A Retrospective Examination of Sibling Bereavement Counseling for Children Ages 6-18

A thesis presented to

the faculty of

the College of Health Sciences and Professions of Ohio University

In partial fulfillment

of the requirements for the degree

Master of Science

Erin E. Naumann

August 2015

© 2015 Erin E. Naumann. All Rights Reserved.
This thesis titled
A Retrospective Examination of Sibling Bereavement Counseling for Children Ages 6-18

by

ERIN E. NAUMANN

has been approved for

the Department of Social and Public Health

and the College of Health Sciences and Professions by

Jennifer M. Chabot

Associate Professor of Social and Public Health

Randy Leite

Dean, College of Health Sciences and Professions
Abstract

NAUMANN, ERIN E., M.S., August 2015, Child and Family Studies

A Retrospective Examination of Sibling Bereavement Counseling for Children Ages 6-18

Director of Thesis: Jennifer M. Chabot

Research on sibling bereavement and the impact bereavement support has on childhood adjustment has grown in size and recognition but limited research has utilized first-hand accounts to determine the effectiveness of bereavement support. This research project conducted a semistructured interview with a past participant of bereavement counseling to evaluate the participant’s perception of the effectiveness of counseling and to determine ways in which certified child life specialists can improve ongoing bereavement support in the hospital setting. Common themes and considerations for effective ongoing bereavement support are discussed and a bereavement support camp aimed at children who lost a sibling due to sudden death is proposed.
I would like to dedicate this work to my loving family, supportive friends, and encouraging professors, without whom this would not be possible. To those who came forward to share their story with bereavement counseling, it was a privilege.
Acknowledgments

I would like to thank my thesis committee, Dr. Jennifer M. Chabot, Dr. Julie Brown, and Dr. Rika Tanda, for their continued support, advice, and dedication to this research project. I would also like to thank Dr. Joan Jurich and Dr. Gregory Janson for their willingness to help in any way possible. Finally, I would like to thank Bethany Karl whose friendship and encouragement helped me to complete this research.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>3</td>
</tr>
<tr>
<td>Dedication</td>
<td>4</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>5</td>
</tr>
<tr>
<td>List of Figures</td>
<td>10</td>
</tr>
<tr>
<td>Chapter 1: Introduction</td>
<td>11</td>
</tr>
<tr>
<td>Background Information</td>
<td>11</td>
</tr>
<tr>
<td>What are Certified Child Life Specialists (CCLS)</td>
<td>13</td>
</tr>
<tr>
<td>Implications for the Field of Child Life</td>
<td>16</td>
</tr>
<tr>
<td>What is Patient and Family Centered Care</td>
<td>18</td>
</tr>
<tr>
<td>Definition of Bereavement</td>
<td>19</td>
</tr>
<tr>
<td>Definition of Bereavement Counseling</td>
<td>21</td>
</tr>
<tr>
<td>Rationale for Present Study</td>
<td>22</td>
</tr>
<tr>
<td>Chapter 2: Review of Literature</td>
<td>26</td>
</tr>
<tr>
<td>Uniqueness of Sibling Relationships</td>
<td>26</td>
</tr>
<tr>
<td>Sibling's Knowledge and Reactions about Death</td>
<td>27</td>
</tr>
<tr>
<td>Impact of Parental Grief on Sibling Bereavement</td>
<td>32</td>
</tr>
<tr>
<td>What Has Helped</td>
<td>34</td>
</tr>
<tr>
<td>Benefits of Group Therapy</td>
<td>36</td>
</tr>
<tr>
<td>Drawbacks of Group Therapy</td>
<td>38</td>
</tr>
<tr>
<td>Benefits of Individual Therapy</td>
<td>39</td>
</tr>
</tbody>
</table>
Drawbacks of Individual Therapy

Theoretical Lens

Family systems theory

Dual process model of coping

Chapter 3: Methodology

Research Design

Participants and Participant Recruitment

Inclusion criteria

Participant recruitment

Informed Consent Process

Procedure and Approach to Analysis

Interview procedure

Approach to analysis

Chapter 4: Findings

Introduction to Findings

Participant Interview Results

Participant perceptions of individual bereavement counseling

Theme One: The Need for Continuing Bonds

Theme Two: The Need to be Involved in the Dying Process

Theme Three: The Need to Reprocess the Death

Theme Four: The Importance of Empowering the Family System

Chapter 5: Discussion
Introduction to Discussion

Considerations for Effective Bereavement Support

The importance of timing

Being an available outlet as children reprocess death

Recognizing when younger siblings become "older" than older sibling

Suggestions for Implementing Ongoing Bereavement Support

Multidisciplinary collaboration

The importance of self-care and maintaining professional boundaries

Proposal for Implementing Bereavement Support Camp: Sibs Fest

Day one: Welcome

Day two: Cabin group day

Day three: Nature day

Day four: Choice day

Day five: Choice day and big sibs/little sibs formation

Day six: Family day

Conclusion

References

Appendix A: Recruitment Tools

Appendix B: Informed Consent

Appendix C: Online Informed Consent

Appendix D: Interview Guide

Appendix E: Debriefing Form
Appendix F: Clay Activity ................................................................. 100
Appendix G: Future Fears Activity .................................................... 101
Appendix H: Letter to the Deceased Activity .................................... 102
Appendix I: Memorial Quilt Activity .................................................. 104
List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Factors that may influence sibling grief and potential coping</td>
<td>29</td>
</tr>
<tr>
<td>Figure 2</td>
<td>A model of surviving sibling’s potential adjustment based on familial and environmental factors</td>
<td>42</td>
</tr>
<tr>
<td>Figure 3</td>
<td>A representation of the dual process model of coping</td>
<td>45</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction

Background Information

It is estimated that approximately 45,000 children under the age of 24 died last year in the United States (Xu, Kochanek, Murphy, & Tejada-Vera, 2010), with many more family members left behind to cope with the loss. The death of a child represents an enormous loss for parents, many times causing marital disruptions, health problems, and psychological distress including depression, feelings of emptiness, anger, guilt, and despair (Fletcher, Mailick, Song, & Wolfe, 2012; Schwab, 1997). In addition, with such a large child mortality rate, each year numerous siblings are affected and influenced by the death of a brother or sister. In fact, a recent study conducted by Fletcher et al. (2012) found in their study that the prevalence of experiencing the death of a sibling before age 25 was approximately 8%. For surviving siblings, “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). With such a disruption in the family system and with the presence of a stressful life event, children may be at a higher risk for a complex and lengthy grief process. The potential for childhood complicated grief adds to the difficulty of how certified child life specialists (CCLS) understand and respond to sibling bereavement, which is an important component of child life services and the role child life specialists fulfill as members of the healthcare team. The full definition of child life will be discussed later in this chapter.

As a result of having less advanced cognitive development compared to adults, children may not understand or experience death the same as an adult would.
Distinguishing and understanding childhood grief reactions compared to an adult’s understanding of death will help clinicians, including child life specialists, identify unique aspects of childhood bereavement (Paris, Carter, Day, & Armsworth, 2009). Since children understand death differently, they may not benefit from the same type of supports adults would. As Paris et al. (2009) explains, social rituals such as funerals bring grieving individuals together to mark the final separation from a loved one, but these social rituals may not be relevant to a child who has a naïve concept of death. The first response dictated by societal traditions often aim to increase closeness after the death; however, many times the bereaved require emotional distance and may be least likely to benefit from emotional closeness immediately following the death (McBride & Simms, 2001).

Children experience many of the same negative emotions as adults, but childhood grief reactions differ in expression and duration and should not be conceptualized from an adult perspective (Paris et al., 2009; Schwab, 1997). An inadequate understanding of childhood grief and bereavement, and the tendency for adults to impose adult views of death on children can result in confusion. Counselors, clinicians, and child life professionals should look at and understand childhood bereavement in terms of a child’s cognitive, emotional, and social development (Paris et al., 2009). This study aimed to use a retrospective, first-hand account of individuals’ experiences with bereavement counseling for children who were at the time between the ages of 6-18 in order to better prepare and equip clinicians and child life professionals to help assist children through the bereavement process. This study also intended to address the possible advantages and
disadvantages of bereavement support conducted in an individual setting as well as a peer-group setting. Using first-hand accounts may expand upon previous research (Vlasto, 2010) and may provide a more in-depth look at how bereavement support may be adapted to the hospital setting.

**Who Are Certified Child Life Specialists (CCLS)**

The Child Life Council, established in 1986, is the credentialing program and governing body of the child life profession (Turner & Fralic, 2009). As stated by the Child Life Council, child life specialists are trained professionals who assist children and families in overcoming challenging events associated with hospitalization. CCLS promote effective coping through play, preparation, education, and self-expressive activities. CCLS encourage optimal development and well-being for infants, children, adolescents, and young adults by promoting coping skills while minimizing the adverse effects of hospitalization and other potentially stressful experiences (American Academy of Pediatrics, 2014).

The current credentials of a CCLS are a minimum of a bachelor’s degree in child life, child development, or a closely related field in addition to courses that include required child life content. Students must then complete a 100-150 hour child life practicum, followed by a 480-600 hour child life internship under the direct supervision of an experienced and practicing CCLS. The field experiences required by child life students provides an opportunity for observation, interaction, and an application of academic theory in order to attain entry-level skills and competencies set forth by the Child Life Council (Turner & Fralic, 2009). Following the completion of the appropriate
courses and internship, students must pass a standardized certification exam. Advance degrees in child life are also available. By the year 2022, a master’s degree in child life or a master’s degree with a concentration in child life will be required for an individual to qualify for the certification exam. By the year 2025, a master’s degree in child life from an academic institution accredited by the Child Life Council will be required before sitting for the certification exam (American Academy of Pediatrics, 2014; Child Life Council, 2014). Through preparation grounded in acquiring an accumulation of theory, knowledge, and skills, child life specialists are able to address, assess, and meet the unique needs of children and families within the health care setting (Turner & Fralic, 2009).

Child life specialists are members of the interdisciplinary, psychosocial team and are responsible for developing a comprehensive care plan that is based on the patient’s and family’s psychosocial needs, cultural heritage, and responses to the health care experience. The goal of child life services is to provide care that is designed to decrease stress, promote normalization, improve preparation, and encourage children’s optimal growth and development (Turner & Fralic, 2009). Siblings of pediatric patients also reveal their own unique anxieties, stressors, and psychosocial needs that sometimes go unnoticed or unaddressed. CCLS can help provide support, education, and offer therapeutic play and educational interventions for siblings during hospital visits. Similarly, CCLS are often involved in end-of-life issues by providing grief support, emotional aid, and legacy activities for siblings and family members (American Academy of Pediatrics, 2014; Parvin & Dickinson, 2009).
Child life specialists help families understand and cope with the many stressors associated with hospitalization, and sometimes the role of child life specialists is to help families navigate the death of a child. Towne (2001) provides an accurate quote for the role that a child life specialist plays upon the death of a child stating,

Many (parents) seek someone who has been a trusted, constant influence in their child’s healthcare experience, someone who has helped them in previous difficult situations related to their child’s care. They look for someone who has knowledge of children and of their child as a unique individual. Often, child life specialists satisfy these needs. (p. 1)

Despite the fact that child life specialists are often times called upon to assist families through this difficult time, there is currently no nationally recognized competency that requires child life students or practicing CCLS to deal with end-of-life issues. Nevertheless, a small number of children’s hospitals are starting to require employees to become competent in end-of-life practices. Some child life programs are following the guidelines set forth by the Children’s Hospital of Philadelphia at the 2010 national child life conference (Polise & McDonough, 2012).

Previous research has highlighted the importance of having CCLS be prepared for and knowledgeable about dying, death, bereavement, and states how formal death education should be an essential part of a child life specialist’s educational and clinical training (Parvin & Dickinson, 2009). When called upon to help assist families through the death process child life professionals need to be prepared for siblings to ask a variety of questions. It is important that CCLS be given ideas on how to respond to sibling’s
inquiries about the death experience and death process. Unfortunately, death is a part of life that all people must experience, but for children it can be especially difficult to endure and understand. Having available outlets for surviving siblings to discuss and share their thoughts, fears, and experiences is essential and child life specialists can be one of the most constructive advocates for surviving siblings, but they must be prepared for such occurrences. Having a practical and working knowledge base about all aspects of death, dying, and bereavement and having a basic understanding of bereavement support is essential for all child life specialists (Parvin & Dickinson, 2009).

