steven’s life. Each year they hold a 5K race and raise money for causes that have aided in their healing. This particular year they raised money to build a toddler

playground at a local park. Jason is included in the process of developing the sprint each year. They found this was a positive way to remember him.

Photo #17: Steven's Sprint



“This is a picture of Steven’s Sprint. It was last year on Oct. 17th. It was on a Sunday. Steven’s sprint was to make money for a park so we can open a park for little kids like toddlers to play on and that is it.” (Jason, 8) “We wanted to make it a family event. We are trying to include them in the process and it will continue to be a healing thing as it grows year after year. Positive way to remember him. It is still very hard and a very crappy situation. We still have so much to live for. We have always wanted to do something for Steven. We wanted to find causes that were really significant in our healing.” (Tiffany, 30)

The examples above show how each family found ways to commemorate their loved one’s life. It was important to each of these families to honor their family member and bring meaning to their lives. Each of these families accomplished this in different ways (stained glass window, running a 5K, and donating money to different causes).

General Theme #10: Reinvesting in Life

Many participants described how they began to *reinvest in life* as part of healing from their loss. Reinvesting *in life* is defined as gaining the ability to move forward and learning to adjust to life without their sibling. *Reinvesting in life* is a theme that emerged from two child participants and four parental participants’ interviews.

This picture represents Mile's desire to keep going. He recognizes that he is like a spinning top that sometimes he will be hit with waves of grief, but he has to keep going and moving. For him, this is how he processed his grief, and it has helped him to move forward.

Picture #18: Top



“The picture is a top spinning on a table top...It is still spinning and going...It kind of reminded me of how sometimes I feel like you are a little top and someone decides to poke this and then it keeps spinning...It is how I ended up working through it. I guess. You got to keep moving on and that sort of thing.” (Miles, 12)

The picture below represented Maddox (7) and his process toward *reinvesting in life* as told from his mom's perspective. She shared the following story: The family was given a tree after Micah died. They planted the tree, and a neighbor's dog chewed the tree, damaging it. This really upset Maddox because the tree was in memory of Micah. The dog chewed the tree until there was only about six inches left. The family tried to nurture the tree and keep it growing. They put a fence around the tree to try and stop the dog from getting to the tree. One day in the spring, Maddox came running in the house, telling his parents there was a miracle in the backyard. The tree had sprouted four shoots and had buds developing. Maddox was able to see past his anger to see new growth and life in the tree.

Picture #19: Micah's Tree



“This one is a picture of a tree. The center of the picture actually focuses in on the cut portion of a Cleveland pear tree. There are four main branches that come off of that tree just below the cut portion. It also represents Maddox and it also represents his anger and his joy...To me the picture means renewal. Well the

neighbor's dog chewed the tree. It decided it would be a fun stick to chew on because it had been given to us. It turned completely black by the time we were able to get it into the ground. Another couple of inches died away once we got it in the ground and we left it...It grew a little bit. It grew a little bit taller. The neighbor's dog thought it would be a great stick to chew on so he just shredded it completely... It was very upsetting to Maddox. He was so mad at this dog...We put a fence around it so the dog couldn't get it again and we just hoped. I had no clue whether it would ever grow...Maddox didn't really say much about it. We really had not paid any attention to it. One day Maddox came running in, “Momma there is a miracle in the backyard!” There were four shoots...The fact that my four sons that were still with me...were shooting off from this one. It meant a lot to me to see four shoots growing...It was very poignant for Maddox to see no matter how much anger you have or how much things look bleak and they seem miserable there is renewal in life. A lot of times you have to cut back way further than you think you can. Way further than you think would ever survive but you can and you can grow from there. I have seen him grow and change. So in just seeing that renewal in him as time has progressed.” (Kristen, 36)

Kristen described seeing Maddox grow and change as time has progressed since the death of Micah. In explaining what the tree meant to Maddox, she shared the hard work he had to do to heal from this significant loss.

Through the process of *reinvesting in life*, Maddox saw a period of personal growth and healing. For Miles, he realized that he had to keep moving forward and not get stuck in the grief process. During *reinvesting in life*, there is a

time when the participants looked back on what they have learned from their experiences of losing a sibling. This shapes how they live out the rest of their lives.

A summary of all of the general themes discussed above is presented in Table 5.3. The table provides a definition for each of the themes as well as an example that represents the theme. Chapter VI, a list of recommendations is made for each of the themes.

Table 5.3

Summary of General Themes, Definitions, and Examples

General Themes	Definitions	Examples
GT 1: Gaining Knowledge and Understanding	Children sought information to understand the siblings' diagnosis as well as knowledge regarding how to cope with the loss.	"His age was just not understanding." (Henry, 31)
GT 2: Processing Grief	Children work through their grief and identify things that are helpful/unhelpful in moving towards healing.	"It is something that you have to work through." (Mason, 10) "Had a hard time for a while of him drawing Mitchell in a casket... Will find these not as frequent as in the beginning..." (Kelly, 40)
GT 3: Expressions of Grief	Children identify different feelings and symptoms that represented their grief.	"Worry Jar has the emotions in it... Anger, grief, fear, and so on." (Henry, 31) "One of the things he really struggled with was anxiety." (Tiffany, 30)
GT 4: Drawing on Faith	Children relied on their faith for strength, answers, and healing during a loss.	"Helps me to remember that he is somewhere better and my family will never forget him." (Mason, 10)
GT 5: Collective Experience	Involves being around other children who have experienced a loss similar to them and support each other.	"Everybody was telling about the people they lost, so I could too." (Maddox, 7) "Just being around people that lost siblings was helpful." (Mason, 10)
GT 6: Communication	Involves verbal and non-verbal communication between the bereaved sibling and other family members and how communication relates to their grief.	"Felt like talking to anybody else in the family would cause them more pain." (Miles, 12) "We try to talk and not let it fester... He was opening up more." (Tiffany, 30)
GT 7: Adjusting to Change	After the loss, children's lives are affected by many changes (e.g. family roles, traditions, relationships)	"I felt like some friends from church were acting weird... With friends it was socially quieter for a while." (Miles, 12)
GT 8: Perceptual Differences	Children recognize that they grieve differently than other siblings or family members; they recognize that each loss is unique.	"Mom was freaking out more... I was more back with it." (Mason, 10) "Not taking it better than my brothers just trying not to show it as much." (Mason, 10)
GT 9: Commemoration of Life	Involves developing rituals, memorializing, and honoring their loved ones' life.	"Ran a 5K in his honor because that is something he wanted to do." (Ricky, 7) "It is important for children to keep their memory alive but not to be stuck in that place." (Kelly, 40)
GT 10: Reinvesting in Life	Children recognize that their life has to keep going and learn to adjust to life without their sibling.	"You can't just quit... You have to keep going and moving forward." (Mason, 10)

Presentation of Unique Themes

The analysis process of Interpretative Phenomenological Analysis (IPA) involves the researcher analyzing each interview to identify common themes. One important step after this process has been completed is to look for individual variations between the participants' interviews. According to Hycner (1985), "this procedure requires the phenomenological viewpoint of eliciting essences as well as the acknowledgement of existential individual differences" (p. 292). Through this process, the researcher also returned to her committee members to verify the findings of the unique themes that were identified. The unique themes identified below are unique to 1 or 2 participants. Thus, there are fewer examples.

Unique Theme #1: Life Exploration

Miles (12) was unique in articulating a recognition that his brother's death helped him come to terms with his mortality and the mortality of others. As he came to the realization that he was not invincible, he began exploring the meaning and purpose of his life through *life exploration*. The theme, *life exploration* is defined as coming to terms with one's own mortality through examining the purpose and meaning of life.

Miles (12) described battling to ensure that his world means something and making sure he did not take life for granted. Many times throughout the grief process, he thought about the person he wanted to be and, through reflecting on the loss of his brother; he made changes in his life to give his life purpose and

meaning. As you can see in reading his description of the picture below, he came to many of these conclusions through looking up at the sun.

Picture #20: The Sky



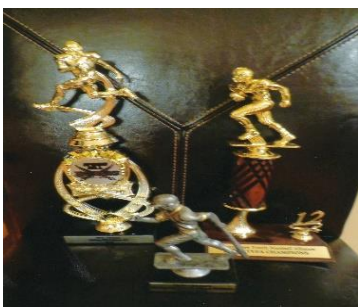
“Well when I look up at the sky and I start thinking existentially, I guess I don’t necessarily get it. I guess I could say I get reverent. I used to be in Boy Scouts, so I know that word really well...I start thinking about life a lot more. I feel like one of those guys who looks up at the stars and says we are futile...When I look up at the sky I start thinking about God, nature, life and purpose. I usually end up thinking about Him...I guess it

sort of reminds me of needing to do something that is worthwhile...You never know when today might be it.” (Miles, 12 years old)

Unique Theme #2: Shattered Expectations

The description of Ricky’s grief experience was unique in that it was the only one that included data that ultimately comprised the theme, *shattered expectations*. This unique theme emerged during his mother’s discussion of the disappointment that Ricky felt when he realized that his deceased brother, Mitchell, would be unable to continue to be part of his life in important ways. Specifically, she described how Ricky responded when he realized that Mitchell would not be at any more of his baseball games.

Picture #21: Trophies



“I remember the first words out of Ricky’s mouth the next morning was I wanted him to see all of my baseball game because he had seen Ricky’s first baseball game ever. Literally it was the first game the Saturday before he died. I think he hit a homerun or something. I can’t remember.” (Kelly, 40)

Unique Theme #3: Protectorship

A unique theme that was ultimately labeled *protectorship* emerged from the data. Both Miles and his mother, Kristen provided data that informed this theme. *Protectorship*, which is illustrated in the photographs and quotations below, is defined as the act of consciously behaving in a way that the child believes will safeguard his loved one's feelings.

In the first picture, Kristen (36) discussed how her oldest son tried to protect her during the grief process. Her oldest son also discussed how he protected his Mom and other family members because he didn't want to burden them with his own grief.

"I felt like talking to anybody else in the family would cause them more pain...I didn't want to disturb their personal grief." (Miles, 12 years old)

Picture #22: A Warrior



"We have always talked about knights and warriors in our home with having so many boys. They don't just represent brute strength or just represent a haul off and hurt him mentality. They can represent a quiet strength of watchfulness and protecting. He really took on that role of protecting me. It was that big brother mentality and he did a number of things with his brothers as well. That is what I really saw in him throughout that whole process." (Kristen, 36)

The only other participant to discuss protectorship was Henry, Jason's father. Henry discussed the weight of knowing his child was trying to protect the

family. He did not feel his son should have to carry that burden. He felt it was his job as a father to protect the family.

Photo #23: Exhaustion



“Sometimes, I felt that Jason was just exhausted. He is a pretty sharp kid, but trying to figure things out and carrying those burdens. I know one counseling session he talked about protecting us and that just weighs on you.” (Henry, 31).

Protectorship was a theme that appeared in the discussion of two different children’s experiences. Miles described his experience of protecting his mother and not wanting to burden her with his grief. Henry described how Jason discussed protecting his parents and sisters during a counseling session. These children consciously chose protection as a way to lessen the burden that their families had to endure.

In Table 5.4 a list of unique themes is displayed. The table provides a definition and an example for each of the unique themes that emerged from individual participants’ interviews. This table will also be provided in Chapter VI with a list of recommendations for each theme.

Table 5.4

Summary of Unique Themes, Definitions, and Examples

<i>Unique Themes</i>	<i>Definitions</i>	<i>Examples</i>
<u>UT 1:</u> Death Exploration	Questioning one's own mortality and life purpose.	<i>"I guess obviously his why was not just me and my philosophical problems. Personally, I think his life helped me think and feel more if that makes sense. I actually lived what I said I lived. I wasn't as fake anymore...It definitely helped with my own thought process and everything."</i> (Miles, 12)
<u>UT 2:</u> Shattered Expectations	Typical expectations of siblings (i.e. graduation, marriage, and firsts) are shattered by the loss.	<i>"When Mitchell died, I lost my playmate."</i> (Ricky, 8) <i>"I would say best friends I would say."</i> (Kelly, 40)
<u>UT 3:</u> Protectorship	Child protects or guards family members' heart from being hurt or burdened.	<i>"He didn't want to talk about it because he didn't want to burden me...He chose to keep those burdens off me...He pointed out that he did not want to add any burdens to me."</i> (Kristen, 36)

Summary

Through the analysis process, general and unique themes emerged. In this chapter, the findings of each of the themes were discussed. This chapter provided an explanation of each of the themes including the definition and an example. Summaries of the general and unique themes were provided in Tables 5.3 and 5.4. In the next chapter, the general and unique themes are discussed further and linked to current literature and relevant theories. Chapter VI, the researcher provides recommendations for health professionals to have in their toolbox as they work with bereaved siblings to better help them through their grief. Finally, Chapter VI concludes with strengths/limitations of the study and areas for future research.

CHAPTER VI

DISCUSSION AND RECOMMENDATIONS

“Experience is often the most valuable thing you have to offer.”

-Randy Pausch

This chapter includes a discussion of the study findings and their implications for practice. Specifically, the researcher provides evidence-informed recommendations for working with bereaved siblings. Congruencies between the findings and current theory and research and opportunities to strengthen existing theories are explored. The end of this section discusses strengths and limitations, future research, and finally concludes with a summary.

The current study has emphasized the value of exploring children’s experiences of the death of a sibling. The experiences of bereaved children have been explicated through the rigorous qualitative process of interpretative phenomenological analysis (IPA). In employing IPA to explicate the experiences of bereaved children and provide a deeper understanding of their loss, the study has expanded the findings of previous research with a method that can inform clinical practice and aid in developing interventions. The findings of this study have enabled the researcher to provide recommendations for health professionals and parents on how to better help bereaved siblings.

As discussed in detail earlier, limited research has been conducted with bereaved siblings. Prior research in this area has used mostly quantitative approaches. While previous research provided a framework to build upon, interpretative approaches such as the one used in this study can clarify and enrich extant findings. These approaches can illuminate new areas that need to be further developed and studied. As the body of bereaved sibling research develops, knowledge is expanded and understanding is strengthened. Through understanding bereaved siblings' experiences, practitioners are better able to design, implement, and evaluate interventions. As parents better understand the bereaved siblings' experiences, parents are better able to support their children.

Discussion and Recommendations for the General Themes

As part of the data analysis process, several general themes emerged as most or all of the participants discussed their experiences of losing a sibling. These themes were defined in Chapter V as the findings were explained. Each general theme will be discussed in detail and recommendations will be presented below. It must be noted that these recommendations, while informed by the in-depth qualitative data obtained during this study and supported by expert opinion and a limited body of existing research, have largely not been subjected to rigorous testing. Thus, while they are useful in shaping practice in a field in which current scientific research is scant, they are more accurately described as recommendations for evidence-informed rather than evidence-based practice

(Nevo & Slonim-Nevo, 2011). The recommendations presented are intended for health professionals and parents to guide how they support children who are bereaved siblings.

General Theme #1: Gaining Knowledge and Understanding

The children in the study were experiencing a loss that they had never been through before. They sought to *gain knowledge and understanding* about their siblings' illnesses and deaths to try to make sense of the world around them. The children asked questions regarding the illness, treatment, prognosis, what to expect, and how it will affect them. Parents were able to explain the answers to the questions based on the children's age-appropriate levels to try to help them better understand the situation they were facing.

As part of trying to learn and understand what has happened, children will seek knowledge regarding their siblings' illnesses, treatment options, and the effect of those treatments on their sibling (Thompson & Payne, 2000). Children also sought to learn how they would be impacted by the illnesses and losses. Thus, children need information when they begin to notice a change in the adults around them to help them better cope. If there is a delay, children will create their own stories to figure out what has happened or how it happened; in doing so, there is a risk that they will develop irrational fears, worries, or fantasies (Smith, 1999).

In Thompson and Payne's (2000) study of what children ages 5-15 wanted to know from a doctor concerning a family member's death, the highest number

of questions regarded the cause of death. Thirty-two of the children had lost a sibling. Other questions concerned life span, doctors, dead bodies, and grieving feelings. These children were interested in the physiological aspect of dying and questioned why people die. Questions were raised regarding the dead bodies and those questions demonstrated an understanding of the concept of death, including the appearance of the dead body, irreversibility, non-functionality, and some continued life form (Thompson & Payne, 2000). A study by Eiser and Patterson (1983) found that 6-12 years old have limited knowledge of the physiology of death and medical terminology. Once these children understood the process of dying, they were able to focus on the process of living. Both studies attested to the large number of questions that children have regarding a family member's death.

Children ask questions in hopes of answers, and studies have found that families who communicate freely and allow children to seek knowledge about the death experience grieve more positively (Harris, 1991; Silverman & Worden, 1992). However, as was the case for some of the families in this study, sometimes parents are so focused on their own grief that they are unable to respond to their children's questions regarding the death. Silverman and Worden also recommended developing language that provides children with the tools necessary to talk about and process death during early bereavement. The health care team can support parents in a variety of different ways, such as providing reading materials, connecting them with reputable online information, and community resources.

The questions children ask demonstrate their levels of understanding regarding the death, but can also reveal the meanings they assign to the loss. Thus, providing children with opportunities to have their voices heard, parents and health care professionals can learn more about how they are making sense of what has happened to their siblings. Adults should provide children with adequate time to formulate their questions and support the children through the process of receiving the responses (Thompson & Payne, 2000). As children *gain knowledge and understanding* about the illnesses and death, it would seem that children would experience more positive adjustment and be better able to cope with the loss (Thompson & Payne). The present study, which was purely qualitative, recommends conducting further testing before findings are generalized.

In summary, children may benefit from receiving information in a truthful and honest manner. Children may value information that will empower them to ask more questions (Thompson & Payne, 2000). For these children, it may be helpful to provide answers to only what the children are asking and not elaborate, as it may confuse them (Smith, 1999).

Recommendation

Professionals: Provide parents with educational materials on age-appropriate development and age-appropriate terminology to explain the illness, loss, and grief process. ***Parents and Professionals:*** Provide opportunities for children to ask questions about the illness and death. ***Interventions:*** Provide educational

materials to parents regarding the illness, death, loss, and grief as well as community resources; such materials should include common questions of children related to death and grief and how one might answer such questions appropriately. Develop a bereavement protocol to respond to sibling loss in the hospital or other inpatient facilities. Such a protocol might include a plan and schedule for offering bereavement support via telephone or in person, development of support groups or referral to existing groups and supportive websites, and/or provision of sibling loss connection activities.

General Theme #2: Processing Grief

The participants in the study described a process of *working through their grief*. During this period, participants reflected on the loss, acknowledged feelings surrounding the loss, and identified things that helped them move through the grief process. This process was different for every participant and there was no set time frame in how long it took participants to move through this process.

All participants explained how they worked through their grief. From these discussions the theme, *processing grief*, emerged. In *Mourning and Melancholia*, Freud (1917) introduced the term, *grief work* and laid the foundation for grief work. The objective of grief work was to help the bereaved to redefine their roles and identities in the absence of the deceased. Freud further explained mourning and described a process that becomes less painful as the bereaved move through the process.

Freud (1917) noted that mourning was a process, and that it became less painful as the bereaved moved through it. He noticed that people had more energy and were able to reconnect with the world and begin to invest in relationships after mourning was complete. The intensity of the grief was dependent on the importance of the relationship. Bonanno (2004) argued that people are naturally resilient and do not always experience the pain of grief as Freud and Worden (1991) described. Many bereaved individuals experience little to no grief; it does not mean that they are uncaring or lacking attachment to the deceased, but rather, that they acquired resilience when faced with the death of loved one (Bonanno, et al., 2002).

Freud concluded that successful mourning involved the withdrawal of loving energy from the images of the deceased because not doing so interfered with the ability to fully invest in new relationships. Modern theories disagree with Freud's concept of *withdrawal of loving energy*. Contemporary theorists would argue that it is important to continue bonds with the deceased to have a healthy grief experience (Attig, 2001; Field & Friedrichs, 2004; Klass et al., 1996; Neimeyer, 2001). Other theorists have discussed the concept of *continuing bonds* with the deceased in childhood grief in relation to parental loss (Christ, 2002; Silverman & Worden, 1991) Packman and Colleagues (2006) discussed a major shift in bereavement literature and proclaimed that it is now acceptable for the bereaved to remain involved and connected to the deceased; the bond can be maintained through an emotional connection. Continuing bonds have also been examined by Davies, 1999; Hogan and Desantis, 1992; Packman, Horsley,

Davies, and Kramer, 2006. Worden (2009) held that the bereaved find ways to restructure the relationship through commemorating the lives of their loved ones.

The way children accomplish Freud's, *grief work* may differ greatly from the way their adult counterparts go through it because children do not have the same developmental understanding of grief as adults. Children often process their feelings better through play or art rather than verbal expression (Salladay & Royal, 1981). If children are not given opportunities to appropriately work through their grief, grief work may be hindered or could lead to pathological disturbances if children perceive that these feelings are unacceptable in the adult world (Salladay & Royal).

As mentioned earlier, Worden's task theory was built upon the work of Freud (1960), Bowlby (1980), and Engel (1961). Dr. George Engel described the mourning process as similar to that of healing. He hypothesized that mourning takes time for functioning to be fully restored. From Dr. Engel's research, Worden later concluded that people must complete four tasks for homeostasis to be restored and the process of mourning completed (meaning that the bereaved person can reclaim the staggering amount of energy sapped from individuals in the grief process and reinvest it forward in living). Incompleted tasks of mourning can result in impaired growth and development. The tasks do not have to be completed in order; however, the definition of the tasks does suggest some linearity to completing them.

When a person dies, the family is often in a state of shock or denial upon learning of the death. The bereaved, over time, must *accept the reality of the loss*

(Worden's First Task of Mourning). The bereaved may not initially be aware of this task during the grief process; however, it is an important task to complete for long-term mourning. *"Anything that continually allows the person to avoid or suppress this pain can be expected to prolong the course of mourning"* (Parkes, 1987, p. 192). The time it takes is different for everyone. During this stage, the bereaved has to come to terms with the reality that the person is gone and will not return. During this stage, the bereaved may often feel a sense of unreality. The bereaved often say things like, *"This can't be true."*

For people to grieve effectively, they must *work through the pain* of the grief (Worden's 2nd Task of Mourning) which some will try to avoid. The challenge lies in finding ways to experience the pain without being so overwhelmed as to become dysfunctional. The intensity of the pain lessens over time and will gradually lead to healthy mourning (Worden, 2009).

Bereaved people attempt to *adjust to their environments without the deceased* (Worden's 3rd Task of Mourning). They must figure out the significance of the relationship with the deceased, identify the various roles the deceased played, and learn to function in their environments without the deceased. The bereaved may try to ignore the tasks at hand or withdraw from the requirements because the pain is too much to bear. However, reinvesting in activities normally performed by the deceased, and engaging in new activities are productive approaches, as well as finding healthy ways of dealing with loss and growing from the death and grief experience (Worden, 2009).

Worden's 4th task is to *emotionally relocate the deceased and move on with life*. Emotional relocation does not mean that the bereaved should forget about the deceased as Freud suggested, but rather modify or restructure the relationship with the deceased in ways that remain satisfying to the bereaved. Completion of this task involves the bereaved developing a new identity without the deceased, creating new relationships, and reinvesting in life (Worden, 1991). Worden later discussed *continuing bonds* in relationship to the deceased. The concept of *continuing bonds* aligns with the findings of this study as the participants express holding on to memory objects of their deceased brothers.

Tasks represent a proactive way of coping, unlike stages or phases that usually represent a linear pattern of completion. Tasks require effort that assists the bereaved in regaining control over their lives, or at least a sense of control. Worden (2009) believed that mourning could be completed by accomplishing each of the tasks. Fox's, *Tasks of Mourning for Children* also mentions grief work and will be further explained in discussing the congruency between this study and theories informing this study.

As mentioned above, the concept of *grief work* has been explained and conceptualized over the years. Participants described a period of time when they focused on their grief and were managing it with their daily tasks. During this period of *processing grief*, they were trying to make sense of it. Each of the participants explained that over time their grief lessened and they spent less time processing their grief. Some could identify exactly when things got better and for

others it happened over time. For example, Mason (10) stated, *“If there was a time that I got over it, it would probably be the time that I was at Camp, but not fully. You still have to work through it.”*

As part of the theme, *processing grief*, the children identified unmet needs, triggers, and things that they found helpful. Primary preventive education may be helpful in preparing children for what to expect when they experience the death of a family member. Social support with secondary professional intervention when indicated may also be appropriate for addressing children’s grief. These interventions might include: attending counseling, support groups, and bereavement camps, which are interventions in which the participants participated during their grief journeys. Grief counseling is not beneficial for everyone; many may find it to be too intrusive and unwarranted (Kissane et al., 2006). For some, counseling can be an effective way to help children cope with the loss of a sibling. Counselors typically help children tell their stories about their losses from their perspectives and children are allowed the opportunity to express a wide range of feelings applicable to the loss (Betz & Thorngren, 2006).

The researcher’s clinical experience led her to conclude that external support may facilitate the processing of grief for children. Counselors can also help validate the children’s feelings and reassure them that their behaviors are typical given the situation. Other things children identified as helpful were talking with other people, participating in rituals, and holding on to memory items. Participants in the Mahon and Page (1995) research identified talking with family, friends, and providing support to the bereaved as helpful. Consistent with Mahon

and Page's findings, the children in this study found talking with family and friends helpful. Mahon and Page found that the bereaved children having possessions of their deceased sibling was often helpful. Foster and colleagues (2012) found that bereaved siblings found talking with their mothers to be helpful. While in Mahon and Page's study, children identified their fathers as not very helpful, although none of the children in the present study concurred with that opinion. Possibly this was because fathers did not participate in this study, or possibly these particular fathers were found to be helpful. The participants in the current study did not identify one parent over the other as being helpful in their grief. They indicated talking with parents to be helpful. Sibling grief requires supportive care or at least parental support as children process different aspects of their grief.

Previous scholars have identified a period of time in which the bereaved spent time processing their grief, engaged in what theorists have coined as *grief work*. Consistent with this literature, the participants in this study identified a period where they spent time processing their grief. Previous scholars have identified *grief work* for bereaved adults and Fox's Theory acknowledged a period where children also work through their grief. This study further validated previous theories on grief as the participant went through a *process of grieving*.

Recommendations

Professionals and Parents: Provide children opportunities to process their grief. Encourage a supportive environment that offers children opportunities to share their grief. ***Professionals:*** Offer activities that allow children to express and

process their grief. **Interventions:** Expressive interventions might include having the children complete a mandala (an organizing structure that represents a model, typically in the form of a circle with separate sections), which allows them to tell their story and helps them process their grief. In each of the sections, children are asked to identify different parts of their grief (e.g. when do their loved one die, what feelings did they experience, who is their support system, etc.). Another example might include having the children create a scrapbook to tell their story. As they complete the scrapbook, it allows them to process and discuss aspects that are important in their grief journey. The research method used in this study, photo-elicitation could also serve as an intervention to be used with children to help them document their grief experience through pictures.

General Theme #3: Expression of Grief

Participants in this study identified and expressed different emotional and physical symptoms in their grief journeys. Participants were able to identify feelings of anxiety, guilt, anger, and physical symptoms such as having difficulty sleeping and clinging more to their parents. The participants recognized these feelings and found ways to deal with these emotions such as talking with family members and friends, attending camp, support groups, and/or counseling.

All of the children who participated in the study identified many physical and emotional manifestations as they discussed their experiences of losing a sibling. As mentioned earlier, children identified strong feelings of anger, denial, fear, regret, guilt, and forgiveness. For example, Henry said, “Jason especially

felt a lot of anger. I think a lot of it was his age and him just not understanding. He felt like he wanted to know why this had happened. What does it mean to me?"

Some children in the study describe a period of time in which they withdrew from their friends. For example, Miles (12) stated,

I felt like she was trying too hard to make me talk. That irritated me so I pulled back from those friends for a while maybe a month or so before I kind of got back in the swing of things socially.