**Implications for the Field of Child Life**

Child life specialists play a vital role in assisting family members through the grief process and if a pediatric patient is not expected to survive, interventions with siblings become a priority for child life specialists. While parents may understand the implications of the declining medical condition and health of their child, healthy children often believe that their sibling’s health will improve and are therefore less able to engage in anticipatory grief work, thus potentially complicating the bereavement process (Pearson, 2009). Child life specialists are often in a position to provide immediate support and provide appropriate tools and information to help bereaved families. Brown (2009) states how child life specialists are integral members of the psychosocial team and must be capable of providing families with quality care in times of crisis, such as the death of child. If practicing child life specialists have a basic understanding of bereavement support, they can help assist families in understanding the complexity of the grief process and provide better services to help families.
In some cases, child life specialists are involved in ongoing bereavement support programs (Brown, 2009). In circumstances where child life specialists are members of ongoing support, this research intended to have an impact on the best practices child life specialists can use to help bereaved siblings. An essential component to supporting bereaved children is communication skills (Brown, 2009). This research aimed to provide a better understanding of communication techniques child life specialists could implement when working with bereaved children by asking past bereavement counseling participants what aided them in the grief process. Similarly, Brown (2009) states how listening skills are equally important when dealing with bereaved siblings and this study was intended to help child life specialists become effective listeners and improve child life specialists’ active listening skills and attending behaviors. Hooghe, Neimeyer, and Rober (2011) explain how when individuals perceive the listener as receptive, supportive, and willing to help, as well as discreet and nonjudgmental, there is an increase in the sharing of one’s grief. If children believe child life specialists display these traits, they will be more likely to open up and communicate about the loss. This increase in sharing of emotions can assist child life specialists in helping siblings move through the grief process. Findings from this research were intended to impact practicing child life specialists by providing them with first hand accounts of past bereavement support participant’s experiences.

Perhaps the biggest implication for the field of child life was that this research hoped to inform and train child life specialist on bereavement support best practices. As a result of the playroom supervision and facilitation responsibilities that child life
specialists have, they possess the ability to assess group as well as individual needs, and running bereavement session calls for similar skills. Brown (2009) urges that specialized training in bereavement support groups for children should be an essential component of all child life education practices. This research provided child life specialists with some information regarding what past bereavement counseling participants felt was helpful and unhelpful in the counseling sessions and what aided in their movement through the grief process. The findings from this study were intended to provide an increase in the knowledge base child life specialists have about bereavement and bereavement support, and may better allow for child life specialists to advocate and collaborate with bereaved families.

**What is Patient and Family Centered Care**

Patient and Family Centered Care is an approach to healthcare that recognizes the vital role that families play in ensuring the health and well-being of pediatric patients. By acknowledging the emotional, social, and developmental support that families provide to patients, a mutually beneficial partnership is formed between the patient, family, and healthcare providers (American Academy of Pediatrics, 2012; Institute for Patient and Family Centered Care, 2010). It is important for CCLS to remember that patients define their family; and families often extend beyond biological relationships. Healthcare professionals should recognize that families are the main support system and source of information for pediatric patients and should engage with the family using open communication and involve the family throughout the treatment plan.
Patient and Family Centered Care involves four core concepts: (a) respect and dignity, (b) information sharing, (c) participation, and (d) collaboration (Institute for Patient and Family Centered Care, 2010). Better health outcomes may result when healthcare professionals recognize and utilize the individual strengths and cultural values of the family unit (American Academy of Pediatrics, 2012). Implementing elements of Patient and Family Centered Care may improve patient and family satisfaction, increase professional satisfaction, decrease healthcare costs, and improve patient health outcomes (American Academy of Pediatrics, 2012; Institute for Patient and Family Centered Care, 2010). Child life professionals should recognize the benefits of Patient and Family Centered Care and apply the core concepts in ongoing bereavement support programs.

**Definition of Bereavement**

In order for professionals and clinicians to be culturally sensitive and culturally competent, a distinction should be made regarding the differences between the concepts of bereavement, grief, and mourning. Bereavement refers to the state of being deprived of something and is an objective situation that is unique to the individual who experienced the loss of a person or thing he/she valued (Balk, 2004; Corr & Corr, 2012). Three necessary elements in bereavement are: (a) a relationship with a person or thing that is valued, (b) the loss of that relationship, and (c) an individual who is deprived of the valued person or thing. While bereavement is most often associated with death, this concept can apply to other situations in which one experiences a loss (Corr & Corr, 2012).
Grief refers to an individual’s reactions to the loss, and includes both internal and external reactions. Emotions and feelings are prominent elements in the expression of grief, but clinicians should recognize that an individual’s reactions to the loss extend beyond feelings (Corr & Corr, 2012; Prieto, 2011). Grief can be expressed in various ways, and is a broader and more complex concept than just an emotional reaction to the loss. Grief can be experienced and manifested in several dimensions of one’s life including physical, affective, cognitive, and behavioral dimensions. Throughout these dimensions, grief can be represented by physical sensations, feelings, thoughts or cognition, behaviors, social difficulties, and spiritual searching. Physical sensations associated with grief can include tightness in the chest or a lump in the throat, and feelings associated with grief often include sadness, anger, and guilt. Thoughts or cognitions such as disbelief or confusion are also representations of grief. Similarly, grief can be represented as behaviors such as sleep or appetite disturbances and loss of previously enjoyed interests. The final dimensions of grief can include social difficulties in maintaining interpersonal relationships, and spiritual searching such as looking for meaning or hostility towards a higher power (Corr & Corr, 2012). If clinicians, including CCLS, react to grief solely as an emotional expression of the loss, they risk misunderstanding and overlooking the full range of reactions that grief often entails, which can hinder their ability to treat an individual in a holistic manner and offer support in every dimension of an individual’s life.

Mourning involves efforts to cope with or manage the experiences surrounding the loss and to incorporate them into ongoing living, and is often conceptualized as a
broader concept than grief (Green, 2013). Many times expressions of mourning are culturally influenced. Mourning is an essential element in helping individuals adapt to their new life without the deceased, and has two corresponding aspects. The first is the internal, private, or intrapersonal process regarding an individual’s inward struggles, while the second is an outward, public, or interpersonal process which involves the shared expression of grief with the hope of obtaining social support (Corr & Corr, 2012). If professionals are sensitive to the various dimensions of one’s life that are impacted by grief and mourning associated with the death of a sibling, they can better meet the needs of the bereaved by facilitating opportunities to grieve and mourn that are both individualized to the sibling as well as culturally significant. Understanding how the concepts of bereavement, grief, and mourning are related to one another, while acknowledging the unique nuances of each concept, can allow professionals to help restore balance and equilibrium in a bereaved individual’s life post-death (Corr & Corr, 2012).

**Definition of Bereavement Counseling**

For purposes of this study, counseling was defined as any type of grief support that is led by an individual who is certified or qualified to assist children and families in understanding grief and death. For example: bereavement camps, such as Camp BEARable, a bereavement camp for children ages 6-15 in Ohio; nationally recognized grief counseling centers such as Ele’s Place, a healing center for grieving children and teens in Michigan; or the Dougy Center, a bereavement support place for children, teens, young adults and their families in Oregon; all qualified as bereavement counseling for
purposes of this study (Dougy Center, n.d.; Ele’s Place, n.d.; State of the Heart Hospice n.d.). Similarly, in-hospital bereavement counseling, such as one run by a child life specialist, also qualified as bereavement counseling for purposes of this study. This study recognized peer-group bereavement counseling as any type of grief support or counseling that took place in a group setting with other children who are also dealing with the death of a loved one. Individual counseling was recognized as bereavement support led by a qualified individual where only the surviving sibling and qualified individual are in attendance.

**Rationale for Present Study**

Despite the staggering number of children who have experienced the loss of a sibling, there is little existing analysis and research that provides a retrospective, first-hand account of siblings’ experiences with bereavement counseling. While research on sibling bereavement is gaining in popularity, many research studies use parental reports to understand siblings’ reactions to loss (Paris, et al., 2009). This study intended to add to the gap in literature by using first-hand, retrospective accounts on how siblings used bereavement counseling, either individual or group counseling, to aid in their movement through the bereavement process. By using first-hand accounts, the research attempted to uncover previously unanswered questions, with more truthful responses. This research aimed to continue to provide CCLS with an understanding of how children ages 6-18 understand and respond to bereavement counseling and support. Increased knowledge of childhood experiences of bereavement, grief, and loss may help distinguish the features of childhood grief reactions and therefore appropriately guide interventions (Paris et al.,...
2009). It was the principal researcher’s hope that through this examination of bereavement counseling, both current and future CCLS may be able to establish a more effective bereavement support program and be better equipped to help surviving children navigate the death of a sibling. This study intended to provide accounts of individuals’ experiences with bereavement counseling in order for certified child life specialists to compare and contrast individual to group bereavement support in order to effectively implement ongoing bereavement support into the hospital setting.

The implications from this research have the potential to have a profound and far-reaching effect on the child life profession. This study aimed to provide an ecologically valid perspective on what children experienced when they participated in bereavement counseling when they were between the ages of 6-18. The findings from this report may broaden the scope of how CCLS conduct and effectively implement bereavement support within a hospital or community based setting. It is possible that the results from this research project may help persuade the Child Life Council, the professional and national association that governs child life specialists, to add a competency that requires child life interns to work with bereaved siblings and pass a bereavement competency before they can apply for certification. Additionally, in child life departments that utilize a ladder system (Level I CCLS for newly hired staff; Level II CCLS for more advanced staff; Level III for senior staff), a bereavement competency can be implemented as part of the promotion process.

Limitations of this study can be attributed to the design limitations of qualitative research. For example, this present research was not intended to be generalized to the
larger population due to the restricted sample size included in this project; readers must keep in mind that the results from this study are limited to the specific population that was researched. A small geographic area also contributes to the limitations of this study. Furthermore, a single data set project design with no follow up limits the participants to answer only the questions that are being asked, again adding a limitation to this study. As a qualitative examination, this research aimed to give an in-depth look at a specific population’s experience with bereavement counseling. Similarly, it is important to keep in mind the impact time has on an individual’s memory and ability to recall the events surrounding the bereavement support received. While past research (Laney & Loftus, 2005; Shobe & Kihlstrom, 1997) has shown that emotionally arousing experiences may be retained better and produce more accurate memories of the central themes surrounding the event, there is disagreement in the current literature regarding the potential for inaccurate memories.

Delimitations of this research project required that participants attended individual or group bereavement counseling, as defined previously in this chapter, due to the death of a sibling. Siblings were defined in this study as biological siblings, adopted siblings, or stepsiblings. Also, participants were required to be between the ages of 6-18 when they attended counseling, in order to focus on the developmental stages of middle childhood and early adolescence. In order to reduce memory editing and false recall, participants were also required to currently be between the ages of 18-30. This age range was selected with the hope that participants would be better able to recall details about their experience with bereavement counseling since a limited amount of time had passed
since the initial experience. Additionally, subjects were required to understand and speak English. Individuals were recruited for this research through flyers, classroom announcements made at universities in the Midwest, and electronic posts made on child life specific media sites as well as other social media sites. Local guidance counselors who work within the city school district, as well as bereavement specialists who work at nationally recognized grief support facilities, were also contacted in hopes that referral sampling would take place. Through data collection and analysis this study aimed to answer the following questions: (a) what did past bereavement counseling participants find helpful and unhelpful in assisting them through the bereavement process; (b) how can child life specialist use this information to implement and improve bereavement support in the hospital setting? By focusing on first-hand accounts, this research aimed to compare and contrast bereavement support conducted in an individual setting to bereavement support conducted in a group setting to help CCLS better assess characteristics of each type of bereavement support that may be adapted within the hospital setting.
Uniqueness of Sibling Relationships

The death of a child impacts the entire family system, including surviving siblings. For surviving siblings, the death of a sibling represents the loss of a role model, confidante, playmate, and friend. Siblings usually develop and share a strong and unique bond with one another because of similar past experiences (Barrera, Alam, D’Agostino, Nicholas, & Schneiderman, 2013; Packman, Horsley, Davies, & Kramer, 2006). Sibling bonds develop quickly because of high access and contact with each other. Siblings use each other as a major influence in regard to the development of a self-identity by using personal exchanges to define one another. Siblings also help each other understand the world around them, so the death of a sibling has a profound effect on the surviving sibling (Packman et al., 2006).