Feelings of anger, aggression, and withdrawal are common in grieving children (Dyregrov, 2008; Smith, 1999). Smith also reports that children should be encouraged to share their feelings in a sensitive and constructive way. If children repress their feelings, problems may develop. Children may inappropriately displace their feelings onto others (Dyregrov, 2008; Smith, 1999). Children may also repress their feelings when they do not align with the feelings of key adults in their lives.

The children in this study expressed several intense negative emotions during their grief processes. However, the children also identified many positive emotions related to the loss of their siblings. They identified feelings of comfort, happiness, hope, peace, strength, gratefulness, genuineness, and trust. An example of trust from Miles, who indicated that it was helpful to trust his friends, *"In who they were and allowing myself to be vulnerable."* All participants' interviews took place 1-2 years after the death; their emotions might not have been as positive had the interviews taken place closer to the time of the siblings'

deaths. The children discussed how their expressions of grief changed over time as they processed their grief, suggesting a strong connection between the themes *processing grief* and *expressing grief*. They discussed at what point they regained their strength to keep going, their hope in the future, and their thoughts that things would be better. Research conducted by Charles and Charles (2006) provided additional support for the connection between these two themes. These researchers found a strong relationship between grief reactions and positive coping methods, while there was no relationship between negatively viewed reactions and positive coping methods. Charles and Charles' study defined positive coping methods as including emotion-focused, support systems, problem-solving, and negative coping method included distancing. This suggests that coping skills training may increase bereaved siblings' experiences of positive grief reactions, but may have little impact on the occurrence of negative reactions.

Physical manifestations of grief reported in this study included difficulty sleeping, clinging to their parents or surviving siblings, and nightmares. Tiffany described her son's difficulty with sleeping. She stated,

He (Jason) is having a hard time staying asleep. He wakes up in a panic.

Every night, Henry and I get frustrated. It has become a habit. As parents, it is a balance. He is afraid that he isn't going to wake up.

Recommendations

Parents and Professionals: *Explore and provide opportunities for children to express their feelings. Model expression of feelings and behaviors for children to*

*learn appropriate ways to express themselves. Normalize and validate children's feelings regarding the loss and grieve with them. **Professionals:** Teach children healthy ways to express their feelings. **Interventions:** The feelings jar is an activity that professionals can use with children. The children identify feelings that they have experienced or currently experiencing during their grief journey. When experienced, they write the feeling down and put it in the jar. This allows the children to express that feeling and let it go. This is an intervention that can be used at home as well because the children can continue to add their feelings to the jar. Another intervention involves the health professional asking the children to identify feelings that they are currently experiencing and then ask them to identify a color that represents each of the feelings. Then, have the children color how much they feel of each feeling on a piece a paper. This gives the children a pictorial representation of how much these feelings are impacting them through the grief process. Discuss with the children each of the feelings and offer healthy options for coping with the feelings.*

General Theme #4: Communication

Parents in the study identified *communication* as being important in their grief journey. Some parents recognized changes in their children's behavior and confronted the children in a loving way to understand the change in their communication. Children identified certain people whom they found comfortable talking to and others that the children did not want to talk with because they did not want to burden others with their grief.

Communication was a theme that emerged throughout this study. Children either found communication very helpful or parents noticed changes in their children's behavior leading to them becoming non-communicative. For instance, one mother found that her son who had previously been very communicative had stopped communicating with her. Some children found that being able to talk with their parents or peers helped them process their grief.

Previous scholars have suggested families that have open discussions about the deceased cope more effectively than families that are not open to discussing the deceased (Worden, 2009). Worden goes on to posit that closed families may provide excuses or make comments that encourage families to remain quiet. For siblings that live in closed families, isolation can result (Kristjanson & Aoun, 2004). The members of a functional family are more apt to communicate effectively with one another, process their feelings regarding the loss, and accept feelings of vulnerability (Davies et al., 1986; Worden, 2009). Open communication (talking freely with one another) can serve as a way to memorialize the deceased, which can also provide a supportive environment for the surviving sibling to share (Horsley & Patterson, 2006; Kristjanson & Aoun, 2004; Siegel, Mesagno, & Christ, 1990). Memorializing the deceased was specifically cited by participants in this study as an important, helpful part of the grieving experience.

Family members are often so focused on their own grief that they become emotionally unavailable to help other family members. Bloch (1991) conducted a study on families who had not dealt with their grief for years after the loss. The

families presented with inadequate adjustment and long-standing symptoms. During this study, two families with grieving parents illustrated patterns of emotional unavailability to their surviving children. In turn, the children were unable to express their own grief. The absence of communication often leads to defective communication.

Bereavement theories in the past have focused on individuals instead of families. Kissane (2008) recognized that more attention needs to be given to the way the individual grieves within the context of the family. Kissane and colleagues (2006) found cohesiveness, conflict, and communication to be key factors in how families deal effectively with their grief. They also found that families who are intimate with each other, share their distress, and provide support to each other adapt better to loss. Conflicting families that exhibit low cohesiveness, low expressiveness, and poor organization have a more difficult time adjusting to losses. These families often argue, do not plan activities carefully, and are not punctual. Avoidant families often exhibit poor communication, little exchange of feelings, and lack of intimacy. Kissane and Bloch (2002) recognized conflictual and avoidant families, and placed them at greater risk for complicated grief because members of the family did not want to address the issues related to their grief, or the death created conflict between the family members, thus these families could benefit from family focused grief therapy. Kissane and colleagues (2006) found that family-focused grief therapy decreased complications of bereavement. All the families in this study, appeared as cohesive and communicative. The rare instances where communication was

limited was due to a need to protect other family members, as discussed below. This is important for a number of reasons. First, the generally cohesive nature of the families included in this study introduces a research limitation in that the experiences of children in non-cohesive families are not represented in the data. In addition, this reveals an opportunity to intervene with children in cohesive families who may be limiting their communication out of concern for family members. If such children were able to view open communication as contributing to the well-being of the family, their desire to protect others might lead them to increase communication, rather than withdraw, resulting in potentially more positive outcomes for all family members.

For example, children may choose silence as a way to protect their parents because they do not want to cause them any more pain or burden. This dynamic of protection makes understanding Family Systems Theory central to this study because appropriate behavior for 7-12 years old is to express grief in much the same way as key adults in their lives (Goldman, 2009). Families often dictate how individuals communicate with each other, they provide an environment that either supports or prevents communication. Thus, if adult family members are unable to express their grief to each other, children may fear that if they identify their own needs, it will upset their parents. Meanwhile, the adults are not picking up on their own children's lack of understanding, expressed as silence when the situation is too much for them to comprehend. Some parents in the study reported that they were so focused on their own grief that they were unable to recognize the needs of their children. Parents need to be cognizant of

changes in children's behavior. When they notice that children who once were verbal are now quiet, it might be because they are having difficulty understanding the world around them. Once one participant noticed her son had quit talking and sharing things with her, she sat him down to inquire about the change in his behavior.

Communication was a key to how these children processed their grief. Children who felt they had open communication could easily express their emotions with people they trusted. Children, who chose to remain silent, did so as a way to protect their parents or siblings. Children may benefit from education on helpful ways to communicate their feelings. It can also be important to inform children on how communication can hurt others when they choose to remain silent.

Recommendations

Professionals and Parents: Provide children a supportive environment that allows open expression and communication of feelings. Provide children various avenues for communicating their feelings. ***Parents:*** Attend workshops or counseling on how to address children's bereavement needs. ***Interventions:*** Meet with children and parents together and practice role modeling with them regarding healthy and unhealthy ways to communicate their feelings. Have the children and parents participate in the role modeling exercises. Help children and parents identify ways communication could be improved.

General Theme #5: Drawing on Faith

The children in the study discussed how they *drew on their faith* for support. They relied on their faith for strength, answers, and healing as they moved through their grief. Some of the children found comfort in knowing their sibling was in a better place and no longer suffering. Others found they drew closer to their faith as they recognized how life can change in an instant and started living out their faith.

Drawing on faith is another theme that emerged in this study. Some of the children found comfort in their belief that their sibling was in a better place and that they would see their sibling again one day. Children also recognized that their sibling was no longer suffering and had found peace. Faith and spirituality are not topics that have been widely studied in childhood bereavement and even less so in relationship to sibling loss. The researcher found one study that focused on adolescent bereavement related to sibling loss (Balk, 1991). Previous research has placed increasing emphasis on religion and spirituality as factors that contribute to a person's overall well-being (Becker et al., 2007). Most of the previous studies on spirituality focus on adult loss. Balk, however, found that many adolescents grieving the deaths of siblings used religion as a way to cope with their losses. This, coupled with the importance of faith to the participants in the present study, suggests much more research is needed in this area.

According to Himelstein, Hilden, Boldt, and Weissman (2004), younger children's involvement with spirituality may not be based on any personal

religious beliefs, values, or practices. For children, spirituality may be built on understanding the meaning of life. Miles chose to draw on his faith after losing his brother. He said he knew he was a Christian but was not really living it until his brother died. He shared that he was no longer going through the motions and was no longer fake, but really lived what he believed.

While the children in this study identified a belief in God and heaven as spirituality, other children may define it differently. As children try to grasp the understanding of why the death of a sibling has occurred, spiritual distress may result. Some of the children found comfort in prayer and sought answers from the Bible on why the loss happened. It may be beneficial to provide children an opportunity for reflection and questioning as part of their normal spiritual development (Himmelstein, Hilden, Boldt, & Weissman, 2004). Children should be able to define what spirituality means to them. Becker and colleagues (2007) conducted a systematic review of spirituality and adult bereavement and found seven studies that reported spirituality had a positive influence on coping with loss. Research is needed to determine the extent to which these findings are applicable to the experiences of bereaved children.

The findings from this study also found the above statement to be true. The children found comfort and peace in knowing that their siblings were in heaven with God and that they would see them again; thus, to the extent that it is consistent with their beliefs or value system, it may be appropriate to incorporate aspects of spirituality into bereavement work with children.

Recommendations

Professionals and Parents: Provide children an opportunity to explore what spirituality means to them and any causes of spiritual distress. **Professionals:** Implement interventions such as story-telling, meaning-making activities, and rituals to address spiritual issues. **Interventions:** Professionals should conduct a spiritual assessment to identify causes of distress. If the child has a connection to a children's minister, youth minister or other spiritual counselor, ask that person to be available to the child for question answering and guidance. Spiritual Distress could also be addressed by engaging participants in story-telling, meaning-making activities and rituals. For example, participants could tell their spiritual story using a story-telling application available via the internet. Participants could also participate in other meaning-making activities using software developed for that purpose.

General Theme #6: Adjusting to Change

Participants described how they had to adjust to many changes as a result of the deaths. Some of these changes included changing traditions, moving rooms, and changing roles in the family. Participants were able to recognize the changes and adapt to them.

Bowlby-West (1983) described several homeostatic adjustments that families might need to make after losing loved ones, e.g. anniversary adjustment and role changes. One adjustment that families face is an anniversary reaction. This can be a stressful time on families, serving as a reminder of the deaths, but

also a way to honor the deceased through rituals. Recall that Tiffany described an experience that her son, Jason, had regarding not going trick or treating during Halloween; this was the anniversary of his brother death, and he thought it would be difficult for him to enjoy that day. In the end, he chose to go.

Role changes often include changes in the management of household activities; others may take on new roles to help the grieving person. For example, Mitchell loved to bake and now Ricky has taken over some of the baking in the house, making some of the cookies and desserts that Mitchell used to make. Role changes can lead to increased stress and misunderstandings if people are not aware of the changes (Byng-Hall, 1981).

The death of a family member brings many secondary losses and changes, including roles and relationships, changes in the family unit, hopes and dreams, status in the family, and loss of control. According to Walsh and McGoldrick (2004), "Loss modifies family structure, often requiring major reorganization of the family system" (p. 8). For example, surviving siblings have to figure out how to live in a family without their deceased siblings. A surviving sibling may become the only child in the family as a result of the death. The parents may become more protective of the surviving child because they are worried that something might happen to this child. It is important to work with families to recognize each of the losses they are facing and work with them to resolve their grief.

With any loss, family members must adjust and adapt to life without their loved ones. Walsh and McGoldrick (2004) proposed four adaptational tasks for

family members similar to Worden's tasks for individuals. Adaptational tasks are for family members who seek to strengthen the family unit: (a) shared acknowledgement of the reality of death, (b) shared experience of the loss, (c) reorganization of the family system, and (d) reinvestment in other relationships and life pursuits. Children may feel empowered if they are allowed to be part of the change process.

Recommendations

Professionals: *Provide children with opportunities to discuss changes that arise associated with the death and discuss how these changes have impacted their life.* **Professionals and Parents:** *Empower children to be involved in the change process.*

Interventions: *An intervention that could be used with children is an activity called the changing tree. Participants identify changes that they have experienced. Participants write down the changes on a leaves. The participants attach each of the leaves to the tree. The professional discusses the changes with the children and allow them to voice the impact the changes have on their life. Another intervention involves children identifying changes from their past, present, and future. The children should be able to identify how they have coped with changes in the past and what changes they may encounter in the future. This will allow children to be better prepared to face changes in the future.*

General Theme #7: Collective Experience

The children in the study appreciated being exposed to other grieving siblings, thus the theme, *collective experience* emerged. The children saw that

they were not the only ones their age experiencing an *off-time* event. For the first time, they felt they could relate to other grieving siblings and those grieving siblings understood their plight. The children met other grieving siblings at camp and support groups.

Since it is uncommon for children to die, children who have experienced the death of a sibling often feel that they are alone and are the only ones to experience this type of loss. Nolbris and Hellstrom (2005) found that children would like to meet other children in the same situation both during the sibling's illness and after the death.

Consistent with this literature, the children who participated in the present study reported that they were not alone in the bereavement process. It was not until their parents enrolled them in support groups or camp that they learned that other children were experiencing a loss as well. These children identified being involved with other grieving siblings as a positive aspect in their grief process. Smith (1999) further validates the above, understanding and alleviating, "The sense of isolation that a child often feels or lack of support they get from their peer groups are important factors in helping children work through their grief" (p.91).

Bereavement support groups or camps are venues that provide children with the opportunity for a shared experience with other grieving children. This creates an environment that promotes a shared identity, thus lessens the isolation that these children feel. These opportunities provide support from

others, increase self-esteem, reduce feelings of powerlessness, decrease stigmatization, and normalize their situations (Smith, 1999). Since children spend a majority of their time at school each day where they may not have the opportunity to connect with other grieving children. Therefore, children may benefit from a supportive environment such as a camp or support group where they can be around others who are grieving a loss and willing to share their experiences with each other.

As a society, we need to do a better job of linking bereaved siblings with one another. Organizations have been developed for children with siblings who are coping with cancer. For example, programs such as Supersibs and Cooper Troopers might extend their services into bereavement, or develop programs specific to bereaved siblings. One organization that has implemented a program specifically for bereaved siblings is called the Sibling Connection in St. Louis, MO. While this organization focuses on adult bereaved siblings, it also works with children who have lost a sibling.

Recommendations

Professionals and parents: Provide opportunities for siblings to be around others who have experienced a similar loss such as support groups, camps, and sibling events. Teenagers may find that connecting with other teens who have experienced a loss through social media is helpful. ***Professionals:*** Remember to remind parents, to monitor children's technology use to ensure safety.

Interventions: Facilitate a sibling loss support group either in person or via

*Skype or teleconferencing as a way for children to connect with other siblings.
Create an event for bereaved siblings that includes connecting with other
bereaved siblings, provide opportunities for play, and engage children in grief-
related activities.*

General Theme #8: Perceptual Differences

The participants in the study recognized that others in their family were grieving differently than they were. Children were able to describe particularly ways their other family members were grieving differently. They acknowledged that some family members such as their parents should be grieving more intensely than they, based on the type of relationship they had with the deceased.

Research has revealed that children and adults grieve differently. Children do not have the same developmental understanding of death as adults, but they grieve just as intensely as adults. By bridging the gap differences between children and their parents, more effective and focused interventions are possible.

When a sibling dies, children feel they not only have experienced the loss of a sibling, but also the loss of their parents' emotional availability. As mentioned earlier, parents are often so overwhelmed with their own grief, they may not have the energy to provide support to their grieving children. Children may interpret their parents' grief as different in degree of intensity, whereas in reality parents and children may be experiencing many of the same emotions. One study found communication to be key to identifying differences in how children and parents

grieve and implementing parent-guided interventions to eliminate the differences (Horsley & Patterson, 2006). As communication improves between parents and children, children may learn to express their grief in healthier ways.

The children in the present study perceived that others around them were grieving differently. For example, Miles stated,

My parents were different in how they reacted and how I tried to process the fact that I had to talk to people and stuff whose loss was equal to or greater than mine especially in the case of my Mom. She knew him better than the rest of us did.

The unique ways in which bereaved children grieved the death of their siblings suggests that interventions specifically tailored to their individual needs may be most effective. In addition, normalizing unique approaches to grief may be important to children who may otherwise feel more isolated by the experiences and feelings they do not see mirrored in other family members or their peers.

Recommendations

Professionals and Parents: Help children identify ways in which family members grieve differently and incorporate ways that they could grieve together.

Interventions: Explore with parents the ways they feel they grieve differently than their children. Explore with children the ways they feel they grieve differently than their parents and/or siblings. Meet together with them to discuss their responses. Identify the ways their grief is similar. Have parents and children set aside time daily to discuss their feelings surrounding the loss.

General Theme #9: Commemoration of Life

The participants in the study valued honoring their brothers through memory-making activities. The children chose to *commemorate the lives* of their brothers by running in 5K's, donating Legos, raising money to benefit organizations, and making a stained glass. The children also maintained memory objects of their deceased siblings as a way to remember them and maintain a connection.

The children in this study explained the importance of honoring and keeping their loved one's memory alive. Smith (1999) further validated that it can be helpful for bereaved children to keep mementos and visual images of the deceased. Fanos, Little, and Edwards (2009) reported that bereaved siblings found it helpful to participate in rituals such as planting a tree, visiting the grave, or placing an ornament on a Christmas tree. Others reported putting candles in the snow to celebrate the deceased's birthday. These findings align with meaning reconstruction theory concept of benefit-finding. The participants had the ability to see *silver linings* from the consequences of the loss (Holland, Currier, and Neimeyer, 2006). The participants took part in rituals such as a 5K race, donating Legos, making a stain-glass window, and planting a tree, which could be considered benefit-finding activities.

All of the participants discussed many aspects of spirituality, which makes it important to note that many faith communities have their own rituals and traditions when responding to a death. If spirituality is important, it may be

beneficial to discuss with the children how their faith rituals fit in the bereavement process. For example, individuals in some Jewish families may sit shiva for seven days for a period of mourning. Modifications may need to be made for children who may not understand the expectations of such rituals, but the importance that children in this study placed on faith suggests that it may be helpful for them to participate if they want to.

Even though a relationship between the bereaved sibling and the deceased may be limited or may have negative aspects, it may still be important for the surviving siblings to keep their loved one's memory alive and not to pretend the deceased never existed (Smith, 1999). If children are not provided this opportunity, it could complicate their grief. Siblings can be reminded that they have the memories of their siblings and can reflect on them as a way to cope with the loss. By allowing children to choose and participate in rituals, adults allow the children to mourn and remember their siblings. Commemoration of life brings honor to the deceased and allows the surviving children not to forget their siblings.

Recommendation

Professionals and Parents: Provide children opportunities to choose and participate in rituals. Allow children to discuss how they would like to spend special days such as anniversaries or holidays, and acknowledge the importance of those special days. Offer suggestions of ways to commemorate that special day. ***Interventions:*** Help children identify holidays or special days that are

important to them and then assist them in identifying ways to commemorate their loved one on that special day. For example, on Christmas, children may choose to have a picture of their deceased sibling on the table so that they feel their sibling is with them during Christmas or they may choose to make their siblings' favorite dessert. Commemoration activities could include decorating an ornament, making a cake, having a party, carving a pumpkin, etc.

General Theme #10: Reinvesting in Life

Participants in the study identified a period during which they began to *reinvest in life* as part of their adaptation to life without their brother. When children engaged in reinvesting in life, they were able to move forward and had learned to adjust to life without their siblings. Children also recognized that they had to keep going and could not remain focused solely on the life of their loved one, as their own lives were still moving forward.

Reinvesting in life means that the bereaved begins to engage in new activities and life changes. This is also considered a time of healing and personal growth as the bereaved reflect back on the grief journey and find meaning in that experience. Tiffany described healing for their family as she stated, *“Find causes that were significant in our healing...Positive way to remember him... I really liked everybody talking about him and I know it is healing for us to do this.”*

Mahon and Page (1995) found that children who had lost siblings described a process of growth as a result of the bereavement process. Post-traumatic growth literature (Calhoun, Tedeschi, Cann, & Hanks, 2010; Meyerson, Grant, Carter, & Kilmer, 2011) explained that children experience psychological

growth and are changed as a result of their loss. Children find positive ways to integrate the loss in their lives resulting in reconstruction of one's self and life transformation, which ultimately leads to post-traumatic growth (Calhoun & Tedeschi, 2006). Meaning reconstruction theory described a process called *identity change*, defined as a reconstruction of meaning regarding the loss that leads the bereaved to reconstruct themselves. As people reconstruct themselves, a new identity is born. This identity can result in positive growth as a result of their grief experiences.

Bonanno (2004) defined the concept, *resiliency*, similarly to that of post-traumatic growth. Children are often resilient when faced with tragedy, and often have the capacity to develop the skills they need to overcome adversities. Kristen described how Mason has grown and changed as a result of losing his brother, Micah. She states, "*I have seen him grow and change...seeing that renewal in him as time progressed.*" Through this process, children may find that they have a new outlook on what life means and what is important to them. For example, Miles stated, "*I started thinking about life a lot more...I think about God, nature, life, and purpose...Thinking about this reminds me that I need to do something worthwhile.*"

Recommendations

Professionals and Parents: *Provide children with opportunities to reflect back on their grief experience and help them to identify things that they found helpful in their healing. Explore how this experience has changed them and what they have learned through the process.* **Professionals:** *Encourage bereaved children*

who are willing to share their experiences with other bereaved siblings.

Interventions: *Have children complete a grief review of their loss experience and document things that they found helpful in healing from their loss. As part of the grief review have children document things they have learned through their grief experiences and then connect newly bereaved children with children who are more experienced in dealing with their grief to mentor the newly bereaved through their grief journey.*

Table 6.1 presents the themes along with definitions, examples, and recommendations for all of the general themes described above. Given the qualitative nature of the study, the results cannot be generalized, but can be used as guide to make recommendations of how to work with these children.

Table 6.1

Recommendations Informed by General Themes

General Themes	Definitions	Examples	Recommendations
GT 1: Adjusting to Change	After the loss, children's lives are affected by many changes (e.g. family roles, traditions, relationships)	"I felt like some friends from church were acting weird...With friends it was socially quieter for a while." (Miles, 12)	Provide opportunities to validate changes and process those changes through activities.
GT 2: Collective Experience	Involves being around other children who have experienced a loss similar to theirs.	"Everybody was telling about the people they lost so I could too." (Maddox, 7) "Just being around people that lost siblings was helpful." (Mason, 10)	Encourage and engage children in activities with other children who have lost a sibling. (e.g. camps, support groups, sibling events, and social media)
GT 3: Commemoration of Life	Involves developing rituals, memorializing, and honoring their loved one's life.	"Ran a 5K in his honor because that is something he wanted to do." (Ricky, 8) "It is important for children to keep their memory alive but not to be stuck in that place." (Kelly, 40)	Allow children to commemorate the life of their deceased sibling (e.g. balloon or butterfly release).
GT 4: Communication	Involves verbal and non-verbal communication between the bereaved sibling and other family members and how communication relates to their grief.	"Felt like talking to anybody else in the family would cause them more pain." (Miles, 12) "We try to talk and not let it fester...He was opening up more." (Tiffany, 30)	Create opportunities for children to talk and process their grief.
GT 5: Drawing on Faith	Children relied on their faith for strength, answers, and healing during a loss.	"Helps me to remember that he is somewhere better and my family will never forget him." (Mason, 10)	Recognize that spirituality is an important way for many children to cope. Explore with kids how they understand the death in relation to their faith tradition.
GT 6: Expressions of Grief	Children named different feelings and symptoms that represented their grief.	"Worry Jar has the emotions in it...Anger, grief, fear, and so on." (Henry, 31) "One of the things he really struggled with was anxiety." (Tiffany, 30)	Explore and provide opportunities for children to express their feelings and teach them healthy ways to express their feelings. Normalize and validate children's feelings regarding the loss.

Table 6.1 Continued Recommendations Informed by General Themes

<p>GT 7: Gaining Knowledge and Understanding</p>	<p>Children sought information to understand the siblings' diagnosis as well as knowledge regarding how to cope with the loss.</p>	<p>"His age was just not understanding." (Henry, 31)</p>	<p>Provide parents with educational material that is age appropriate and explains the disease and physical changes. Provide them with information regarding illness, loss, and grief process that they can use to explain to their children.</p>
<p>GT 8: Perceptual Differences</p>	<p>Children recognize that they grieve differently than other siblings or family members as well as recognize that each loss is unique.</p>	<p>"Mom was freaking out more...I was more back with it." (Mason, 10) "Not taking it better than my brothers, just trying not to show it as much." (Mason, 10)</p>	<p>Help children identify ways in which family members grieve differently and create opportunities for them to discuss their unique grief experiences with other family members. Family counseling may be helpful.</p>
<p>GT 9: Processing Grief</p>	<p>Children work through their grief and identify things that are helpful/unhelpful in moving towards healing.</p>	<p>"It is something that you have to work through." (Mason, 10) "Had a hard time for a while of him drawing Mitchell in a casket...Will find these not as frequent as in the beginning...I have been grateful from the beginning that he could express where he was and what he was feeling." (Kelly, 40)</p>	<p>Provide children an outlet to explore and work through their grief. Validate and normalize grief.</p>
<p>GT 10: Reinvesting in Life</p>	<p>Children recognize that their life has to keep going and learn to adjust to life without their sibling.</p>	<p>"You can't just quit...You have to keep going and moving forward." (Mason, 10) "The world has to go on. Everything can't stop and neither can you. You have to keep moving forward." (Miles, 12)</p>	<p>Provide children opportunities to reflect on their grief experience and help them identify things that they found helpful in their healing. Explore how this experience has changed them and what they have learned through the process.</p>

Discussion and Recommendations for the Unique Themes

As part of the data analysis process, several general themes emerged and were discussed by most or all of the participants; however, individual themes unique to one or two participants also emerged as they discussed their experiences of losing a sibling. Unique themes were defined in Chapter V as the findings were explained. The unique themes are discussed in detail and recommendations are presented below.

Unique Theme #1: Life Exploration

A unique theme that emerged in the findings was *life exploration*, which was defined as coming to terms with one's own mortality through examining the purpose and meaning of life. Miles was the only participant who identified the theme of *life exploration*. Through the loss of his brother, he recognized the importance of life and sought for his life to have meaning. As a part of the exploration, he began to change things in his life to better align with his purpose.

When a significant loss happens, children question the world around them in an attempt to make sense of the loss. Children often begin exploring different aspects of their lives. Janoff-Bulman (1992) described this process in her Assumptive World Theory. Children must recreate their lives without their siblings. For example, Miles stated, "*I think about life, purpose, and Micah and what it all means.*" With help from adults, children can overcome and thrive despite such a devastating loss.

Neimeyer (2000), *Identity change* as previously mentioned described how the bereaved reconstruct meaning and themselves. Children reflected back on their grief experiences and described what they have learned and how they will use these experiences to shape their futures. This process gives meaning to their loss and initiates healing.

Recommendation

Professionals: Invite children to complete a review of their lives and identify how the death has impacted them now and how it may affect them in the future.

Interventions: Engage children to complete a life review that involves children evaluating their life to determine what changes they would make or what they would choose to keep the same. Discuss with children their own view on mortality and have them complete a mortality survey.

Unique Theme #2: Shattered Expectations

Shatter expectations was a theme that emerged as Ricky discussed his deceased brother missing out on certain key events in his life. *Shattered expectations* were defined as a loss of expectations that were originally identified by participants as their goals, dreams, and activities for the future. Ricky was sad that his brother, Mitchell would no longer be part of his life in important ways.