Sibling relationships are a unique and powerful bond. Siblings may share many experiences with each other that they do not share with anyone else because they typically spend most of their day together. These relationships most often last a lifetime and the death of a sibling results in a profound change in the entire family system (Brown, 2009; Foster et al., 2011). The loss of a sibling represents a major shift in the life of the surviving sibling, and because children have less adequate coping skills compared to that of adults, bereavement during childhood has many psychological and physiological consequences (Birenbaum, 2000; Brown, 2009; Tonkins & Lambert, 1996). Bereaved siblings may feel guilty or disloyal in moving on in their life, and may feel like they are leaving the deceased sibling behind. Bereaved siblings may also feel guilt for the
negative things they had said or done prior to the sibling’s death. Similarly, surviving siblings may feel they have unfinished business and have remaining regret if they did not have a chance to say good-bye, apologize, or tell the deceased sibling how much they meant to them (Packman et al., 2006). As a result of the uniqueness of sibling relationships, the death of a sibling may provide the surviving sibling with a complex and lengthy grieving process.

It is important to remember, however, that not all sibling relationships are healthy or positive relationships. While much of the literature (Brown, 2009; Foster et al., 2011; Packman et al., 2006) displays sibling relationships as integral and intimate relationships within the personal lives of the siblings, professionals, including CCLS, should be weary of generalizing all sibling relationships as positive. In fact, research regarding sibling abuse and maltreatment is growing in popularity and prevalence (Kiselica & Morrill-Richards, 2007). It is critical that all professionals be knowledgeable about the unique family system and interpersonal relationships within an individual family unit in order to offer the most effective bereavement support.

**Sibling’s Knowledge and Reactions about Death**

When studying child bereavement it is critical to take into account the developmental age of the sibling and the ability the sibling has to understand death (Barrera, et al., 2013). Death is a concept that is learned over time and children younger than 10 years of age appear to have a limited understanding of the concept of death (Barrera et al., 2013; Brown, 2009; Pearson, 2005). Understanding death includes multiple aspects such as: (a) understanding the irreversibility of death; (b) knowing that
death is irreversible, permanent, and a natural and unavoidable part of life; and (c) that death is usually caused by factors outside one’s control. 

A child’s grieving process may be complex and lengthy because immature cognitive development may interfere with the sibling’s understanding of the irreversibility of death and as the sibling continues to develop and mature cognitively, the feelings of grief and loss are continually reprocessed (Paris et al., 2009). A sibling’s reactions of death can vary drastically based upon many factors including the cause of death, the sibling’s age, gender, coping styles, and extended support networks (Brown, 2009; Pearson, 2005) (see Figure 1).

<table>
<thead>
<tr>
<th>Individual Factors</th>
<th>Death-related Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Type of death</td>
</tr>
<tr>
<td>Developmental stage</td>
<td>Anticipated/sudden</td>
</tr>
<tr>
<td>Cognitive level</td>
<td>“Timeliness” of death/preventability</td>
</tr>
<tr>
<td>Temperamental characteristics</td>
<td>Degree of pain</td>
</tr>
<tr>
<td>Past coping/adjustment</td>
<td>Presence of violence/trauma</td>
</tr>
<tr>
<td>Home</td>
<td>Element of stigma</td>
</tr>
<tr>
<td>School</td>
<td>Contact with the deceased</td>
</tr>
<tr>
<td>Interpersonal/peers</td>
<td>Present at death</td>
</tr>
<tr>
<td>Hobbies/interests</td>
<td>Viewed dead body</td>
</tr>
<tr>
<td>Global assessment of functional DSM-III-R, Axis V</td>
<td>Attended ceremonies</td>
</tr>
<tr>
<td>Medical history</td>
<td>Visited grave/mausoleum</td>
</tr>
<tr>
<td>Past experience with death/loss</td>
<td>Expression of “good-bye”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family/social/religious/cultural Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nuclear family</td>
</tr>
<tr>
<td>Grief reactions</td>
</tr>
<tr>
<td>Extended family</td>
</tr>
<tr>
<td>Grief reactions</td>
</tr>
<tr>
<td>School</td>
</tr>
<tr>
<td>Recognition of bereavement</td>
</tr>
<tr>
<td>Peers</td>
</tr>
<tr>
<td>Response to bereavement</td>
</tr>
<tr>
<td>Religious affiliation</td>
</tr>
<tr>
<td>Membership/participation</td>
</tr>
<tr>
<td>Beliefs about death</td>
</tr>
<tr>
<td>Cultural affiliation</td>
</tr>
<tr>
<td>Typical beliefs about death</td>
</tr>
<tr>
<td>Extent of child inclusion</td>
</tr>
</tbody>
</table>
Child bereavement is known to affect two dominant areas of functioning, psychosocial and physiological (Birenbaum, 2000; Vlasto, 2010). Psychosocial reactions to bereavement include negative emotions, disturbed thought processes, hostile reactions, and changes in normal patterns of living. Bereavement emotions that children often feel include guilt, anger, fear, sadness, hopelessness, rejection and self-doubt, inferiority, isolation, and anxiety, worry, and depression. A few thought processes that children can experience include confusion, distorted understanding of illness and death and the relationship between illness and death, frequent thoughts about death, trouble concentrating, and a decrease in academic performance. Finally, hostile reactions and modification in daily activities that children exhibit include strained familial and social relationships, blaming themselves or family members for the death, withdrawing, trouble sleeping, and changes in eating habits (Birenbaum, 2000). Children’s often times do not verbalize their distress so parents may misinterpret and overlook these negative behaviors. These negative behaviors, actions, and thoughts displayed by grieving children, in turn, give added strain to grieving parents thus creating a cyclical process of distress and unbalance within the family (Schwab, 1997).

Bereavement can also manifest as physiological reactions that include bed-wetting, headaches, abdominal pains, stomachaches, speech and sleep disturbances, and bodily pain. Illnesses such as asthma, ulcerative colitis, and psychosomatic disease have also been linked to bereavement responses (Birenbaum, 2000). Children may be an especially vulnerable population to the bereavement process. Children’s grief reactions differ from adults because of differences in cognitive ability, coping styles, and children’s
need for identification figures and their dependency on adults for support (Birenbaum, 2000; Tonkins & Lambert, 1996).

Previous research (Packman et al., 2006) has demonstrated four general responses to the death of a sibling that coincide with both psychosocial and physiological reactions. The first category focuses on emotional responses that are normally associated with grief. These reactions include sadness, anger, frustration, loneliness, fear, anxiety, irritability, and guilt. Children may express these emotions by withdrawing, seeking attention, misbehaving, complaining of aches and pains, arguing with parents or peers, having nightmares, and experiencing changes in eating habits.

The second response includes a misunderstanding of death. As stated previously, the understanding of death is associated with the developmental age and cognitive abilities of the surviving child (Barrera et al., 2013), and as children grow, their understanding and response to death changes. When children reach new developmental levels they may need to reprocess the events associated with their brother/sisters’ death, and if they are not assisted in their understanding of death and death related events, they may become confused and unable to cope (Packman et al., 2006).

The third category of general responses associated with sibling bereavement is a feeling of inadequacy. Packman et al. (2006) explains how during the bereavement process parents and other family members tend to immortalize or idolize the deceased child and only focus on the positive qualities that child had. This can sometimes leave the surviving sibling feeling like he/she is not enough and if parents are consumed with their own grief, siblings may feel unrecognized in the family.
The final category explained by Packman and colleagues (2006) is a feeling of not belonging. The death of a child disrupts daily activities of family life and any sense of normalcy is temporarily lost. Figuring out the new family system can sometimes make surviving siblings feel like they have “lost their place” in the family. Similarly, bereaved children often feel separated or different from their peers, which may add to the feelings of not belonging.

**Impact of Parental Grief on Sibling Bereavement**

One cannot sufficiently look at the bereavement process of siblings without examining the entire family system. The death of a child creates total disruption in the family equilibrium and puts the family in an almost crisis-like state (Packman et al., 2006). One main problem of sibling bereavement is that just when the surviving sibling is in a vulnerable state and most needs the stability and security of parental support, parents may be unable to provide this. Previous research (Packman et al., 2006) has referred to sibling loss as a “double loss” because children experience the death of their sibling and the loss of parental support. Sometimes parents are so overwhelmed by their own grief, their capacity and ability to look after the needs of the surviving sibling are limited. Parents simply do not have the emotional energy to reach out to the surviving sibling, which may cause children to experience difficulty in the bereavement process (Brown 2009; Packman et al., 2006; Pearson, 2005).

Witnessing parental distress, vulnerability, and explosiveness of emotions may then compound the grief of the surviving sibling, again adding to the cyclical process of disorganization within the family. Children often attribute their parents’ behavior to some
fault of their own and children may become overwhelmed and impatient with their parents’ grief reactions (Packman et al., 2006). In some cases, parental grief is so intense that bereaved siblings can feel the need to protect their parents by not mentioning the deceased child because they believe it will upset the parents even more. When children are not able to openly express their feelings and emotions and talk freely about the deceased child, surviving siblings often feel overlooked and alone in their grief process (Packman et al., 2006; Schwab, 1997). When children see their parents withdrawn or upset, this may produce unsettling emotions or anxiety in the child because children’s well-being and sense of security is reliant on their parents. This time of disorganization within the family may be potentially problematic for children (Schwab, 1997).

Furthermore, parents who become preoccupied with immortalizing the deceased child by placing altars throughout the home, placing numerous pictures of only the deceased child, or daily visits to the grave site, may leave parents without any emotional energy, space, or time to help the surviving sibling. These reactions may in turn affect a sibling’s well-being and ability to cope and cause the surviving sibling to take on grown up roles (Packman et al., 2006). On the other hand, parents who are avoidant and demonstrate no activities that involve the deceased child may limit a sibling’s ability to continue a relationship with the deceased child (Packman et al., 2006), and further affect the surviving sibling’s ability to move through the grief process.

The bereavement process for siblings may further be complicated by the failure of others to acknowledge that they are suffering a tremendous loss as well. Children are often the “forgotten or invisible mourners” (Packman et al., 2006, p. 826) because they
receive explicit or hidden messages to repress their grief. For example, bereaved adolescents are often told to ignore or hide their grief in order to remain “strong for their parents” (Packman et al., 2006, p. 826). Hearing statements such as “the death must have been really difficult for your parents” (Packman et al., 2006, p. 826) also minimize children’s own grief and often leaves them feeling invalidated, ignored, and unacknowledged in their own grief process.

Parental mourning is a lifelong progression that involves movement through fluid stages of grief work. Previous research (Schwab, 1997) has shown the potential emergence of childhood cognitive distortions regarding death due to lack of open communication between parents and surviving children. Many times parents feel the need to protect the surviving child from memories or events surrounding the death. However, when children are not provided with sufficient information about their sibling’s death or there is limited opportunity for the sibling to ask questions and openly express his/her reactions to the death, misunderstanding can occur. Especially with younger children, the surviving child can resort to using his/her imagination, which may result in a distorted view of death (Schwab, 1997). These potential cognitive distortions may create maladaptive behavior after the death and hinder the child’s ability to move through the grief process.

What Has Helped

The bereavement process of children is a complicated and complex task, and while there continues to be inconclusive and contradictory empirical findings regarding the effectiveness of bereavement interventions (Currier, Holland, & Neimeyer, 2007;
Jordan & Neimeyer, 2003; Kato & Mann, 1999), children appear to be a special population and are more likely to benefit from primary intervention (Schut & Stroebe, 2005). When children receive bereavement counseling, they may benefit from a decrease in symptomatology, an increase in communication, and an improved understanding of the concept of death (Tonkins & Lamerbert, 1996; Vlasto, 2010). Bereavement support may be most beneficial for high risk youth or children who are experiencing a complex and lengthy bereavement response (Currier et al., 2007).

A research study conducted by Tonkins and Lambert (1996) studied the effectiveness of bereavement counseling sessions in children 7 to 11 years old. This research examined if grieving children who participated in therapy had a decrease in symptoms associated with bereavement compared to children who did not receive therapy. The results of this study found that the experimental group of children who received treatment had a significant decrease in overall emotions including sadness, anger, withdraw, guilt, anxiety, and loneliness compared to the control group of children who did not receive therapy.