Often siblings develop a close relationship with each other from a very young age. Siblings may do life together, meaning that they share many of the same goals, dreams, and activities. When a sibling dies, these dreams, goals, and expectations are shattered. "Death ends sharing a life together on earth now

and in the future. This realization shatters all expectations and anticipation the children had for a shared future in life and on earth with the deceased brother or sister” (Hogan & DeSantis, 1996, p. 239). For example, Ricky explained that Mitchell will not get to see him play baseball. These *shattered expectations* can bring a whole new layer of grief that has to be explored when siblings realize how the death impacts their life.

Children begin to realize that their deceased sibling will miss their birthday parties, weddings, graduations, proms, etc. Janoff-Bulman (1992) described a process of rebuilding shattered assumptions. Bridging the distance between old and new assumptions can minimize the potential for negatively impacting the surviving sibling. By bridging the gap, the bereaved is attempting to reestablish cognitive and emotional stability.

Recommendations

Professionals: *Help parents identify ways to incorporate the deceased in significant events. Parents:* *Consider helping children incorporate their deceased siblings into important events such as weddings or birthdays. Interventions:* *Give parents examples of ways to incorporate the deceased in significant events. For example, the researcher buys her sister a birthday card every year and then writes a note to her sister about the events that have transpired throughout the year. Another way might be to light a candle at a wedding in memory of the loved one. The family could purchase a Christmas ornament in memory of the child who died and place it on their tree each year. Have children identify their involvement in this activity and how they will be affected.*

Unique Theme #3: Protectorship

Protectorship was identified through two participants' experiences and was defined as an act of consciously behaving in a way that the child believes he will safeguard his loved one's feelings. Both participants felt the need to protect other family members, but especially their parents as they did not want to burden their family members with their grief. The participants felt the need to protect their family from the pain as a way of loving them.

Adjusting to the death of a loved one has been seen as more difficult than any other life change for parents and siblings, especially when the family member is a child (Holmes & Rahe, 1967). Most clinical and research attention has focused on a linear perspective in relation to how people grieve. Individuals may exhibit personal symptoms with little attention focused on how the individual interacts within the family. For example, when a sibling dies, surviving children may hide their feelings from their parents because they do not want to burden or cause undue pain to their parents.

Smith (1999) also discussed the concept of protection and considers this to be typical of bereaved children between ages 5 and 9. She argues that children within this age group "will watch adults' reactions to grief and will sometimes deny their own grief in order to protect an adult's feelings" (p.21) Smith explained that this may be partly due to them having a greater awareness of guilt and feeling responsible for the death through illogical reasoning such as "My brother died, because I would not share my toys."

Horsley and Patterson (2006) found that children were reluctant to talk about their grief in front of their parents as it might illicit parental expressions of grief. When parents grieve openly in front of their children, it delivers the message that death is not taboo (Horsley & Patterson). While Horsley and Patterson found it is better for parents to openly grieve, other cultures may have a different view on expressing grief. According to National Child Traumatic Stress Network (2009), "Beliefs and attitudes about death and expressions of grief are strongly influenced by a family's culture, religion, spirituality, and rituals related to mourning" (p.1). Therefore, it is important for the health community to accommodate different communication patterns that look different from western cultures. Children may also benefit from education on how to communicate their grief and informing them that it can be helpful to talk about their grief.

Two children in this study viewed their silence as protecting other family members during the grief process. These children did not want to add any more pain to the grief their family was already feeling. Children may benefit from reminders that grief is difficult and painful and it is okay to share their pain as it will help them feel better.

Recommendations

Parents: Share your grief with your children and work through it as a family. The more open you are the less they will feel the need to protect you from their emotions. Empower children to maintain their roles in the family as a child and remind children that your job as a parent is to protect them. ***Professionals:*** Provide ways children can re-direct their feelings of protectorship or activities for

*coping with those feelings. Encourage parents to find examples of things children can control. **Interventions:** Create a list of the parents' roles in the family and a separate list of the children's roles in the family. Discuss with the children the parents' responsibilities as well as their own. Have parents identify the ways they keep their children safe and protected. Have parents and children role play each other's role in protecting one another then have them role play how they would like their relationship to be in the future based on the previous role play.*

The interventions provided were formulated from the researcher's previous clinical experience and the findings from this study. The interventions that have been provided may be useful when working with bereaved children. These interventions need to be tested in future studies to determine if they are effective with this population.

As mentioned above, three unique themes emerged: life exploration, protectorship, and shattered expectations during the analysis process. These themes are considered unique because only one or two participants expressed these as part of their grief processes. In conclusion, these experiences are unique to the individual; however, they should be placed in context of their overall grief experience to gain an in-depth understanding of their experience.

Congruencies between Findings and Theoretical Frameworks Informing the Study

In Chapter II, the researcher reviewed multiple theoretical frameworks to provide a foundation to develop the current study. The researcher chose four

theoretical frameworks that most closely align with the phenomenological methodology on which the study is based. Given the findings of the analysis, the following section will explain how these theoretical frameworks align with the current findings. Throughout this chapter, other theories are mentioned to support the findings; however the results of this study support components of several theoretical frameworks mentioned earlier: Assumptive World Theory (AWT), Dual Process Model (DPM), and the researcher now outlines how each of the constructs from these theories is supported by the findings.

Assumptive World Theory (AWT) suggests that individuals' world views involve three key beliefs: that the world is benevolent, the world is meaningful, and self is worthy (Janoff-Bulman, 1992). All of these belief can be brought into question when a loss or trauma happens. The beliefs can change together or independently of one another. In this study, it became evident that the participants had questioned these beliefs throughout their grief process.

The concept of a benevolent world is questioned during Miles' (12) grief process:

Just any other thing that changes your world dramatically...Even though the world has to go on (after a death), the world is not doing it just to get at you. It has to. Everything can't stop and neither can you.

Miles discussed how his world is turned upside down from losing his brother and describes how people's worlds change when someone close to them dies. Even though Miles may not feel like he wants to go on or rebuild his world, he realizes that he has to keep going and not stay stuck in his grief. In general, Miles's world

around him is good, but he recognizes times when his world may disappoint him, and he understands that he has to adjust to the changes the loss has caused for him. Rather than perceiving the world as evil or bad or creating loss “just to get at you”, Miles recognizes loss as a normal part of life.

As mentioned earlier, AWT asserts that people believe events in the world have meaning and make sense. Assumptions about meaning include not only simple beliefs about why events happen in our world, but more specifically, why they happen to certain people. People want to understand meaning and events. In the example below, Miles and others questioned why his brother was dying. While he sometimes blamed his parents, he also realized that there was nothing that they could have done to prevent his brother’s death. Others said that God would not cause his brother to die, because God doesn’t let bad things happen. Miles (12) stated,

Everybody was like, “God has a plan for this or he is going to miraculously survive because God wouldn’t let that happen to such and such.” The latter group, I felt they were trying to comfort themselves. They didn’t really like the thought that his death could be possible. I didn’t really blame myself because I can’t really control a genetic disorder. At times I would think, “Is there anything my parents could have done?” Then, I would blame them for half a second, then I would realize that is kind of ridiculous because I can’t do anything about that.

The final belief of the AWT is that the *self is worthy*. According to AWT, people perceive themselves as good and moral individuals (Janoff-Bulman,

(1992). As mentioned earlier, self-worth includes the evaluation of one's essential goodness, decency, and morality. Self-esteem and evaluation of one's wisdom and effectiveness of their actions is also explored. Miles (12) goes on to describe his grief and how his grief has affected him.

My grief became a part of me but not in a revenge super hero who must avenge things but a part of me. It just kind of affects who I am even though it is not part of me. Even if I don't think about it all the time.

As part of self-reflection, he realized that his grief affected him, but does not overtake him.

Dual Process Model (DPM) describes how individuals oscillate between loss-oriented and restoration-oriented processes. Oscillation is process of confronting and avoiding the different stressors associated with bereavement (Stroebe & Schut, 1999). During loss-oriented grief processes, the griever attends to his feelings and emotions surrounding the loss and works through the grief. Loss-oriented processes were presented in this study as the children discussed ways that they processed their grief, expressed the emotions that they experienced during their grief, and explained changes that happened as a result of their losses. Many participants identified feelings that they experienced through the grief process, i.e. anger, guilt, blame, anxiety, and sadness. Physical and behavioral manifestations of grief included difficulty sleeping and children clinging to their parents.

In addition to loss-oriented processes, the children in this study discussed drawing on their faith to move forward in their lives, adjusting to change, and

reinvesting in life. These things can be seen as part of the restoration-oriented phase of the dual process model. At any time, the bereaved can move back and forth between loss-oriented and restoration-oriented phases.

Meaning reconstruction theory explores how people find meaning through the loss of a loved one. This is a theme that was heard consistently throughout the interviews. For example, *“Our biggest prayers for his life are that it would have meaning and God’s perspective would be told through his story... We use the kids to give meaning or help them to have meaning through his life” (Mark, 38).*

Each of the families identified ways to honor their loved one, thereby bestowing meaning on the deceased’s life. The following items are all benefit-making activities: for the Carter family, they chose to do a 5K race every year to raise money for organizations that carry special meaning for them. The race was named after their deceased son, Steven. They donated money to the bereavement camp that Jason attended as well as to a public library and a local park for a toddler playground. The Lancaster family collects Legos to donate to area children’s hospitals on Mitchell’s birthday. Legos were Mitchell’s favorite toy. Also, shortly after Mitchell died they ran in a 5K race because that is something that he wanted to do, but didn’t live long enough to accomplish. The Newsome family had people draw a symbol for a block of the stained glass window commemorating Micah’s life. The blocks were then made into a stained glass

window. The news station aired Micah's story on TV. The family chose to participate in the newscast so that people would know about Micah and others would be impacted by his story.

Meaning reconstruction theory also discusses how people will seek a cause or reason for the death. Several participants grappled with questioning why the loss occurred. For example, Miles (12) shared that he sometimes asked, *"Is there anything my parents could have done to cause this?"* Jason (7) also questioned why the death of his brother happened. Henry stated, *"Jason felt like he wanted to know why this had happened. What does it mean to me? I couldn't give him the answers as a dad he wanted."*

Fox's (1988), *Tasks of Mourning* is another theory that can be linked to the findings in this study. This theory suggests that grievors must understand and make sense of the loss, express emotions and other strong responses, commemorate the loss, and eventually go on living (Fox). Each of these tasks aligns nicely with the themes identified in the present study including *gaining knowledge and understanding, expressions of grief, commemoration of life, and reinvesting in life*. An example of *gaining knowledge and understanding*, *"I didn't really know him that well, but he was one of the few people that understood. He knew what I was talking about. That was one of the things that helped me"* (Miles, 12).

That day was the ultrasound and it was a big heavy day. I don't know if it was exactly that same day or pretty soon after. We usually just kind of lay out everything. Probably a little more detail and little above their level sometimes. We are kind of under the philosophy of just give them more detail and not just sugar coat it. We kind of laid out the thoughts of a good

possibility that he'll never be born. Obviously he'll be born, but he might not actually be alive. Who knows what it is going to be like really. (Mark, 38)

The second task is *to express emotions and other strong responses.*

Several examples are presented for the reader to see how this task relates to the data. *"It was very sad. I felt like crying a lot" (Mason, 10)* or *"I felt guilty. I should have been there because I woke up 10 minutes after he died. I should have been up" (Mason, 10)* or *"I didn't really trust my friends to actually help me...Trusting them in who they were and allowing myself to be vulnerable" (Miles, 12).*

The third task is *to commemorate the loss.* This picture is an example of how the Lancaster family chose to commemorate the loss of Mitchell. The bottom bunk of the bed represents things that were important to Mitchell. These items serve as a way to memorialize his life and his legacy.



The fourth task is *to learn how to go on living and loving.* This task involves growing and reflecting on what you could learn through the grief process. To further illustrate this task, *"I think other families need to know that you hold on to the memories that you have but you have to keep going" (Kelly, 40)* or *"Learning to live life and learning there is still a future...A year after, I felt like I could let go of the anger and focus on what could I learn" (Miles, 12).*

Opportunities to Strengthen Existing Theoretical Frameworks based on Study Findings

The results of the current study can be connected to many constructs included in the theoretical frameworks described. However, none of the frameworks captured the entirety of the children's experiences of losing a sibling, or permitted unique experiences to be told by individuals. The study findings revealed that children really value and want to be around other children who have lost a family member, and especially a sibling. Children reported appreciating that *collective experience* of knowing they were not alone. The desire to be around other bereaved children was motivated in part by the children's recognition that there were *perceptual differences* in grief among family members. They were aware that they were often psychologically processing their loss differently than the adults in their lives, and they found value interacting socially with others who might share more of their perceptions. Thus, they connected the psychological and social aspects of grief. This was further evident in the *protectorship* theme. Children reported feeling reluctant to socially engage with family members, fearing that giving voice to their pain would injure others. Here again, study participants' psychological reactions (i.e. their thoughts and feelings) shaped their social interactions (relationships with others). A theory that incorporates this interconnectedness of the psychological and social components of grief would more accurately reflect study participants' experiences.

The findings revealed children really value being around other children who had also lost a sibling. The theme, *collective experience* emerged from the

data through participants sharing about their experience of being with other grieving children. Worden (1991) and earlier theorists were criticized for not considering the influence of social support on the grief process. Therefore, the development of a theory that incorporates psychological and social aspects of grief is fundamental to the sibling bereavement experience.

Grief is an emotional process where people express their feelings regarding the loss and work through a grief process while being surrounded by others who understand their experiences. Family members often try to protect one another as they do not want to cause additional pain and they perceive differences in relationships with the deceased. For example, Miles explained that his mother had a deeper relationship with his brother so he expected her to have a harder time coping with the loss. With open discussion, perceptual differences may lessen as people see each other experiencing similar grief reactions.

The theme, *reinvesting in life* emerged from the data as participants described their experiences of losing a sibling. Participants described learning to move forward and make sense out of the loss. Post-traumatic growth theories discuss a concept of growth and reinvestment. The Substance Abuse and Mental Health Services Administration (SAMHSA, 2014) stated,

Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or

emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional or spiritual well-being.

It is important to note that none of the participants used the term, *trauma* to describe their experiences, but they may well have been experienced as such. Ideally, since the participants did not understand the experiences as traumatic, we have the opportunity to strengthen theory in this area by developing a framework that helps us understand how children grow and develop new skills after experiencing events that do not meet the clinical definition of trauma.

Religion/spirituality has been associated with post-traumatic growth (Pargament, 1997; Tedeschi & Calhoun, 1995). Tedeschi and Calhoun (1995) posited that people who are experiencing post-traumatic growth seek out religious experiences or their religious participation prepares them for spiritual growth. Increased religiousness has been reported as an outcome of stressful experiences (Calhoun, Cann, Tedeschi, & McMillan, 2000; Park, Cohen, & Murch, 1996). This increase lends itself to improve already existing theories or develop a more comprehensive theory that integrates spiritual/religious constructs. The children in this study drew upon their faith to help them cope with the loss of their siblings. Limited research has been conducted with child grief and spirituality and even less with child sibling grief. Given the importance that these children placed on spirituality during their bereavement experience, it an area that should be further explored and developed.

Few existing bereavement theories are evidenced-based. Due to the lack of relevant theories specifically focusing on sibling bereavement, more emphasis should be placed on incorporating the multiple aspects of sibling bereavement into a comprehensive theory. Through the use of grounded theory which evolves from research, sibling bereavement theory can be developed and tested. Developing an evidenced-based theory of sibling bereavement would be an important contribution to the field of sibling bereavement which could guide assessment and intervention.

Implications of the Findings

The interpretation of the findings leads to the conclusion that children could benefit from psycho-spiritual support as a means to help them work through their grief. Specialized counseling support incorporating emotional and spiritual modalities should be available to help these children process the emotional and spiritual issues related to their losses. Given that some of the parents reported focusing on their own grief and were unable to recognize their child's needs, the study recommends that these services start prior to the death or immediately following the death so that the children's needs are being met in a timely manner. Children could also benefit from specialized programs that focus specifically on bereaved sibling loss, as many children in the study identified *collective experience* as a common theme. These children benefited from being around other bereaved siblings and felt supported. Children's bereavement experiences may be improved if health professionals and parents are united. Health professionals should work with the children during counseling sessions

and educate and prepare parents for what to expect at home. This promotes open communication between all parties involved. As mentioned earlier, open communication involves all parties talking and sharing their thoughts and feelings freely with one another.

Two of the deceased siblings from the study died in the hospital, thus bereavement services should have been offered to these families (and possibly were). Since some families may have a difficulty returning to the place their loved one died, offering these services either off campus or at an outpatient clinic may be helpful. If families are unable to come in for services, it might prove beneficial to have professionals who can provide these services in the home. It may be helpful to offer families a bereavement packet with bio-psychosocial and spiritual education on how to help their children cope with the loss of a sibling. The hospital could offer events several times a year to connect bereaved siblings. This would provide an opportunity for children to offer peer to peer support. Providing death education for everyone would be helpful to prepare children and parents for the time when they experience a death.

The findings in this study identified that these children recognized that members of their family grieve differently. Based on these findings, bereaved siblings may benefit from family counseling. As family members discuss their grief, the children may feel more open to express their own grief. Children may feel safer expressing feelings if they know someone else is experiencing similar feelings. Counseling would also provide an opportunity to explore their

differences. Even though the family members may express grief differently, family counseling provides the opportunity to educate both the children and parents on grief and offer ways to cope.

The findings revealed that *Commemoration of life* was important for these children. Helping children find ways to incorporate rituals and memory-making activities into their grief journeys appeared to be beneficial. Another aspect that was important for these children is legacy-making. The children in this study identified ways to keep their siblings' memory alive and bring honor to them. Health professionals should explore meaning and legacy-making activities with bereaved siblings and identify ways to accomplish these tasks.

As part of the bereavement, the children in this study began reinvesting in life. For these children, this was a time of renewal and new memories. For some, it was also a period of growth and self-exploration. Some children were able to explore how their life had changed and what they had learned as a result of their loss. Children may find engaging in planned self-exploration helpful. Such exploration would consider what they would like their future to look like, what they have learned, and how they have grown from this experience. Children may benefit from suggestions on how to re-engage in life with their peers such as explaining the death/grief to classmates or exploring new hobbies or adventures.

Strengths and Limitations of Study

The current study chartered new territory by exploring the phenomenon of sibling grief in a novel way, using photo-elicitation to help children and parents

describe the children's lived experiences. While this study supported portions of existing theories, it also added to what is known about child sibling grief by highlighting the importance of the social and spiritual aspects of grief for bereaved children. Given that the focus of this study was to understand sibling grief through qualitative methods, future quantitative studies can apply these findings to further conceptualize or quantify sibling grief.

In addition, this study followed a rigorous process. Rigor was enhanced by being transparent in describing the methods, by providing concrete examples of each of the methodological steps, and through systematic exploration of the phenomenon. In Chapter III, the researcher provided a discussion of how rigor would be accomplished in this study. This included a discussion of triangulation, establishment of trustworthiness and insistence on rigor through prolonged engagement, and member checking.

Previous studies have used photo-elicitation with children (Epstein, Stevens, McKeever, & Baruchel, 2006; & Mandleco, 2013). However, this is the first photo-elicitation study that has been conducted with bereaved children who have experienced the death of a sibling. The successful employment of photo-elicitation with children in this study demonstrates the feasibility of using this method with children in future studies.

This study demonstrated strengths in several areas. The research presented here is its ability to generate findings that reflect a deep understanding of bereaved children's experiences. The researcher met with multiple family

members on multiple occasions to learn about the experiences of bereaved siblings. The researcher personally recruited all study participants, conducted and transcribed over 450 pages of interview data and engaged in a detailed analytic process over the course of several months. This reflects the qualitative standards of prolonged engagement (Padgett, 2008) and immersion in the data (Green et.al, 2007).

The aim of this study was to gain an understanding of the children's experience of losing a sibling. While it is important to capture the children's perspective, the researcher also felt it would be important to gather the parents' perspective of how they viewed their children's experiences of losing a sibling. Parents in many cases accurately reflected what the children had experienced, as evidenced by the parents giving accounts similar to their children's. For example, Jason described his experience at camp and finding comfort being around other children who had lost a sibling. Both of his parents also discussed the value of his shared experience of being around others at camp. Jason used the same picture as his dad to describe that experience, while his mother chose to take a picture of Jason's camp shirt.

The application of multiple sources of data (photographs and interviews) was successfully combined in this study. This was accomplished by having the children and parents take pictures that represented aspects of their grief and then interviewing them on multiple occasions. This provided participants multiple avenues through which they shared their stories.

Given that the researcher had five years of experience working with bereaved children and families prior to beginning this research, she was able to use her clinical skills to establish rapport, build trust, show empathy, and employ high-quality interviewing skills regarding a sensitive topic. Although this project was not conceptualized as an intervention, these skills supported the research process and may have increased the quality of the findings that were ultimately generated. The researcher's continued work in the field of child illness and grief during the analysis phase of the study ensured that she was sensitized to the issues that may have impacted participants' stories. While the substance of these professional experiences was bracketed to reduce their impact on the study findings, they nonetheless strengthened the researcher's ability to obtain meaningful data from the study participants.

The limitations enumerated below can be further addressed in future research. While some experiences were common to most of the participants, there were experiences that were unique to certain individuals. A larger sample could provide a greater opportunity to generalize the results to the broader bereaved sibling population. By developing and conducting a larger qualitative study, trustworthiness would be intensified.

The study is further limited by the homogeneity of the sample. All of the child participants were Caucasian boys and all had lost brothers. All of the children were members of western traditional, nuclear, two-parent households. A previous study (Paris, Carter, Day, & Armsworth, 2009) found that girls tended to struggle differently with loss than boys do, thus it will be important in the future to

explore the phenomenon of child sibling grief with a sample including both genders. As different ethnic groups view death differently, it would be interesting to see whether such differences are reflected in how they grieve. Also, all of the participants were survived by other siblings; none of the participants became only children as a result of their losses. This may have dramatically impacted their grief experiences.

Individual differences among participants could be attributed to age or relational factors, but most experiences were common across all child participants. Some experiences that were unique: see, particularly, those of Miles (12), who was the oldest in the group and to Ryan (8) who was very close to his brother. For example, Miles was the only participant where *life exploration* emerged as a theme; and *shattered expectations* was the only theme that emerged as Ryan shared his story. These two themes were unique to these individuals. Ideally, a larger sample that could divide participants in age groups and/or compare grief experiences based on relationship to the deceased would provide more generalizable findings.

Children were given a choice to have parents present during their interviews. While two children chose to discuss their picture alone with the interviewer, three children (7 & 8 years old) chose to have their parents sit in on the interviews. Given the parents presence, the children may not have been as candid with the interviewer, which could have produced some bias in the children's responses. Others limitations of this study will be further explored in areas for future research.

Future Research

The findings resulting from this study have provided an impetus to explore other areas in future research. For example, future research would benefit from exploring whether children cope differently depending on whether the loss is sudden or expected. One study found that regardless of whether the loss was sudden or expected, grief and trauma were highly correlated and difficult to separate (Paris, Carter, Day, & Armsworth, 2009). Some children do not have the developmental capacity to fully understand and anticipate a death (Paris, Carter, Day & Armsworth), even one that is expected; thus they may perceive even so-called “anticipated deaths” as traumatic. While this one study shows that children perceive trauma and grief as being interrelated, the intensity of the loss is worth investigating.

Given that the sample consisted of all Caucasian boys who had lost a brother, future research would be helpful to determine whether gender plays a role in how siblings grieve. Previous literature reveals that gender may be an important factor to consider when evaluating a child’s responses to loss (Worden, Davies, & McCown, 1999). Literature reveals that girls tend to be nurturers and caregivers and may be more distressed than boys who are often identified as independent and strong (Paris, Carter, Day, & Armsworth, 2009). Paris, Carter, Day, and Armsworth found that girls experience a higher level of grief than boys after a loss. The participants in this study had others siblings who survived the loss of their sibling. Future research should be conducted to determine whether being the only surviving sibling makes a difference in how siblings grieve. Gender

of the sibling should also be explored to see if a girl losing a brother has more or less of an impact than a girl losing a sister and vice versa. Research would be helpful to determine whether ethnicity or culture influence how children grieve the loss of a sibling. It would also be valuable to see how this research could be applied to other cultures and ethnic groups around the globe, especially cultures that have higher mortality rates and less access to resources. Previous studies have used photo-elicitation methods with other ethnic groups with success (Didkowsky, Ungar, & Liebenberg, 2010; Mitchell, 2008). Participants revealed information that would not typically be disclosed in a traditional interview setting, but was rather evident by viewing the images alone.

The children identified in this study expressed having difficulty with coping with their grief as well as their unmet needs. Bereaved sibling research has been limited but research focused on evaluating effective interventions with this population has been even more limited. Future research should include identifying and testing interventions with this vulnerable population. While the methods used in this study were not intended to be a practice intervention, it is worth investigating whether these methods could be used as a therapeutic intervention.

Another area that should be explored in future research is how to grant access to resources. The children in this study identified many things that they found helpful to them during their grief process. They found counseling, support groups, and camp helpful. While these parents identified that their children

needed additional support and sought out resources, other families may not have access to such resources or be able to identify that their children need extra support.

Future research addressing the limitations of the current study could be beneficial. Qualitative studies such as this produce a smaller sample size with rich and in-depth data, but a larger sample size focusing on a wider group of participants would provide more generalizable findings.

Summary

The experience of losing a sibling at a young age can have lasting impact on the surviving siblings. Study participants gave voice to their experiences through the use of pictures and interviews. Many of the children's experiences echo phenomena described in previous literature or theory. Their experiences resonate with that which is already known about sibling bereavement: (a) children should be encouraged to identify and give voice to their experiences, (b) being a bereaved sibling can be challenging, (c) while certain aspects of grief can be generalized, there are certain aspects that are unique to the individual and population, and (d) children have individualized needs. The findings of this study also add to the knowledge of child sibling grief by illustrating the importance of the social and spiritual contexts of grief.

The discussion and recommendations were generated from the findings. The recommendations offered are general guidelines for working with bereaved siblings. However, a clinical assessment should always be performed and

interventions tailored based on the child's individual needs. While the recommendations provided here can be considered evidence-informed, the field would benefit from rigorous testing of these interventions for bereaved siblings. While this study was not intended to test interventions, the use of photos as a therapeutic intervention may be worth testing.

Finally, the findings from this study reveal the need for a theoretical framework that accounts for the interdependent nature of the physical, psychological, social, and spiritual aspects of grief in the development of theory and interventions, consistent with the bio-psycho-social-spiritual perspective commonly employed in social work. Perhaps the development of such a framework will be the next item on this researcher's agenda.

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Appendix A-1

Grief and Developmental Theories

<i>Theorists</i>	<i>Theory</i>	<i>Description of the Theory</i>
Colin Parkes & Ronnie Janoff-Bulman (1971 & 1989)	Assumptive World Theory	<ol style="list-style-type: none"> 1. Benevolence- in general people believe that the world is a good place. People form assumptions about their world. 2. Meaning- people believe events in their world have meaning and make sense. Assumptions about meaning not only involve simple beliefs about why events happen, but more specifically why they happen to certain people. 3. Self-worth- People perceive themselves as good, capable, and moral individuals. It involves the evaluation of one's essential goodness, decency, and morality as well as self-esteem and evaluation of one's wisdom and effectiveness of their actions.
Margaret Stroebe & Henk Schutt (1999)	Dual Process Model	<ol style="list-style-type: none"> 1. Loss-oriented- stressors focus on dealing with the different aspects of processing the loss such as making meaning of the loss, efforts to emotionally relocate the deceased due to their no longer being physically present, separation distress, and examining the emotions associated with the loss. 2. Restoration-oriented- stressors focus on helping the grieving person concentrate on the daily tasks of reintegrating back into society such as adjusting to new roles, learning new skills, and attending to life changes.
Neimeyer (2000)	Meaning Reconstruction	<ol style="list-style-type: none"> 1. Sense making- is a search for meaning to make sense of the loss and the events surrounding the loss. 2. Benefit Finding- is the ability to find benefits in the grief experience. This involves finding benefits through the means of building new meaning structures. 3. Identity change- as people grieve they reconstruct meaning regarding the loss that leads the bereaved to reconstruct themselves
Fox (1988)	Tasks of Mourning for Bereaved Children	<ol style="list-style-type: none"> 1. To understand and make sense out of what is happening or has happened- children seek information surrounding the events of the death, find ways to understand, and make meaning of the death. 2. To express emotional and other strong responses to the present or anticipated loss- this involves recognizing, expressing, and validating feelings or strong reactions. Also finding appropriate ways to express those emotions and reactions. 3. To commemorate the loss through some formal or informal remembrance- involves activities of memorializing or remembering the life of the person who died. 4. To learn how to go on with living and loving- this involves finding ways to go on with a healthy life after a significant loss and successfully integrating the loss in their life.