A similar study conducted by Metel and Barnes (2011) looked at the benefits children experience when they participated in a community based bereavement support program. Metel and Barnes (2011) stated that children who utilized the bereavement program had an increase in communication with parents, a decrease in feelings of isolation, and a better understanding of coping strategies. The benefits and drawbacks of both individual and group bereavement support are discussed below. Child life
professionals should recognize the pros and cons of each type of bereavement support and offer the support he/she believes will most benefit the surviving sibling.

**Benefits of Group Therapy**

One of the biggest reasons group therapy has a positive impact, particularly on children, is because children appear to benefit from meeting others who are in a similar situation (Metel & Barnes, 2011). Group therapy creates an atmosphere that facilitates expressions of feelings and thoughts that are often manifested by children who are experiencing grief. By being involved in a group settings children are able to learn that others have similar thoughts and feelings and understand that they are not alone in their grief (Hooghe et al., 2011; Tonkins & Lambert, 1996). Bereavement during childhood is not uncommon (Potts, Farrell, & O’Toole, 1999), and children benefit from meeting peers who share a similar experience. When bereaved children are in a group therapy session they are validated as griever/s and can therefore begin to rebuild their self-esteem, grow in the understanding of self and others, and can process their grief in a positive way (Potts et al., 1999). Group therapy also allows for siblings to get permission, as well as be encouraged, to not feel guilty about moving on with their lives. In these group bereavement sessions, siblings can be motivated to pursue activities and interests that enhance their self-concept and establish new life-goals (Packman et al., 2006).

Hooghe et al. (2011) explains the ongoing tensions that an individual faces with wanting to be open and share emotions with others but the desire to keep certain thoughts and feelings private. Group therapy is able to recognize and accommodate the tension between these two needs: the need for disclosure and the need for secrecy. Child life
specialists working with bereaved children in a group setting can create a space and an opportunity that allow siblings to explore shared grief while at the same time acknowledge the difficulties of sharing and the reasons siblings may choose not to share. Similarly, sharing in the grief experience with others reduces emotional distress and facilitates coping because group settings validate emotions and offer social support. Sharing bereavement stories brings others closer together, creates stronger bonds, and enhances a sense of togetherness and relational intimacy (Hooghe et al., 2011). Overall, children and adolescents appear to respond better to group settings when dealing with the bereavement process (Barrera et al., 2013).

A research study conducted by Vlasto (2010) is perhaps the best example that emphasizes the effectiveness of group bereavement counseling. In his study, Vlasto (2010) interviewed current bereavement therapists about the benefits and drawbacks of both group counseling and individual counseling. The benefits of group counseling include social contact, social skills practice, social support, the challenge of witnessing differences and the opportunity to overcome these differences, a culture of honesty, and the normalizing of grief. Vlasto (2010) explains how sharing feelings and experiences in the group setting, along with witnessing others at various stages of grief, conveys a message of hope. The group setting allows individuals to experience differences in the way individuals grieve, but understand that the processing of grieving was normal. The supportive nature of groups allowed for individuals to be both the supported and the supporting person, which increases trust and interaction among group members. This
dual interaction of giving and receiving support taught group members that while it is acceptable to grieve, they still had something of value to offer others (Vlasto, 2010).

Overall, Vlasto (2010) found that group support help individuals feel less isolated in their bereavement process and have a better understanding of how others grieve. The witnessing of others in a group setting may help individuals generate ideas, skills, and motivation to move on in their grief process and reconnect with the outside world. Perhaps the biggest impact of group bereavement counseling, particularly with children, is the normalizing aspect of being a member of the group. This normalizing effect allows individuals to better understand there are others who share similar experiences. Normalizing grief does not take away the pain, but rather it shows that pain can be endured. This allows individuals to understand that there is nothing wrong with them and that movement through the bereavement process is possible (Vlasto, 2010).

**Drawbacks of Group Therapy**

While there is ample discussion regarding the benefits of participating in group bereavement support, Vlasto (2010) also explains the disadvantages of such an environment. One potential drawback of participating in group session can be the development of group norms and regulations. For example in a group environment certain subjects may become unmentionable, such as expressing relief regarding the death. Similarly, individuals may feel embarrassed if they believe they shared too much information or displayed too much sorrow. A final potential disadvantage mentioned by Vlasto (2010) could be the perception by some individuals that their voice was not being heard within the group, or that competition could emerge regarding whose situation is
worse. Practitioners and CCLS should be aware of the potential risks and benefits of children engaging in group support and continually assess the needs of the group and the needs of the individual child.

**Benefits of Individual Therapy**

While group therapy offers many potential benefits, based upon the child’s temperament, personality, and age, individual bereavement support may be more beneficial. Again Vlasto (2010) offers therapists’ views regarding benefits of individual support, which can include an environment of safety. Individual counseling was viewed by many to be a “gentler” and “safer” method when dealing with grief (Vlasto, 2010, p. 62). Similarly, this form of bereavement support was regarded to offer an opportunity for exploration of deeper material and emotions due to the intimate and personal relationship often times formed between client and practitioner. Individual counseling may limit an individual’s encounter with feelings of embarrassment due to the confidential nature of therapy, and may be most beneficial to vulnerable clients in the beginning stages of grief. Finally, one-on-one bereavement support allows for a more individualized approach to treatment, where the practitioner can assess and identify individual needs and assist the client in reaching specific goals (Vlasto, 2010).

**Drawbacks of Individual Therapy**

There appears to be substantially less potential disadvantages to individual bereavement support as compared to group counseling, with many of the drawbacks mentioning the limited opportunity for social interaction. Similarly, bereavement support conducted in a one-on-one environment may also foster dependence on the practitioner,
especially if the client is experiencing complex grief (Vlasto, 2010). Aims of this research study are attempting to expand upon the previous research conducted by Vlasto (2010) by directing attention to childhood experiences with bereavement counseling, focusing on bereavement within sibling relationships, and by using first-hand, retrospective accounts of individual’s experiences with bereavement support.

**Theoretical Lens**

**Family systems theory.** Possibly one of the best theoretical lenses when examining the death of a child and the impact bereavement counseling sessions has on surviving siblings is family systems theory, sometimes called systems theory. Family systems theory acknowledges an individual’s coping within a larger family context. The foundation of family systems theory was developed from the marked disruption, and eventual rebuilding, of family relationships as a result of World War II (Helm, 2014). What makes this theory unique is the central idea that a family is an interconnected unit/system in which the actions of one family member affect all members in the family system. Systems theory is focused on the organization, structure, and complexity of families and relationships within families (Helm, 2014). Systems theory examines the relationships between individual parts of a system (i.e., a family) and the qualities of the whole system emerge from the relationship of its parts. Similarly, just as the whole family must be understood by examining the relationship among its members, family members can only be understood in context of the whole family (Jurich & Myers-Bowman, 1998).
Brown (2009) explains how grief is ultimately a family process and it is within the context of an individual family that grief can be best understood. The death of a child represents a change in the sibling hierarchy and the interpersonal relationships within a family structure, and grief impacts the surviving family member’s ability to perform their roles within the family (McBride & Simms, 2001; Schwab, 1997).

Families are an interdependent system and a change in one member creates a ripple effect that impacts the entire family. When a child dies, an entire family system is affected and new roles and relationships must be formed. Surviving siblings must learn to define their new roles in the absence of the deceased sibling and reconstruct and readjust their place within the family system (Packman et al., 2006; Potts et al., 1999). In the bereavement process families play a critical role in supporting one another.

One cannot completely and effectively look at the bereavement process of surviving siblings without examining the entire family system (see Figure 2). The death of a child is perhaps one of the most painful and difficult experiences a family can go through, and this disruption in the family system threatens the family’s equilibrium (Packman et al., 2006). Packman and colleagues (2006) explain how after the death of a child, family life is forever changed. Grief is both an individual and family process and this process disrupts the way the family functions, alters the way parents and surviving siblings relate to each other, and modifies expectations family members have for themselves and for the family as a unit (Packman et al., 2006).

Systems theory explains how systems are comprised of smaller units, called subsystems, as well as larger units, called suprasystems (Jurich & Myers-Bowman, 1998). In the family system, subsystems include the sibling-sibling relationship as well as the sibling-parent relationship. After the death of a child, each subsystem is affected. Any sense of normalcy is lost after a child dies, and surviving siblings are left to navigate their new place in the family as well as how to define the new sibling-sibling relationship (Packman et al., 2006).

As mentioned previously, parental grief also influences the bereavement process for the surviving siblings (Packman et al., 2006; Jessee & Gaynard, 2009). The way one member of the family grieves affects the way other members of the family grieve. As
explained by family systems theory, one cannot look at how a particular family member works through the bereavement process without looking at the larger family context. Children’s grief reactions are different from adults and because children rely on adults for support (Birenbaum, 2000) if an adult is incapacitated by the bereavement process this will ultimately have an effect on the way siblings grieve and the entire family system will be disrupted.

When individuals participate in bereavement support, they may be provided with a sense of feedback. Jurich and Myers-Bowman (1998) explain feedback as “a circular process in which input is transformed by the system into output, and the output is brought back into the system as input” (p. 77). The feedback process allows families to regulate and modify their behavior. Through bereavement support sessions, siblings will receive either positive or negative feedback on their grieving process. This interchange among bereaved individuals, family members, and practicing clinicians may help families return to a sense of homeostasis.

Bereavement counseling sessions may also help the family system become more of an open system. An open system is one that allows more exchange between the family and the environment (Jurich & Myers-Bowman, 1998). Families may need outside and additional support in order to work through and resolve the chaos that the death of a child may leave on the family system (Potts et al., 1999). Bereavement counseling may offer a safe environment that permits open communication that encourages a sibling to work through the bereavement process. By participating in bereavement counseling, siblings may also learn new communications skills in order to communicate more effectively at
home and in turn, allow the family system to become more open. Overall, a greater openness and an increase in communication about the loss have a positive impact on family life (Potts et al., 1999). Through family systems theory, this research intended to examine the impact that bereavement counseling sessions have on a sibling’s ability to define new roles and assess whether bereavement support sessions help families maintain a sense of equilibrium. Family systems theory has guided this research by taking into account the impact each interpersonal relationship within the family unit has on the surviving sibling and addresses the unique aspects of sibling bereavement by taking into perspective the impact parental grief has on surviving sibling’s potential adjustment.

**Dual process model of coping.** The dual process model of coping (DPM) also provides a unique perspective when examining bereavement within a pediatric population. The DPM proposed by Stroebe and Schut (1999) addresses bereavement as a dynamic process where an individual fluctuates between stressors associated with the loss. This theory of bereavement explains how individuals put forth an effort to cope with loss-oriented stressors and restoration-oriented stressors, and that coping with bereavement does not occupy all of a bereaved individual’s time. Loss-oriented stressors involve processing aspects of the death experience and can include longing for the deceased and renavigating bonds with the deceased. Restoration-oriented stressors focus on what aspects or tasks of family life need to be addressed following the death, and can include things such as taking over tasks the deceased once dealt with or developing a new identity after the death of a loved one. The dual process theory differs from traditional models of bereavement because it is not a phasal model or a sequence of stages but rather
a fluctuation over time that involves attending to various stressors of bereavement (see Figure 3).

This model of bereavement explains that coping is a complex and regulatory process that involves attending to, or avoiding, in varying degrees, these two types of stressors. Coping is, therefore, an oscillation between confronting and avoiding aspects of the loss in order to achieve an adaptive transition to life after a loss (Stroebe & Schut, 2010). When coping with the loss of a child, each surviving family member must actively work to cope with various stressors associated with the loss. For example, children must navigate how to continue a relationship with a deceased loved one (loss-oriented stressors) and children must learn new roles within the family and possibly take over
tasks their loved one once completed (restoration-oriented stressors). This model also explains that as time goes on stressors can be reprocessed, so as children continue to grow and pass through the next developmental stage, they can put forth effort to reprocess stressors associated with the loss (Stroebe & Schut, 2010). Through the guiding of the dual process model of coping, this research may better allow for CCLS to meet the needs of bereaved siblings by facilitating coping with both loss-oriented and restoration-oriented stressors. When dealing with the complex nature of childhood grief reactions, it is vital to take into account the child’s support system and network and address individual manifestations of grief that may be unique to a family unit. Cultural variations of the bereavement and mourning processes should also be considered when adapting bereavement support to the hospital setting in order to maintain a culturally sensitive atmosphere where the family systems and various stressors associated with the loss can be considered.
Chapter 3: Methodology

Research Design

This research project was an IRB-approved qualitative study that used a semistructured interview guide to provide a retrospective examination of individual experiences with bereavement counseling. This report relied on narrative research and a case-study format to address the following objectives:

1. Discover what past bereavement counseling participants found helpful and unhelpful in assisting them through the bereavement process,
2. Adapt this information to help child life specialists implement and improve bereavement counseling in the hospital setting, and
3. Expand upon a previous study conducted by Vlasto (2010) by using first-hand accounts of past bereavement counseling participants’ perceptions about the benefits and drawbacks of various bereavement counseling.