Appendix B-1

Dissertation Timeline

May 2011- September 2011	<ul style="list-style-type: none">• Wrote Dissertation Research Proposal
September 2011- December 2011	<ul style="list-style-type: none">• Met with Vanderbilt to discuss conducting research at Vanderbilt Children's Hospital• Applied to Vanderbilt IRB and Scientific Review Committee• Received Approval from Vanderbilt's IRB and Scientific Review Committee• Applied to Louisville's IRB
January 2012- October 2012	<ul style="list-style-type: none">• Dissertation Proposal Approval Meeting• Waited for Referrals from Vanderbilt Social Workers• Received Approval from Louisville's IRB
October 2012- December 2012	<ul style="list-style-type: none">• Mailed Recruitment Letters to families and recruited 1 family.• Met with the family and enrolled them in the study.• Met with Alive Hospice to inquire about recruiting participants from Alive Hospice. Alive Hospice approved for me to recruit from Alive Hospice. In the process of determining how they would like the recruitment process to go.• Completed Vanderbilt's Continuing Review Process and gained approval to continue the study for one more year.
January 2013- February 2014	<ul style="list-style-type: none">• Mailed Recruitment letters to families.• Met with the families and enrolled them in the study.• Transcribed interviews
March 2014- August 2014	<ul style="list-style-type: none">• Made photobooks and mailed each photobook to the families.• Finished transcribing interviews.• Analyzed the data from the interviews.• Spoke with each family about the completed interviews and analysis to verify results.
September 2014- November 2014	<ul style="list-style-type: none">• Wrote up findings and discussion chapters.• Defended dissertation

Appendix C-1

Steps to Complete Phenomenological/Photo-Elicitation Study

1. Meet with Vanderbilt to secure Research Site
2. Apply to Vanderbilt's IRB and Scientific Review Committee
 - a. Complete IRB Application
 - i. Informed Consent
 - ii. Assent Form
 - iii. Vulnerable Population Form
 - iv. Letter to Families
 - v. Telephone Script
 - vi. Demographic Questionnaire
 - vii. Minimally-structured Interview Questions
 - viii. Photographic Reflection Form
 - b. Complete Scientific Review Committee Application
3. Apply to Louisville's IRB
 - a. Submit all approved Vanderbilt Forms to Louisville's IRB for Approval
4. Once both schools have approved the study, the study can begin.
5. Researcher contacted Vanderbilt Social Workers and gave them the information regarding how to make referrals for the study. The social workers would email the researcher when they had a family that matched the criteria that fit the study.
6. The researcher would then mail a letter to the family informing them about the study and also letting them know that she would contact them by phone in three weeks or they could opt out of the study by calling an 800 number.
7. The researcher then contacted the family on the phone and discussed the details of the study if they agreed to hear more and participate then the researcher will schedule an appointment to go out to the participant's home to go over consent/assent forms and explain the study in greater detail.
8. At the participant's home, during the first meeting have participants sign consent/assent form, have parents fill out demographic questionnaire, provide participants with study related materials (i.e. camera, batteries, envelopes, memory card, and binder), and go over study related material with each participant.
9. Participants are given three weeks to take pictures. Participants will mail memory card to the researcher. The researcher will print off the pictures and mail the pictures back to the family. The participant will then tape the pictures to the photograph reflection sheet and complete the photograph reflection sheet.
10. The researcher will contact the family to schedule an appointment with participant to interview about his/her pictures.
11. Steps 9 & 10 will be repeated for each participant in the family that participates.

C-1 Continued Steps to Complete Phenomenological/Photo-Elicitation Study

12. The researcher met with the participants and interviewed them about their pictures. The researcher asked the participants the following questions about each of their pictures:
 - a. What is this picture?
 - b. What is the story or experience behind the photo?
 - c. What does this picture mean to you?
 - d. What have you learned during this process?
 - e. Are there things that you have learned that you think would be helpful for other children (parents) to know to help them during their grief journey?
13. The researcher transcribed the data from the interviews
14. The researcher analyzed the data from the transcribed interviews
15. The researcher wrote up the results from the analyzed data.

Appendix D-1

Date

Mr. and Mrs Z
123 Ave
Nashville, TN 37xxx

Dear Mr. and Mrs. Z.,

We would like to express our deepest sympathy to your family. While we cannot begin to imagine how difficult this time is for you now, please know that all of our staff was honored to assist you in caring for (child's name). We wanted to make you aware that we are trying to learn more about how we can better help families cope, particularly children who have lost a brother or sister. Currently, little is known about the needs, thoughts, and feelings of children who have experienced the death of a sibling, and even less information is known about how parents and professionals can help them.

Edith Gunter, a doctoral student and Licensed Clinical Social Worker under the supervision of her faculty advisor, Dr. Barbara Head has begun a study to explore the issues that children face after losing a sibling in order to understand how best to serve them. Prior to her academic pursuits, Edith was a grief counselor at Alive Hospice. She would like to contact you in a few weeks to give you more details about her study and answer any questions you may have.

You are under no obligation to participate in this study. If you prefer not to be contacted, please call 1-800-xxx-xxxx and leave a message. Your message will only be heard by Edith and will be a confidential communication between you and her.

Thank you for taking the time to consider participating in this special project. We believe this work will provide parents and professionals with insightful information about how to help grieving children. We also hope the results of the study will help us provide a more comprehensive model of care for children and their families in the future.

Sincerely,

Alive Hospice Monarchs Team

Appendix D-2

Date

Mr. and Mrs Z
123 Ave
Nashville, TN 37xxx

Dear Mr. and Mrs. Z.,

I would like to express my warmest sympathy to your family. Our staff was honored to work with (child's name) and your family during his/her illness. I wanted to make you aware that we are currently trying to learn more about how we can better help families cope with the loss of losing a child, in particular siblings. Currently, little is known about the needs, thoughts, and feelings of children who have experienced the death of a sibling and even less information is known about how parents and professionals can help them. Thus, Edith Gunter, a doctoral student and Licensed Clinical Social Worker under the supervision of her faculty advisor, Dr. Barbara Head has begun a study to explore the issues that children face after losing a sibling to better understand how we can serve these children.

You are under no obligation to participate in this study. Edith Gunter, Licensed Clinical Social Worker from Vanderbilt will be contacting you in a few weeks to give you more details about the study and answer any questions that you may have. If you prefer not to be contacted, please call 1-800-xxx-xxxx and leave a message. The hospital operator can transfer you to the extension, and you can leave a confidential message in the voice mailbox.

Thank you for taking the time to consider participating in this special project. I believe this work will provide parents and professionals with insightful information about how to help grieving children. We also hope the results of the study will help us provide a more comprehensive model of care at the hospital for children and their families in the future. My best wishes to you and your family.

Sincerely,

Debra Friedman, M.D.
Chief of Pediatric Oncology
Department of Hematology/Oncology

Appendix E-1

Telephone Script

Hello, may I speak to Mr. or Mrs. Z? This is Edith Gunter, a researcher from Vanderbilt Children's Hospital or Alive Hospice. How are you doing today? Did you receive the letter that Dr. Friedman or the Monarch team sent a few weeks ago? In the letter, it mentioned that I would be calling to discuss an opportunity for your family to participate in a study that we are currently conducting here at Vanderbilt or Alive Hospice to learn more about how we can better help children deal with losing a sibling. Would you be interested in hearing more about the study?

This is a study for children who have a lost a sibling. The children must be ages 7-12 and need to have at least one of their parents or guardians participate in the study, however if possible we would like both parents or guardians participate if available. You and your child will be asked to take pictures of objects, things, or people that represent your child's experience of losing their sibling. You and your child will then be interviewed about the pictures that each of you take. I will come out to your home and go over consent forms and have you fill out some questionnaires lasting about 45 minutes. You will be asked to participate in 1-2 interviews lasting 1-2 hours and a follow-up phone call lasting around 30-45 minutes. As a result of participating in this study, you or child may experience some emotional discomfort as a result of sharing your grief experience of losing your child. You and your child would be free to withdraw from the study at any time. Does this sound like something that your family would be interested in? Yes, See Below Paragraph #1. No, See Paragraph, #2.

Yes: The next step in the process is to set up a meeting to discuss the details of the study and go over consent forms. When would be a good time for me to come out and meet with your family? I look forward to meeting with your family. Do you have any questions before we hang up? Thank you so much for taking the time to speak with me. Good-bye.

No: Thank you for your time. Take care. Goodbye.

Follow-Up Interview Telephone Script

Hello Mr or Mrs. Z,

This is Edith Gunter from Vanderbilt. I am contacting to you today to discuss the results of your interviews. Is this a good time to speak with you? Yes. This discussion should take about 30-45 minutes. This discussion will vary depending on what the results of each interview reveal so it is difficult to give a very specific script. Is there any additional information that you would like me to know that you feel was not revealed in the interviews? Thanks so much for your time and participation in this study.

Appendix F-1

Subject Informed Consent Document

The Lived Experiences of Children who have Survived the Loss of a Sibling to Cancer

IRB assigned number: 13.0404

Investigator(s) name & address: Dr. Barbara Head, MDR Building, Suite 110, Louisville, KY 40202 & Edith Gunter, 8615 Mallard Reserve Dr., #201, Tampa, FL 33614

Phone number for subjects to call for questions: 502-852-3014 or 615-390-2297

Site(s) where study is to be conducted: Alive Hospice & Monroe Carell Jr. Children's Hospital

This informed consent document applies to parents of typically developing children.

Name of participant: _____ **Age:** _____

Introduction and Background Information

The following information is provided to inform you about this research study and you and your child's participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and the information given below. You will be given a chance to ask questions, and your questions will be answered. Also, you will be given a copy of this consent form.

You are invited to participate in a research study. The study is being conducted by Dr. Barbara Head, Ph.D and Edith Gunter, LCSW and current doctoral candidate. The study is sponsored by the University of Louisville, Kent School of Social Work. The study will take place at Alive Hospice, Suncoast Hospice, and Monroe Carell Jr. Children's Hospital at Vanderbilt. Approximately 10 subjects will be invited to participate.

You do not have to be in this study. You can stop being in this study at any time. If we learn something new that may affect the risks or benefits of this study, you will be told so that you can decide whether or not you still want to be in this study. You may choose not to participate.

1. Purpose of the study

The purpose of this study is to learn about your child's experiences of losing a sibling. It is also to learn more about your experience of parenting a child who has lost a sibling.

F-1 Continued Subject Informed Consent

You and your child are being asked to participate in a research study. This is because your child has lost a brother or sister and is between 7-12 years old.

2. Procedures to be followed and length of the study

The researcher will meet with your family for an entrance interview. At this time, the researcher will go over the study, ask you questions about you and your child and train your family how to use the camera. This will take about 45-60 minutes. In this study, you and your child will be asked to take pictures of objects, things, or people that represent your child's grief experience. You and your child will have three weeks to take the pictures. During the three weeks, you and your child can take as many pictures as you like, however for the interviews you will be asked to choose 10 pictures to discuss. Once everyone has finished taking all of their pictures you will be interviewed. The interviews for the parents will be completed separately, which will last about 1-2 hours each. Your child can be interviewed with you in the room if you prefer or alone if you and your child prefer. The child interview will also take about 1 hour to complete.

You and your child will be interviewed by Edith Gunter, Licensed Clinical Social Worker (LCSW). You will be asked to take your pictures first in case you need to help your child take his/her pictures. At any time, if you and your child feel uncomfortable with a question then you may decline to answer that question. In addition to the above, you will also be asked to participate in a telephone call that will last 30-45 minutes.

The study duration will be approximately four to eight weeks assuming one visit per week depending on the number of family member who choose to participate. (If both parents and child participate, the expected duration is approximately eight weeks). This requires you to review what you have said during your interviews. All meetings with participants will be audio-recorded. This will include interviews, phone conversations, and an initial meeting to go over consent forms, surveys, and the details of the study.

The researcher will give you and your child as many breaks as you or your child may need during the interviews.

3. Description of the discomforts, inconveniences, and/or risks that can be reasonably expected as a result of participation in this study

There are minimal risks associated with you and your child's participation in the study. The risk is emotional discomfort as a result of answering questions about your child's grief experience.

There may be unexpected risks that the researcher cannot anticipate. An inconvenience is the amount of time that is required of participants to participate in the study.

F-1 Continued Subject Informed Consent

4. Good effects that might result from this study

The information collected as part of this study may not benefit you or your child directly. Such data may be helpful to provide additional resources, education, and make recommendations for how care should be provided to siblings in the future.

5. Compensation for participation

Your child will receive a \$15 target gift card for participating in the study as thank you for participating in the study. You and your child will receive individual photobooks/DVDs with your pictures and your interviews.

6. Circumstances under which the Researcher may withdraw you from study participation

As long as you continue to agree to participate in the study you and your child will continue to be included in the study. However, if your child displays certain behaviors the researcher will discuss with you the possibility of withdrawing the child from the study. These behaviors include: excessive crying, refusing to participate or discuss their photos, hiding behind the parent, or becoming angry.

7. What happens if you choose to withdraw from study participation

If you and your child decide to be in this study, you and your child may stop taking part at any time. If you and your child stop taking part at any time, you and your child will not lose any benefits for which you and your child may qualify. Participants can withdraw from the study by contacting the researcher at 615-390-2297 or may inform the researcher during a home visit. The researcher will be happy to discuss the process of withdrawing with the participant.

8. Consent to Publish Pictures

_____ You and your child want to participate in the research study.
Signature

However, you do not want your pictures to be published even if there is no identifiable information that can be linked to the pictures and your privacy can be maintained.