Individual interviews were conducted based upon a semistructured interview guide, recorded using a digital voice recorder, and then transcribed verbatim to assess for themes. The transcribed interviews were then analyzed by the principal researcher for common and emerging themes. To add validity, the faculty research advisor also reviewed the transcripts and aided in the identification of prominent themes. Any similar themes found by both the principal researcher and the faculty advisor were deemed as prominent and then expanded upon within the analysis. Thematic coding was used to analyze and interpret the interview transcriptions.
Participants and Participant Recruitment

**Inclusion criteria.** The following inclusion criteria were established to form the necessary requirements for participation in this study. To be eligible for inclusion in this study, subjects needed to meet the following criteria; (a) participants needed to presently be between the ages of 18-30, (b) they needed to partake in a minimum of one peer-group or individual bereavement counseling session due to the death of a sibling, either biological, adopted, or step-sibling, (c) participants needed to be between the ages of 6-18 when they attended bereavement counseling, and (d) subjects needed to have the ability to understand and speak English. These inclusion criteria are an integration and adaptation of the original inclusion criteria due to an inability to recruit participants.

The original inclusion criteria for this study were expanded upon following an inability to recruit participants and after all participant recruitment options had been exhausted. The original inclusion criteria stated that participants needed to presently be between the ages of 18-24, that participants needed to be between the ages of 6-12 when they attended bereavement counseling due to the death of a sibling, and in the original criteria only peer-group bereavement counseling qualified for the study. Due to limited time and resources, the original inclusion criteria did not result in any eligible participants, so requirements were expanded.

The desired sample size of this study was between 5-8 participants, but following an exhaustion of all participant recruitment methods, only one eligible and willing participant was recruited for participation in this study. The participant was a 20-year-old
male who classified himself as White/Caucasian. The subject participated in individual counseling following the sudden death of his biological brother.

**Participant recruitment.** Recruitment for this study included multiple outlets, including various flyers posted around a large public university in the Midwest, announcements made by the principal researcher in 12 academic classes, and media posts on various social media sites, including child life specific professional and student forums (see Appendix A). Several other academic institutions were also targeted with the hope of expanding the possible participant pool. Individuals were informed about the study at four other public and private colleges and universities located in the Midwest. At these universities, electronic mail announcements were sent out to students, and at one specific private university, professional colleagues of the principle researcher made announcements in various psychology courses.

Two different bereavement services in the Midwest were contacted in addition to university specific counseling services as a means to induce referral (snowball) sampling. Similarly, guidance counselors working throughout the local school districts were also notified of the study and the inclusion criteria with aims of referring individuals to participate. A local, free standing children’s hospital was also contacted with the aim of recruiting participants who may have had previous experience with hospital specific bereavement support.

It was made known to interested persons that participation in this research study could occur through various outlets including in-person interviews, phone interviews, or interviews via electronic modalities (e.g., Skype). Following the expansion of the original
inclusion criteria, similar actions and steps were taken to recruit participants. In total, approximately four waves of recruitment were completed throughout various times during academic semesters, with the principle researcher repeating the participant recruitment methods mentioned above. Confidentiality and sensitivity was honored throughout the recruitment process due to the emotional nature of the research topic.

**Informed Consent Process**

Recruitment efforts resulted in the interviewing of one candidate and upon voluntary agreement to participate in the study, the participant met with the principal researcher to discuss the informed consent process and explain the purpose of the study. The participant was notified that his participation was voluntary and that signing the consent form (see Appendix B) was necessary to continue participation within the study. Although there were no interviews conducted via electronic modalities, a separate informed consent sheet was available if needed (see Appendix C). The participant was provided time to read the informed consent and encouraged to ask questions or request clarification.

The subject was made aware that the interview would be recorded using a digital voice recorder. Similarly, the participant was informed that confidentiality would be upheld by keeping digital recorded interviews and interview transcriptions in a locked cabinet within a locked office and that a pseudonym would be used in the transcriptions and final manuscript. The participant was provided with a copy of the informed consent to take with him and the principal researcher also secured a copy of the signed consent form that was placed within the same locked cabinet as the interview transcriptions. The
participant was also reminded that he could stop the interview at any time without penalty and he was not required to answer every question. Due to the sensitive nature of the research topic, the participant was also informed if he needed a break from the interview, one would be provided.

Procedure and Approach to Analysis

**Interview procedure.** The interview was conducted in a mutually agreed-upon location that provided an environment where confidentiality would be upheld and distractions would be limited. The participant was informed about the purpose and procedures of this study and reminded that the interview would be digitally recorded. It was also explained to the participant that steps to ensure confidentiality and privacy would be taken. The subject was provided ample time to ask questions and reminded that he could stop the interview at any time without penalty or he could stop the interview for a break due to the sensitive research topic. A semistructured interview guide was used to conduct the individual interview (see Appendix D).

The interview guide began by obtaining basic demographic characteristics of the participant. This information was used to gather a background on the subject in addition to establishing rapport and a working relationship with the interviewee. The interview guide then progressed to more open-ended questions regarding the participant’s family and relationship with the deceased sibling and was followed by specific questions asking the participant about his individual experience with bereavement counseling. As a result of the sensitive nature of this research, throughout the interview procedure steps were taken to monitor and safeguard the emotional safety of the subject.
The investigator created a protocol so that if the participant began to display intense negative emotions, steps could be taken to safeguard the subject’s emotional well-being. The protocol included the following steps: (a) the principal researcher reminded the participant that he/she was not required to answer every question and could choose to not discuss the prompt that was being asked; (b) the participant was offered a break if he/she was visibly upset or if the participant asked for a break; and, (c) the participant could choose to end the interview. The protocol also stated that if the participant was too upset to continue, the principal researcher would offer to stop the interview and the participant was offered the choice to come back at a later date or withdraw his participation in the study. At the close of the interview, regardless of the participant’s outward emotional expression, the participant was given a debriefing form that contained local counseling services information (see Appendix E). This form was provided due to the sensitive nature of the study and was provided to ensure that the participants had additional information regarding various bereavement support services if he believed he needed to seek additional support. At the conclusion of the interview, the participant was encouraged to contact the principal researcher if he wanted to share additional information.

**Approach to analysis.** This research project used a case study format to examine an individual’s experience with bereavement counseling due to the death of a sibling. The information and first-hand account presented by the participant is the first step in an endeavor to improve ongoing bereavement support within the hospital setting. CCLS are often times in a position to provide immediate and developmentally appropriate support
during times of crisis, so having a thorough understanding of effective bereavement support should be a critical component of educational and clinical experiences for child life students (Parvin & Dickinson, 2009).

The interview was recorded using an Olympus recording device and then transcribed verbatim. Following the transcription, the transcribed interview was reviewed and edited to provide an accurate representation of the interview. Identifying information, such as the name of the deceased and the name of the participant, was changed to guarantee the confidentiality and privacy of the interviewee. The transcription was then examined by the principal researcher, followed by the faulty advisor, to call attention to common and emergent themes. The faculty advisor overseeing this research study also examined the transcription to add validity. The themes were then organized and assessed in order for certified child life specialists to be more prepared to adapt these themes into their own in-hospital bereavement support programs. Through data collection and research, four major themes emerged as noteworthy when adapting bereavement support into the hospital setting.
Chapter 4: Findings

Introduction to Findings

Using a qualitative data collection approach and relying on narrative research, the interview conducted for this research project was analyzed and compared to previous research conducted on sibling bereavement (Packman et al, 2006; Potts, Farrell, & O’Toole, 1999; Tonkins & Lambert, 1996; Vlasto, 2010). This research project was intended to help CCLS adapt current ongoing bereavement support techniques into the hospital setting to ensure that bereaved families receive the best possible care before, during, and after the death of a child. A comparison was made to Vlasto’s (2010) study and four additional major themes were identified and expanded upon that were noted to correspond with previous research.

Participant Interview Results

Over an extended period of time, various avenues were taken to achieve the desired sample size for this research project. Following multiple attempts to recruit subjects, and following the exhaustions of all recruitment methods, the principal researcher was able to conduct one interview. The interview was conducted face-to-face in an agreed upon location that allowed for privacy and minimal distractions, and a semistructured interview guide was used. The principal researcher asked follow up and probing questions when need. To protect the participant’s confidentiality, a pseudonym will be used.

The subject, Mark, was a 20-year-old White male who was recruited using referral sampling. Mark participated in one session of individual counseling following the
sudden death of his biological brother. Mark cited many reasons, including the unhelpful nature of the counselor’s questions, for why he decided to not return to counseling (Mark, interview, 11 March 2015).

Mark’s family consisted of him, his biological brother, a half-sister, his mother, and his father. Mark’s parents divorced when he was 3 years old but stated that his parents remained amicable and that he spent time with both his mother and his father following the divorce. When Mark was 7 years old, his 13-year-old brother committed suicide by hanging himself. Mark’s brother committed suicide at their grandmother’s house, and Mark’s aunt was the one who found him.

Following the sudden death of his brother, Mark’s parents decided he should participate in counseling. Mark was 8 when he attended counseling, and saw the same counselor his brother had seen before his death. Mark said, “because he actually, he had a lot of problems. He was bipolar and he was always in trouble and stuff like that, so he went to the counselor. I went to her once and I decided I’m never going to counseling again.” One should be aware that seeing the same counselor as his brother might have been disadvantageous to Mark. The transcribed interview with Mark was then compared to past research and emerging and consistent themes are expanded upon below.

**Participant perceptions of individual bereavement counseling.** One aim of this study was to expand upon previous research (Vlasto, 2010) that focused on therapists’ views of the benefits and drawbacks of both individual and group counseling. Due to limitations in this research project and the limited sample size, only individual counseling will be discussed. Mark cited many reasons for not wanting to continue counseling
following the sudden death of his brother due to suicide, one reason being his
chronological age and developmental level. When asked about his initial experience with
counseling Mark responded,

You know it’s like the same thing as they always do, they ask you how you feel,
how are you dealing and grieving and coping with it. And I think at the time, as I
remember, I didn’t really have those answers, partially because I was so young.

When prompted about the usefulness of the counselor’s questions, Mark stated that the
questions were not useful or helpful, saying, “stuff that doesn’t really change anything, it
almost just brings negative thoughts to the surface versus positive thoughts to the
surface,” and “you can only say ‘I don’t know’ how many times.” Mark’s responses to
the counselor’s questions were developmentally appropriate responses to death
perceptions, because children in the developmental stage of early school age may have
difficulty verbally expressing their emotions and feelings (Barrera et al., 2013; Brown,
2009; Pearson, 2005). Also, Mark’s limited understanding of the concept of death at age
eight may have limited the effectiveness of intervention services.

Another reason Mark decided not to continue participating in bereavement
counseling was due to Mark’s desire to “figure it all my [himself].” During the interview
conducted for this research project Mark said,

I have no regrets on not going to counseling. I think when you figure it out
yourself you not only, you know look at it from your perspective, not an altered
version that they put into your head, but you also learn a lot about yourself. And I
think, with me personally, when you go through counseling, even just the little
things that they add to the end of your sentences changes the way you think a little bit, and I think you learn a little bit less about yourself and the death.

Child life professionals can use this information during ongoing bereavement support to refrain from projecting their own views and ideas regarding the concept of death, and focus more on providing coping strategies and helping the surviving sibling maintain a relationship with the deceased. Child life specialists are at an advantage because they are trained to meet a child where he/she is at developmentally, emotionally, psychologically, and so forth, and not try to change these emotion responses but rather work through them. Allowing the child to take the lead during ongoing bereavement support is a unique lens that child life can bring to this type of bereavement support.

Similar to results found by Vlasto (2010) the interview conducted for this research project also reinforced the perceived benefit of individual counseling being less threatening than group counseling. When asked about his comfort level in individual counseling versus his perceived comfort of group counseling Mark responded by saying, 100% definitely better if it’s just one on one because I have, you know if someone were to ask you something about it, and not necessarily a group, but even more than one person, it’s a lot more kind of like ‘well, I don’t really want to talk right now,’ you know. So, I would agree that having it one on one, you know cause like my parents would drop me off when I went. They just kind of said ‘go head in there and we’ll walk away.’ That’s much better than them sitting in there because then you got to kind of almost answer how they would want you to answer.
While Mark discusses both group and family counseling above, it is important to note that overall, Mark felt more comfortable being in an individual setting during bereavement support interventions. This idea corresponds with Vlasto (2010) stating that individual counseling is a safer and less threatening environment.

One unique finding of this research project that differed from Vlasto’s (2010) study was the idea that individual counseling allowed for deeper material and emotions to be accessed due to the intimate relationship formed between client and counselor. Mark however, discussed how he felt vulnerable meeting the counselor for the first time and being expected to talk about such a personal experience and topic. Mark said,

I mean when you are meeting her, this is just me personally, when you are meeting someone just completely random you don’t want to, I mean it’s just a really vulnerable topic so you don’t want to just, especially when I was younger I didn’t want to just spill my guts or whatever.

Mark also stated how it would be beneficial to spend more time “feel[ing] it out to where they are at, and then once the person is more comfortable with them, then they can start digging deeper.” Child life specialists are at an advantage and can help combat the hesitations that surviving siblings may feel about opening up due to the relationship that is formed with the family before the time of death. In the cases of long-term illness, child life specialists may have been involved in the patient’s care for months or years, and because of this therapeutic relationship that has formed prior to death, child life professionals are in a unique position to provide ongoing bereavement support. In the cases of sudden death, such as Mark’s, many emergency departments have child life
specialists on staff, so despite meeting after the time of death, the surviving sibling has already been introduced to the child life specialists before the initiation of bereavement support. The professional and trusting relationship that is often formed between families and child life professionals may enhance the value of bereavement support.

Additional results from this research project were categorized into four major themes. These themes are identified and expanded upon below. Utilizing elements of Patient and Family Centered Care and implementing suggestions from this research may help clinicians better meet the needs of bereaved children and families.

**Theme One: The Need for Continuing Bonds**

The topic of continuing bonds was prevalent in much of the research regarding bereavement during childhood (Foster et al, 2011; Packman et al, 2006; Potts, Farrell, & O’Toole, 1999), and was noted again during the interview conducted for this research project. Siblings often share a unique and powerful bond, and the cessation of a relationship that is expected to last a lifetime can greatly impact the surviving sibling’s well being (Barrera, Alam, D’Agostino, Nicholas, & Schneiderman, 2013; Packman, Horsley, Davies, & Kramer, 2006). When asked about his relationship with his brother prior to his death, Mark responded that it “was good. Best friend.” Having an understanding of the intimate bond siblings typically share with one another will better allow clinicians to grasp the overwhelming sense of loss a child often feels.

Facilitating opportunities for siblings to continue a relationship with the deceased should be a critical component in bereavement support. As stated by Mark,
You know since then I haven’t sat down and met with people but people will ask you, ‘how’s this feel’ or whatever, and I personally feel like those questions never help. You know [pause] I feel like just reminiscing on memories of them, happy memories of them, helps more than seeing how you’re feeling because your memories of them are much more important. I mean that’s what configures how you feel about it.

Allowing siblings to reminisce and openly express and talk about memories involving the deceased can help surviving siblings successful adjust to life post death (Packman et al, 2006). Again Mark talks about how, “the only times I would bring it up would be like ‘oh remember when this happened’ and it would kind of be a laugh or whatever, not really sitting down and talking about it.” Child life professionals can use this information to appropriately guide activities or sessions during bereavement support and also inform parents to encourage conversations at home revolving around happy memories of the deceased in order for surviving siblings to have a sense of a continuing relationship with his/her sibling.

Parents and other family members play a vital role in ensuring that a continuing bond is maintained between the siblings, especially if the surviving sibling was younger at the time of death. Mark discussed how one of the most influential people in his mourning process was his mother. He states,

I would say most of all my mom really helped, because she would always really, I mean like, every year on his birthday we would do something fun. Like, I’d skip school and we’d go to an amusement park. Stuff like that, just to really like,
almost make it like a happy time to remember him versus everyone is kind of down and stuff. I would say that was probably, as far as remembering him, that was the most helpful thing.

Empowering and advocating for families to find unique and fun ways to reflect upon the deceased should be adapted into hospital programs that offer ongoing bereavement support. Younger children learn through observation of their parents, and this is true for mourning as well (Packman et al, 2006). If child life professionals can inform parents of developmentally appropriate ways to honor important days involving the deceased, such as the deceased’s birthday or the anniversary of the death, parents can model adaptive coping. In addition, this can give the surviving sibling permission to maintain a continuing bond and relationship with the deceased sibling (Packman et al, 2006).

Surviving siblings may feel unfaithful in moving forward with their lives and may feel that they are leaving the deceased sibling behind (Packman et al, 2006). Child life specialists and other professionals involved in bereavement support can use this information to encourage siblings to continue to engage in activities they find enjoyable while still maintaining a relationship with the deceased. Informing parents that siblings may feel apprehensive about moving forward in life should be an important conversation in order for the entire family system to feel supported.

**Theme Two: The Need to be Involved in the Dying Process**

It was previously thought that children’s grief would be intensified or complicated if children were involved in the dying process, but this idea has recently been challenged. Research conducted by Murray-Parkes, Reif, and Couldrick (1996), stated that children
are more supported and coped better through direct involvement and open discussion surrounding death and the dying process. During the dying process, child life specialists play a vital role in emotionally supporting the family system in addition to helping the family explain death to younger siblings (Parvin & Dickinson, 2009). In the cases of sudden death, like Mark’s experience with the death of his brother, child life specialists can offer immediate and developmentally appropriate support. Mark explains the one thing that bothered him most regarding the events surrounding his brother’s death was his inability to be involved and the opportunity he felt he missed to say “good-bye” to his brother. Below is an excerpt from the interview transcription between Mark and the principle researcher.

Mark: When it happened they all went to the hospital but they left me, like they dropped me off somewhere because they didn’t really know what was going on. The next day they didn’t tell me for most of the day and they, I mean everyone in my entire family knew but me, and then they drove me to my grandma’s house after. I’m pretty sure we went to church and then once we got there, you know, it was, I mean my dad and my mom were separated but everyone was there, so I already knew something was up and they told me and I almost laughed at, actually I think I did, because I was just like ‘ha, like no really where is he at?’ and they were like ‘he’s gone.’ And kind of everyone lost it but, yeah, I don’t think that was a good way to do it [slight laugh] in hindsight.
Researcher: Yeah, so you really wished they would have included you more in that process?

Mark: Yeah, I would say. That was, I would say, in everything that happened that was the only thing that, I don’t know if it like bothered me, I mean it kind of did though because everyone got their little goodbye almost when he was in the hospital. I mean he was already dead but like, I feel like you had a little more of a goodbye when [pause] I don’t know, when they are in the hospital versus when they are in a casket.

In the cases of long-term illnesses and an extended dying process, child life specialists are in a position to offer a variety of services including memory making, emotional support, and advocacy for the pediatric patient and his/her family. Child life specialists can ensure that siblings have a presence in the dying process, and use this time to educate and prepare siblings by offering coping strategies and explaining death in a developmentally appropriate way.

In the post-death period, child life specialists can use their expertise in child development to help educate parents about ways to involve siblings in the funeral process. Younger children appear to cope better and feel more involved if they are given a job or task to complete during the funeral. For example, children can be assigned various jobs such as informing funeral guests where the restrooms are or telling guest the location of the coatroom. With older siblings, child life specialists can validate and acknowledge the difficulty of the situation while giving adolescents permission to grieve
in their own way. In ongoing bereavement support, child life specialists need to ensure their availability to bereaved families throughout the funeral time.

Child life professionals should also educate parents regarding the various responses and behaviors siblings may display throughout the grief and mourning process. Mark explains how at his brother’s funeral he was “selling tissues for a nickel.” Informing parents that children often do not benefit from societal traditions such as funerals the same way adults do (McBride & Simms, 2001) may ease parent’s mind and make the transition into adapting to life without the deceased easier. Informing parents of the differences between childhood and adult grief reactions may result in parents being less likely to impose adult views of death on children. With their knowledge of child development and child grief reactions, child life specialists can help promote an emotionally supportive final separation (Towne, 2001).

**Theme Three: The Need to Reprocess the Death**

As a result of children having a less advanced understanding of the concept of death, children often reprocess the meaning of death as they advance to the next developmental stage. Many bereavement support programs offer immediate support following the death, but this time period may actually be a time when children and families are least likely to benefit from services (McBride & Simms, 2001). Mark states, “I have this like, probably 6 months, of just I don’t remember anything.” To ensure that children are continuing to positively cope with and adapt to life post death, child life specialists need to make certain they are available as an outlet for children and families as children pass into the next developmental stage.
Mark talks about how at the time immediately following his brother’s death, he did not cognitively understand the permanent implications of the loss. Consistent with previous research (Barrera et al., 2013; Brown, 2009; Pearson, 2005) Mark explains how he was not fully aware of the permanent nature of death, saying,

It never really settled in until I was, I mean it was almost like he was on a vacation until I was like 10. And then like I started to realize, well I guess he’s not coming back, and then once you hit, once I hit his age when he died that’s when I really started to comprehend like he was where I’m at now when he died so, I mean this is what his life built up to and then it ended. And I think once I started to figure that out and really dig deeper on it is when I really started to like comprehend death.

To the best of the principal researcher’s knowledge, very few previous research articles have addressed the implications of younger siblings forever becoming “older” than their older sibling. When adapting ongoing bereavement support into the hospital setting, child life specialists should understand that a critical time for services might be when the younger sibling becomes the same age as the deceased sibling. If the child life specialist is an available outlet during this time, the transition may become easier for siblings.

The timing of bereavement support services is a significant element in determining the effectiveness of services and ensuring that surviving siblings positively adapt and cope with the loss. Although Mark was 7 at the time of his brother’s death and attended counseling at the age of 8, Mark explains how he “didn’t really hit the grieving process until [he] was 13.” He continues on to say, “it got progressively worse until I hit
about 16, and then I kind of got over the little hump. But yeah, at 15 I was really
depressed all the time about it.” As children age and pass into the next developmental
stage, they often reprocess the meaning and events surrounding traumatic experiences
(Howarth, 2011; James, 1989). Child life specialists can use their expertise regarding
child development to inform parents that surviving siblings may reprocess both the
concept of death and the unique situation of their sibling’s death as they age.
Encouraging parents to have open and honest discussion regarding the death in addition
to reaching out to the surviving sibling as he/she ages could improve the effectiveness of
bereavement support programs.

Theme Four: The Importance of Empowering the Family System

One unique aspect and lens that CCLS could bring into ongoing bereavement
support is the importance of empowering the family unit to adapt to life post loss without
the need for further services. In the hospital setting the role of child life professionals is
to empower pediatric patients and their families to advocate for themselves and utilize the
strengths of the family system to overcome challenging events. In the case of ongoing
bereavement support, the role of child life should be similar and it is imperative that child
life specialists do not overstep professional and therapeutic boundaries or begin to fulfill
roles outside the scope of child life. In addition to ensuring that surviving siblings
maintain a continuing bond and relationship with the deceased, ensuring that siblings are
involved in the dying process, and being an available outlet for families while surviving
siblings reprocess death as they pass into the next developmental stage, bereavement
support that is run by child life professionals should focus on empowering the family unit
as a whole. Past research and past successful bereavement support programs has found that active involvement of caregivers is vital to the attainment of positive adjustment post loss (Corr & Corr, 2012; James, 1989; Potts, Farrell, & O’Toole, 1999). Informing parents and other family members of the unique and varied behavioral responses, questions, and cognitive thought processes of bereaved children may allow for an easier transition to life without the deceased.