_____ You and your child consent to allow Edith Gunter to publish pictures
Signature

F-1 Continued Subject Informed Consent

from the study for use at conferences, journal publications, and books. In no way will any identifiable information be linked to the pictures, and your privacy will be maintained.

9. Contact Information

If you have any questions about this research study or possible injury, feel free to contact **Edith Gunter, LCSW** at **615-390-2297** or Faculty Mentor, **Dr. Barbara Head** at **(502) 852-3014**.

For further information about giving consent or your rights as a participant in this study, to discuss concerns and questions, or to offer input, please feel free to contact Louisville Institution Review Board at (502) 852-5188.

10. Confidentiality and Privacy

All efforts, within reason, will be made to keep your personal information in your research records confidential but total confidentiality and privacy cannot be guaranteed. Your privacy will be protected to the extent permitted by law.

The interview records and photographs, and flash drives of this study will be kept private. They will be stored in the Office of the Researcher in a locked file cabinet. Only those involved with this study will have access to collected data. They include: Edith Gunter, LCSW, University of Louisville; the Institutional Review Board; the Human Subjects Protection Program Office, Office for Human Research Protections, and other regulatory agencies. This data will be held in confidence to the extent permitted by law. Interview records and pictures will be kept securely for (6) years after this study ends. At which time, all records related with this study will be destroyed.

If the results from this study are published, you and your child's name will not be made public. As part of the study, you and your child's information may be shared with the following: University of Louisville Institutional Review Board, Federal Government Office for Human Research Protections. This information will be shared if you, your child, or someone else is in danger or if we are required to do so by law.

11. Voluntary Participation

Taking part in this study is voluntary. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify.

F-1 Continued Subject Informed Consent

12. Research Subject's Rights, Questions, Concerns, and Complaints

If you have any concerns or complaints about the study or the study staff, you have three options.

You may contact the principal investigator at (502) 852-3014 or co-investigator at (615) 390-2297.

If you have any questions about your rights as a study subject, questions, concerns or complaints, you may call the Human Subjects Protection Program Office (HSPPO) (502) 852-5188. You may discuss any questions about your rights as a subject, in secret, with a member of the Institutional Review Board (IRB) or the HSPPO staff. The IRB is an independent committee composed of members of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. The IRB has reviewed this study.

If you want to speak to a person outside the University, you may call 1-877-852-1167. You will be given the chance to talk about any questions, concerns or complaints in secret. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

Continued F-1 Subject Informed Consent

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS STUDY

This paper tells you what will happen during the study if you choose to take part. I have read this informed consent document and the material contained in it have been explained to me. My signature means that this study has been discussed with me and my child. It also means that my questions have been answered. Finally, my child and I freely and voluntarily choose to take part in the study. My child and I are not giving up any legal rights by signing this informed consent document. My child and I will be given a signed copy of this paper to keep for your records.

Signature of Subject/Legal Representative Date Signed

Signature of Person Explaining the Consent Form Date Signed
(if other than the Investigator)

Signature of Investigator Date Signed

LIST OF INVESTIGATORS PHONE NUMBERS

Dr. Barbara Head (502) 852-3014

Edith Gunter, LCSW (615) 390-2297

UofL Institutional Review Boards IRB NUMBER: 13.0404 IRB APPROVAL

DATE: 10/16/2013 IRB EXPIRATION DATE: 10/15/2014 UofL Institutional

Review Boards

Appendix G-1

SUBJECT ASSENT

The Lived Experiences of Children who have Survived the Loss of a Sibling. This assent document applies to children ages 7-12.

Name of participant _____ Age _____

Below are the answers to some of the questions you may have. If you have any questions about what is written below or have any other questions about this research, please ask them. You will be given a copy of this consent form.

1. Why are you doing this research?

I am invited because I have lost a brother or sister.

2. What will I do and how long will it take?

I will be asked to take pictures of my experiences of losing a brother or sister. I will be asked to discuss what those pictures are and what those pictures mean. I will have three weeks to take my pictures. I can take as many pictures as I would like, but I will have to choose 10 pictures to talk about. The researcher will audio record what I say about my pictures.

3. Do I have to be in this research study and can I stop if I want to?

If I want to stop, I just need to tell the researcher or my parents and we will stop.

4. Will anyone know that I am in this research study?

My family, the researcher, and the professor will know that I'm in the study. If anyone else is given information about me, they will not know my name. A number or initials will be used instead of my name.

5. How will this research help me or other people?

There are no direct benefits to me for participating in the study. There may be some risks with this study. These risks may include feeling upset as a result of answering questions about my experience of losing a brother or sister. This research may help other children in the future who will lose a brother or sister based on what I have to say so that we can better know how to help them.

G-1 Continued Subject Assent

6. Can I do something else instead of this research?

No.

7. Will I receive anything for being in the study?

I will receive a \$15 target gift card as a thank you for participating in the study. I will also receive an individual photobook/dvd that contains my pictures and the things I said about my pictures.

8. Who do I talk to if I have questions?

If I have any questions, I can ask Edith Gunter, Licensed Clinical Social Worker and she will answer my questions.

I have been told about this study and know why it is being done and what I have to do. My parent(s) have agreed to let me take part in the study.

Printed Name of Subject

Signature of Subject

Date Signed

Printed Name of Parent/Guardian

Printed Name of Investigator

Signature of Investigator

Date Signed

For IRB Approval Stamp

UofL Institutional Review Boards IRB NUMBER: 13.0404 IRB APPROVAL
DATE: 10/16/2013 IRB EXPIRATION DATE: 10/15/2014 UofL Institutional
Review Boards

Appendix H-1
Demographic Questionnaire

Age of child: _____ Male or Female

Age of guardian #1: _____ Male or Female or N/A

Age of guardian #2: _____ Male or Female or N/A

Number of people in the home _____

Marital Status of guardian #1: Single Parent Married or N/A

Marital Status of guardian #2: Single Parent Married or N/A

Occupation of guardian #1: _____ or N/A

Occupation of guardian #2: _____ or N/A

Religious Affiliation: _____

Income: (under 19,999), (20,000-39,999), (40,000-59,999), (60,000-79,999), or (above 80,000)

Prior to the death was your child involved in social activities? Yes or No

Since the death has your child been involved in social activities? Yes or No

If so, what activities are is he or she involved currently involved in? _____

Appendix I-1

Minimally-Structured Interview Questions

Taken from Photovoice research, the interview questions were:

1. What is the picture?
2. What is the story or experience behind the picture?
3. What does this picture mean to you?
4. What have you learned by participating in the study?
5. Are there things you have learned that you think would be helpful for other children to help them as they as they grieve?

Appendix J-1

Photograph Reflection Sheet

Participant Code Number:	Photo Number:
Child or Parent	Date:

What is the picture?

Brief Description of the photo:

Why did you choose this photo?

J-1 Continued Photograph Reflection Sheet

What does the picture mean to you?

What is the story or the experience behind the picture?

Any other information that you would like the researcher to know about the picture or about your experience of losing a sibling or parenting a bereaved child:

CURRICULUM VITAE

EDITH CRUMB GUNTER
8615 Mallard Reserve Dr. #201
Tampa, FL 33614
(615) 390-2297
edith.crumb@gmail.com

Research Interests	Cancer Trauma Sibling Grief	Pediatrics Hospice & Palliative Care Bereavement
Education	Doctor of Philosophy in Social Work University of Louisville Kent School of Social Work Louisville, KY Specialization: Childhood Sibling Grief and Cancer	December 2014
	Master of Social Work Spalding University Louisville, KY Specialization: Death and Dying Issues	June 2005
	Bachelor of Arts in Social Work Middle Tennessee State University Murfreesboro, TN Specialization: Generalist	December 2003
	Associate of Arts Pellissippi State Technical Community College Knoxville, TN Concentration in Nursing Phi Theta Kappa National Honor Society	May 2001
Grant Support	American Cancer Society (2011-2013) Doctoral Training Grant Recipient in Oncology Social Work \$40,000	
Teaching Experience	Nashville State Community College SWRK 2040 Interviewing Skills Adjunct Professor Spring 2013, Fall 2012	
	Nashville State Community College SWRK 2030 Introduction to Social Welfare Policy Adjunct Professor Fall 2012, Spring 2012	

Nashville State Community College
SWRK 1020 Human Behavior and The Social Environment
Adjunct Professor
Spring 2012

Kent School of Social Work
BSW Teaching Assistant (Spring 2011)
Human Behavior and The Social Environment II
Lecturer for Infancy and Childhood Development Section
(1/18/11 - 2/10/11)

Kent School of Social Work
BSW Program (Lecturer)
SW 322 Issues in Social Policy and Service Delivery
(Spring 2010)

Kent School of Social Work
BSW Program Teaching Assistant (2009-2010)
Generalist Practice I &II (Fall 2009 and Spring 2010)
Guest Lecturer on Building Communication (February 2010)
Issues in Social Policy and Service Delivery (Fall 2009)

Kent School of Social Work
BSW and MSW Program
SW 397 & 697 Social Work and Trauma
Guest Lecturer on Childhood Traumatic Grief on June 17,
2010

**Research
Experience**

Kent School of Social Work for Dr. Karla Washington
Graduate Research Assistant Fall 2010-Summer 2012
National Institutes of Health, NINR; R21NR010744: *A
Technology Enhanced Nursing Intervention for Hospice
Caregivers*, Principal Investigator: George Demiris, PhD,
University of Washington School of Nursing. Completed:
Conducted qualitative data analysis of intervention sessions
with bereaved hospice caregivers & Conducted a qualitative
analysis the VALUE communication principles in ACTIVE
hospice team meetings.

Kentuckiana Regional Planning and Development Agency
Evaluated Emergency Homecare Program
Completed Summer 2010
Research Practicum
Evaluated Gilda's Club Cancer and Bereavement Groups
Completed Summer 2010

Data Collector

First Steps Program, which is grant that is funded by the Eunice Kennedy Shriver National Institute of Child Health & Human Development (R01; Budget Period: 12/01/2008-11/30/2013). Dr. Ed Feil and Dr. Hill Walker are co-PIs (Oregon Research Institute) on the project and Dr. Andy Frey (University of Louisville) is the site PI (co-investigator) for this multi-site study. The award to the Oregon Research Institute was for \$3,013,692 and the UL subcontract is for \$947,666. This is an efficacy study of the First Step to Success intervention for use in early childhood settings. Data is collected at baseline, post, and follow-up. Completed Spring 2011

Professional Experience

Clinical Social Worker for Bone Marrow Transplant/Hematology Program

Part-time

All Children's Hospital

Provides emotional support to patient and families, conducting psychosocial assessments, assist with locating resources.

Pediatric Palliative Care Licensed Counselor, 2013-2014

Part-time

St. Joseph's Hospital

Provides emotional support to patients and families, assist families with complex medical-decision making, and assist families with understanding the medical information that they are given and facilitate communication between the family and the medical team.

Grief Counselor, 2011-2013

PRN

Alive Hospice

Perform initial assessments for grieving clients/crisis counseling as needed.

Emergency/Trauma Social Worker, 2007-2013

Part-Time

Vanderbilt Children's Hospital, Nashville, TN

Provide emotional support to patients and families, identifies resources for families, conducted psychosocial assessments, & serves as a liaison between the staff and families during a trauma.

Grief Intake Counselor, 2005-2009

Full-Time

Alive Hospice – Nashville, TN

Perform initial telephone assessments for grieving clients/crisis counseling as needed. Provide individual and group therapy to grieving clients.

Foster Care Counselor, 2003-2005

Residential Services Inc., Nashville, TN

Full-time

Provide therapeutic/intensive services for special needs children that are in state custody. Facilitated, assessed, and established individual treatment plans and social assessments for each client.

Professional Publications

Washington, K. T., Wittenberg-Lyles, E., Parker Oliver, D., Demir, G., Shaunfield, S., & Crumb, E. (2012). Application of the VALUE communication principles in ACTIVE hospice team meetings. *Journal of Palliative Medicine*.

Washington, K., Demir, G., Oliver, D., Wittenberg-Lyles, E., & Crumb, E. (2011). Qualitative evaluation of a problem solving intervention for informal hospice caregivers. Accepted to *Journal of Palliative Medicine*.

Crumb, E. & Taylor, A. (2010). Children, unintentional injuries, and homicide. In C. Corr & D. Balk (eds.), *Children's Encounters with Death, Bereavement, and Coping*.

National Presentations and Symposia

Presentation at Society on Social Work Research (2012) - Making a Difference for Family Caregivers of Hospice Patients: Qualitative Evaluation of a Problem Solving Intervention

Presentation at National Alliance for Grieving Children's Annual Conference (2011) – Photovoice: A Boy's Traumatic Journey of Losing a Sibling

Presentation at Association of Death Education and Counseling Annual Conference (2011) – Photovoice: A Boy's Traumatic Journey of Losing a Sibling

Presentation at Association of Oncology Social Work's Annual Conference (2011) - Evaluation of a Community-Based Program that Offers Cancer and Bereavement Support Groups

Presentation at the National Children's Symposium (2008) - Promoting Resilience in Children Experiencing Traumatic Grief

Presentation at the Association on Death Education and Counseling's Annual Conference (2008) - Promoting Resilience in Children Experiencing Traumatic Grief

Presentation at International Society for Traumatic Stress Studies (2007) - Promoting Resilience in Traumatized Children

Presentation at the Association on Death Education and Counseling's Annual Conference (2007) - Education on Death and Dying Issues Among Health Professional Students

Presentation at the Council on Social Work Education's Annual Conference (2006) - Education on Death and Dying Issues Among Health Professional Students

**Professional
Certifications**

Licensed Clinical Social Worker (LCSW)

Awarded in 2013
Florida License #11408
Expires: March 31, 2015

Certification in Gerontology

Middle Tennessee State University
Awarded in 2005

**Volunteer
Experience**

Alive Hospice- Camp Evergreen & Camp Forget-Me-Not (Bereavement Camps for Children)
Teen Retreat (Bereavement Weekend Camp for Teens)
American Cancer Society- Camp Horizon (Sibling Camp for Children with Cancer)

References

Professional References Available Upon Request