Using a family systems theory lens and recognizing that grief is ultimately a family process (Brown, 2009) child life specialists can utilize the individualized strengths of a family unit to aid in movement through the grief process. CCLS can interpret the typical grief reactions of children and help eliminate concern and confusion that adults may face in deciphering the emotional well being of surviving siblings (Towne, 2001). By assisting families in redefining the new family system and empowering the family as a whole to overcome one of life’s most challenging events, child life specialists can help facilitate positive adjustment and coping after a family experiences the death of a child. The educational training child life specialists receive and their knowledge of Patient and Family Centered Care provides a unique and valuable perspective that should be added to ongoing bereavement support.
Chapter 5: Discussion

Introduction to Discussion

This research project attempted to add to the existing and growing literature regarding bereavement during childhood. By using first hand, retrospective accounts this study expanded upon previous research (Vlasto, 2010) that solely focused on therapists’ views of bereavement counseling. Additionally, four major themes were identified and analyzed as important considerations that child life specialists should reflect upon when adapting bereavement support to the hospital setting. The educational and clinical experiences that child life specialists must complete provides a solid theoretical framework and understanding of concepts such as child development, family systems, and stress reactions that may help child life specialists adapt bereavement interventions. If a bereavement competency is added to the repertoire and skill set of child life professionals, the validity of child life specialists facilitating bereavement support will be enhanced.

A few critical components that should be taken away from this research project are the importance of timing in regard to bereavement support services, the need for an available outlet as children reprocess death, and the critical time period when a surviving sibling forever becomes “older” than the deceased sibling. These components are briefly discussed below.

Considerations for Effective Bereavement Support

The importance of timing. Current practices of many bereavement and grief support services are to offer immediate support following the death of a loved one. The
results from this research project have found that this time period may actually be a time when children and families are least likely to benefit from support. McBride and Simms (2001) stated similar findings in their research. Bereavement support should take into consideration the family’s need for “emotional distance” as they process the loss and begin to adapt family life without the deceased (McBride & Simms, 2001). As Mark stated in his interview with the principle researcher, there was a six month gap in his memory immediately following the death of his brother from suicide. Child life specialists, and any professional managing bereavement support services, should consider an appropriate time frame when offering services, recognizing that this timeframe might be a year after the death.

**Being an available outlet as children reprocess death.** As children age and develop emotionally and cognitively, their understanding of death becomes more mature (Howarth, 2011; James, 1989). As Mark stated in his interview, he did not fully understand or begin to recognize the permanent implications of his brother’s death until around age ten. Mark talked about how his grieving process became more complex and difficult during his adolescent years because he became more fully aware of the implications and events surrounding his brother’s suicide. Past research (Birenbaum, 2000; Herberman Mash, Fullerton, & Ursana, 2013; Keenan, 2014) has also found that a child’s grieving process may be more problematic during his/her adolescent years due to advanced cognitive understanding of death. As children continue to reprocess death as they advance through developmental stages, child life specialists should ensure their availability to families during this time. Being a consistent and available resource, while
following the ethical principles and remaining within the ethical boundaries of the child life profession, for bereaved children and families may improve the effectiveness of such services and may produce more adaptive coping and adjustment within the entire family system.

**Recognizing when younger siblings become “older” than older sibling.** One significant and novel finding from this research project was the difficulty younger siblings might encounter when they forever become “older” than their deceased older sibling. During his interview, Mark talked about how he had a difficult time accepting that his brother’s life culminated at a certain age and he was now the same age as his brother. Mark stated, “he was where I’m at now when he died so, I mean this is what his life built up to and then it ended.” If professionals recognize that this transitional period may be a difficult time for surviving siblings, services could be individualized and adapted to address this complex time period of the grief process. If child life professionals take these considerations into account when implementing bereavement support services, they can better meet the needs of children and families by assessing when, and what supportive services, would be best for each individual sibling.

**Suggestions for Implementing Ongoing Bereavement Support**

**Multidisciplinary collaboration.** One advantage that child life specialists may have when adapting ongoing bereavement support into the hospital setting is the ability to collaborate with multiple disciplines. In addition to the individualized timing of when supportive services are implemented, in-hospital bereavement support has the opportunity to involve other members of the psychosocial team. Music therapy, art therapy, play
therapy, psychology, chaplaincy services, and other hospital-specific services should be called upon when needed in order to provide a holistic view of healing. Other clinicians who specialize in treating childhood trauma have also recognized the importance of having a support team when working with children, pointing out that the needs of children typically cannot be effectively met by a clinician working alone (James, 1989). Other supportive services, in addition to the involvement of caregivers, are critical components for successful treatment outcomes (James, 1989). Bereavement during childhood often impacts various dimensions of a child’s wellbeing including physical, cognitive, emotional, and spiritual aspects and in order to address these specific domains, a collaborative and multidisciplinary approach to bereavement support services must be implement (Corr & Corr, 2012; James, 1989). Similarly, taking an individualized approach to bereavement support by recognizing the importance of timing in regard to when to initiate bereavement services, continuing to be an available outlet for children and families as they reprocess the death, and acknowledging the critical time period when younger siblings become “older” than their older sibling may improve the effectiveness of services as well as improve client satisfaction. A multidisciplinary and psychosocial team should be formed beforehand, and each member of the bereavement support team should have an adequate educational background regarding death, dying, and bereavement.

The importance of self-care and maintaining professional boundaries.

Working with bereaved children and families and providing bereavement support may bring a risk of personal suffering for the clinician (Puterbaugh, 2008). Burnout,
compassion fatigue, and disenfranchised grief are common risks and experiences of individuals who work with bereaved children and families. Compassion fatigue stems from an inability to maintain healthy boundaries, inadequate self-care, and limited personal and professional support (Puterbaugh, 2008.) In order to avoid these negative consequences that may accompany bereavement work, child life specialists and other professionals should ensure appropriate self-care and have access to professional colleagues to help offset the emotional demands of bereavement work.

It is also important that when implementing bereavement support services, child life specialists remain within the professional scope of child life work. Knowing professional boundaries and roles is vital to make certain that members of the bereavement support team do not overstep bounds. Adding a bereavement competency may help limit the confusion and uncertainty of what role child life professionals should play in ongoing bereavement support. A hospital policy should be outlined and fully understood prior to the initiation of a bereavement support service in order to avoid negating the legitimacy of the services.

**Proposal for Implementing Bereavement Support Camp: Sibs Fest**

Using well-established and effective bereavement support camps (Camp Erin, n.d.; Comfort Zone Camp, 2012) as a model and implementing considerations from this research project, a framework and structure for a bereavement support camp, Sibs Fest, will be outlined below. This camp differs from previously established bereavement support camps because the population intended for this camp is children ages 6-18 who experienced the sudden or unexpected death of a sibling.
With some of the leading causes of death in children in this age range being unintentional injuries, suicides, and homicides it is important to not overlook the unique needs of these surviving siblings whose brother or sister died suddenly (National Vital Statistics System, 2010). In many hospitals great emphasis is placed on siblings of long-term patients, but child life professionals need to be cognizant not to overlook the siblings of patients who may have presented to the emergency department or had a short-term stay in the intensive care unit. Recognizing the need to offer support to children and families who experienced a sudden or unexpected death while utilizing hospital services should be a critical component when implementing ongoing bereavement support in order to ensure that every bereaved sibling who may benefit from ongoing services is offered the opportunity to accept services.

Sibs Fest is a bereavement support camp that is target at children ages 6-18 who experienced the sudden death of a brother or sister. Sibs Fest is a 6-day, 5-night camp that offers traditional camp activities integrated with grief support and education. Sibs Fest should be offered twice a year, with one camp session being aimed at children 6-12 and the other camp session being intended for children ages 13-18. Camp should be divided into separate sessions according to age in order to ensure that the activities being offered are developmentally appropriate in addition to the hope that close friendships with same-age peers will form between campers. Sibs Fest should implement activities that foster a sense of self-worth, improved self-esteem, offers choice and control to campers, and improves camper’s coping skills. A few examples of activities that would be appropriate at Sibs Fest can be found in an activity packet put together by Elizabeth Mahaney (n.d).
Some notable activities that would correspond with the traditional camp activities offered at Sibs Fest include a clay activity where campers explore their emotions manipulating clay (see Appendix F) or an activity where campers explore their future fears regarding events where the deceased will not be present (see Appendix G). Other activities may include a letter to the deceased (see Appendix H) or a memorial quilt made by campers (see Appendix I). A proposed structure for Sibs Fest is outlined below.

**Day one: Welcome.** This day will feature an orientation for campers, including the rules and safety procedures of camp. Icebreaker activities will be utilized throughout the day and at the end of the orientation session, campers will break-off into their cabin groups.

**Day two: Cabin group day.** Day two of Sibs Fest will feature activities intended to develop friendships between campers as well as establish camaraderie within the cabin groups. Obstacle courses and “minute to win it” games will be utilized. These activities are aimed at developing friendships, but also at enhancing camper’s self-esteem and self-worth.

**Day three: Nature day.** Day three will offer nature themed activities, arts and crafts, and a nature walk. Day three is also intended to be the memorial day for the deceased sibling with a camp-wide memorial services being held at night.

**Day four: Choice day.** Day four will allow campers to choose what traditional camp activities they want to engage in that day. At night, a camp-wide bonfire will be held where astronomy night will take place. A representative from the International Star
Registry should be brought into camp to educate campers as well as offer the opportunity to name a star after their deceased sibling.

**Day five: Choice day and big sibs/little sibs formation.** Day five is another opportunity for campers to engage in traditional camp activities of their choosing. One element of Sibs Fest is the formation of a mentor-mentee program where a camper from the 13-18 camp session is matched up with a younger camper. If an older camper has attended Sibs Fest at least twice, they would be eligible to be a “Big Sib” to younger campers. This element is intended to offer another support system to younger campers in addition to showing older campers they still have something of value to offer others.

**Day six: Family day.** Day six is the last day of Sibs Fest where families are welcome to join campers for the day. In the morning, parent activities are intended to be integrated but separate from camper activities in order to offer support to the whole family system. The family will then have the opportunity to engage in choice activities, with a family meal closing the day. At the end of family day a camp-wide balloon release will be held in order to honor and remember the deceased member of the family.

Sibs Fest will also integrate grief educate and support into camp structure, with a psychosocial and multidisciplinary team being available throughout the length of camp. Each evening, grief specialists should visit the various cabins to ensure that campers are positively coping and to use this time to educate campers regarding different coping techniques.

A multidisciplinary team, such as music therapists, art therapists, certified child life specialists, psychologists, and chaplaincy services, should be on staff at Sibs Fest.
Each professional should organize and run a different activity aimed at helping campers positively cope and adapt, while enjoying the camp environment. Volunteers and cabin leaders that offer their services at Sibs Fest should go through an extensive and rigorous orientation that educates these staff members about bereavement and the unique aspects of experiencing a sudden death.

Sibs Fest will allow for both individual as well as group counseling sessions for campers who may benefit from such services. The Big Sib/Little Sib program is intended to create a lasting friendship that extends beyond camp in hopes that campers will reach out to each other in times of need. It is the principle researcher’s hope that Sibs Fest will be an open and safe environment where children impacted by sudden loss are given permission to grieve so they can begin to heal.

**Conclusion**

While this research project intended to add to the existing knowledge base and current literature regarding childhood bereavement, this study is not without limitations. Due to limited timeframe and limited services, in addition to a strict geographical area, the sample size for this research project was restricted to one participant. In addition, a single data set project design with no follow up limits the scope of the participant’s answers. This study was intended to give an in-depth, first-hand account of individual’s experiences with bereavement counseling due to the death of a sibling and this research project is not intended to be generalized beyond the population that was studied.

Further research is warranted using first-hand accounts of children’s experiences rather than relying on parental or therapists’ interpretations. Using this research project as
a model, a pilot study implementing this type of individualized bereavement support should be launched within a child life department within a hospital in order to test the effectiveness and practicality of the considerations mentioned. Furthermore, a bereavement competency should be considered in order to elevate the professional standing certified child life specialists have within bereavement support programs.

The death of a child is perhaps one of the most challenging events a family must endure, but child life specialists are in a unique position to offer ongoing support. The implementation of a bereavement support program will require education, collaboration, continued advocacy, and knowledge regarding personal and professional boundaries. However, if an individualized and multidisciplinary approach can be utilized, movement through the grief process may become easier for children and families. When a family experiences the death of a child, their life is forever altered and child life specialists must be prepared to walk with, and assist, the family through the complex path of redefining the family system. A holistic approach to bereavement support services in addition to the use of elements of Patient and Family Centered Care may make the transition easier.
References


Appendix A: Recruitment Tools

Recruitment Tools

Flyers

Thesis Participants Needed:

• Have you experienced the death of a sibling (biological, adopted, or step-sibling)?
• Did you attend any form of bereavement counseling (individual or group counseling) as a result of the death?
• Were you between the ages of 6-18 when you attended counseling? And between the ages of 18-30 now?
• Can you understand and speak English?

If you are interested in sharing your experience about peer-group counseling in order to improve the effectiveness of this type of counseling, please consider participating in a short phone/skype/in-person interview. Please contact: Erin Naumann at en852013@ohio.edu, or (216) 870-7723, to set up an interview.

For this research project, counseling is defined as: the participation in any time of grief support that is led by an individual who is certified/qualified to assist children and families in understanding death, dying, and bereavement.

For example, bereavement camps, nationally recognized grief-counseling centers, or in-hospital bereavement support all qualify as group counseling so long as they were conducted in a group or individual setting.

Classroom Announcements

I will state my name, the title of my thesis project, and the inclusion criteria to be eligible for the study. I will then ask the class to please consider being a participant in my research project. I will then pass out the above flyer to everyone in the class and thank the classroom and the instructor for their time.

Social Media Posts

In order to recruit participants, I will post an electronic version of the above flyer on various Ohio University and other social media sites, such as Facebook and Twitter.
Appendix B: Informed Consent

Consent Form

Title of Research: A Retrospective Examination of Sibling Bereavement Counseling for Children Ages 6-18

Researcher: Erin Naumann
Faculty Advisor: Dr. Jenny Chabot

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study
This study is being done in order to evaluate the effectiveness of bereavement counseling for children between the ages of 6-18. If you agree to participate in this study you will be asked about your own experience with grief counseling and your own thoughts about the bereavement process. This interview will be audio recorded. You should not participate in this study if you are under the age of 18 or over the age of 30, have not attended a minimum of one (1) individual or group bereavement counseling session as the result of the death of a sibling, or did not attend bereavement counseling when you were between the ages of 6-18. Your participation in this study will last between 15-90 minutes depending upon the extent of your answers to the research questions.

Risks and Discomforts
Risks or discomforts that you might experience if you agree to participate in this study include feelings of negative emotions as you recall your sibling’s death. You may experience negative emotions or sad memories from that time. You may also experience feelings of frustration because you may feel like you are not being helpful because you cannot recall enough details about your counseling experience. You should feel no obligation to answer every question or continue with the interview.
Benefits
This study is important to society because this research project may provide new information to the scientific community and the findings of this research may help others move through the bereavement process by suggesting improvements that could be made to individual and/or peer-group grief counseling sessions. You may also benefit from this opportunity to openly talk about your deceased sibling and this interview may be viewed by you as cathartic or a good way to honor/remember your sibling. You may benefit from knowing that your involvement in this research project will provide testimonials that may improve future counseling for others.

Confidentiality and Records
Your study information will be kept confidential by keeping the audio recordings of this interview in a locked drawer that only the principle researcher has access to. That locked drawer is located in a locked office that is housed in a locked hallway in one of Ohio University’s academic buildings. During the interview, you should not verbalize any personal demographic information such as your name, the name of your deceased brother/sister, your hometown, etc. Once your interview is complete, I will write out the recorded interview with DragonSpeak software and/or by hand. Once I write out your recorded interview the original recording will be destroyed by May 2015, and the written transcriptions will be kept by the principle researcher. Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU.

Contact Information
If you have any questions, or after thoughts, regarding this study, please contact the principle researcher, Erin Naumann by email at en852013@ohio.edu or by phone at (216) 870-7723. You may also contact the researcher advisor Dr. Jenny Chabot by email at Chabot@ohio.edu or by phone at (740) 593-2871. If you have any questions regarding your rights as a research participant, please contact Chris Hayhow, Director of Research Compliance, Ohio University, at hayhow@ohio.edu or at (740) 597-1267.

By signing below, you are agreeing that:
• you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
• you have been informed of potential risks and they have been explained to your satisfaction.
• you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
• you are 18 years of age or older
• your participation in this research is completely voluntary
• you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature ___________________________________________ Date ____________

Printed Name _________________________________________

Version Date: 02/13/2015
Appendix C: Online Informed Consent

Online Consent Form

Title of Research: A Retrospective Examination of Sibling Bereavement Counseling for Children Ages 6-18

Researcher: Erin Naumann
Faculty Advisor: Dr. Jenny Chabot

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to participate in this study. You may print a copy of this document to take with you.

Explanation of Study
This study is being done in order to evaluate the effectiveness of bereavement counseling for children between the ages of 6-18. If you agree to participate in this study you will be asked about your own experience with grief counseling and your own thoughts about the bereavement process. This interview will be audio recorded. You should not participate in this study if you are under the age of 18 or over the age of 30, have not attended a minimum of one (1) individual or group bereavement counseling session as the result of the death of a sibling, or did not attend bereavement counseling when you were between the ages of 6-18. Your participation in this study will last between 15-90 minutes depending upon the extent of your answers to the research questions.

Risks and Discomforts
Risks or discomforts that you might experience if you agree to participate in this study include feelings of negative emotions as you recall your sibling’s death. You may experience negative emotions or sad memories from that time. You may also experience feelings of frustration because you may feel like you are not being helpful because you cannot recall enough details about your counseling experience. You should feel no obligation to answer every question or continue with the interview.
Benefits
This study is important to society because this research project may provide new
information to the scientific community and the findings of this research may help others
move through the bereavement process by suggesting improvements that could be made
to individual and/or peer-group grief counseling sessions. You may also benefit from this
opportunity to openly talk about your deceased sibling and this interview may be viewed
by you as cathartic or a good way to honor/remember your sibling. You may benefit from
knowing that your involvement in this research project will provide testimonials that may
improve future counseling for others.

Confidentiality and Records
Your study information will be kept confidential by keeping the audio recordings of this
interview in a locked drawer that only the principle researcher has access to. That locked
drawer is located in a locked office that is housed in a locked hallway in one of Ohio
University’s academic buildings. During the interview, you should not verbalize any
personal demographic information such as your name, the name of your deceased
brother/sister, your hometown, etc. Once your interview is complete, I will write out the
recorded interview with DragonSpeak software and/or by hand. Once I write out your
recorded interview the original recording will be destroyed by May 2015, and the written
transcriptions will be kept by the principle researcher.
Additionally, while every effort will be made to keep your study-related information
confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose
  responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review
  Board, a committee that oversees the research at OU.

Contact Information
If you have any questions, or after thoughts, regarding this study, please contact the
principle researcher, Erin Naumann by email at en852013@ohio.edu or by phone at (216)
870-7723. You may also contact the researcher advisor Dr. Jenny Chabot by email at
Chabot@ohio.edu or by phone at (740) 593-2871.
If you have any questions regarding your rights as a research participant, please contact
Chris Hayhow, Director of Research Compliance, Ohio University, at hayhow@ohio.edu
or at (740) 597-1267.

By participating in this study, you are agreeing that:
• you have read this consent form (or it has been read to you) and have been
given the opportunity to ask questions and have them answered
• you have been informed of potential risks and they have been explained to
  your satisfaction.
• you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
• you are 18 years of age or older
• your participation in this research is completely voluntary
• you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Version Date: 02/27/2015
Appendix D: Interview Guide

Interview Questions—Group Counseling

Participants are to fill out this part of the interview on his/her own.

Demographic Information:
1. What is your current age?
2. Do you classify yourself as male, female, or transgendered?
3. What race/ethnicity do you classify yourself as?

White/Caucasian ________  Black/African American ________  Asian____
Middle Eastern ________  Hispanic ________  Bi-Racial _____  Other _____
REMIND PARTICIPANTS: For this research project, counseling is defined as: the participation in any time of grief support that is led by an individual who is certified/qualified to assist children and families in understanding death, dying, and bereavement. For example, bereavement camps, nationally recognized grief-counseling centers, or in-hospital bereavement support all qualify as group counseling so long as they were conducted in a group setting.

Open Response Questions/Prompting Questions:

4. Tell me about your family.
   a. How many other surviving siblings?
   b. Any adopted or step-siblings in your family?
   c. What is the birth order?

5. Tell me about your relationship with your brother/sister who passed.

6. Tell me about their illness/medical history and how he/she passed.

7. How old was your sibling when he/she passed?
   a. What was the cause of your sibling’s death?

8. Tell me about your experience with peer-group bereavement counseling.
   a. How did it come to be that you attended group counseling? Did your parents suggest it?
   b. Did you also participate in any family counseling?

9. How old were you when you participated in peer-group bereavement counseling?
   a. How long after your sibling’s death did you start participating in bereavement counseling?
   b. How many sessions, or how long, did you continue to participate in bereavement counseling?

10. What type of bereavement counseling did you attend? Who ran the sessions?
    a. Please describe what happened in the sessions.

11. What do you feel was the most helpful aspect of your counseling experience? Why?
12. What do you feel was the least helpful aspect of your counseling experience? Why?

13. What is one thing you wish to see changed about peer-group bereavement counseling?

14. Did counseling help you develop new and positive coping strategies? YES NO
   a. If yes, what are a few examples of these coping strategies?
   b. If yes, do you still use these coping strategies today?

15. Did counseling help you make new friends? YES NO
   a. Do you feel you would have been more comfortable opening up if counseling was conducted in a one-on-one environment?

16. Did attending counseling help teach you about the concept of death? YES NO
   a. If yes, how?
   b. If no, do you wish it did?

17. Did attending counseling help you to maintain a relationship with your deceased sibling? YES NO
   a. If yes, how?
   b. If no, do you wish it would have?

18. Did attending counseling help you maintain a positive relationship with your parents at that time? YES NO
   a. If yes, how?

Final Thoughts:
19. Is there anything else you wish to say about your experience with peer-group bereavement counseling?
Interview Questions—Individual Counseling

Participants are to fill out this part of the interview on his/her own.

Demographic Information:
1. What is your current age?
2. Do you classify yourself as male, female, or transgendered?
3. What race/ethnicity do you classify yourself as?

White/Caucasian ________ Black/African American ________ Asian____
Middle Eastern ________ Hispanic ________ Bi-Racial _____ Other ____
REMIND PARTICIPANTS: For this research project, counseling is defined as: the participation in any time of grief support that is led by an individual who is certified/qualified to assist children and families in understanding death, dying, and bereavement. For example, bereavement camps, nationally recognized grief-counseling centers, or in-hospital bereavement support all qualify as group counseling so long as they were conducted in a group or individual setting.

Open Response Questions/Prompting Questions:

4. Tell me about your family.
   a. How many other surviving siblings?
   b. Any adopted or step-siblings in your family?
   c. What is the birth order?

5. Tell me about your relationship with your brother/sister who passed.

6. Tell me about their illness/medical history and how he/she passed.

7. How old was your sibling when he/she passed?
   a. What was the cause of your sibling’s death?

8. Tell me about your experience with individual bereavement counseling.
   a. How did it come to be that you attended individual counseling? Did your parents suggest it?
   b. Did you also participate in any family counseling?

9. How old were you when you participated in individual bereavement counseling?
   a. How long after your sibling’s death did you start participating in bereavement counseling?
   b. How many sessions, or how long, did you continue to participate in bereavement counseling?

10. What type of bereavement counseling did you attend? Who ran the sessions?
    a. Please describe what happened in the sessions.

11. What do you feel was the most helpful aspect of your counseling experience? Why?
12. What do you feel was the least helpful aspect of your counseling experience? Why?

13. What is one thing you wish to see changed about individual bereavement counseling?

14. Did counseling help you develop new and positive coping strategies? YES NO
   a. If yes, what are a few examples of these coping strategies?
   b. If yes, do you still use these coping strategies today?

15. Did you feel more comfortable opening up in individual counseling because it was not a group setting? YES NO

16. Did attending counseling help teach you about the concept of death? YES NO
   a. If yes, how?
   b. If no, do you wish it did?

17. Did attending counseling help you to maintain a relationship with your deceased sibling? YES NO
   a. If yes, how?
   b. If no, do you wish it would have?

18. Did attending counseling help you maintain a positive relationship with your parents at that time? YES NO
   a. If yes, how?

*Final Thoughts:*
19. Is there anything else you wish to say about your experience with individual bereavement counseling?
Appendix E: Debriefing Form

Debriefing Form

Thank you for your participation in today’s study.

This research project is attempting to use retrospective, first-hand accounts of individual’s experiences with bereavement counseling in order to uncover common characteristics of a positive counseling experience. This study is aiming to better understand how bereavement counseling influences children in the developmental stages of Middle Childhood and Adolescence, characterized by the ages 6-18, movement through the bereavement process.

The interview conducted today did bring up some emotional topics and sensitive issues. If you feel like you may need additional help in dealing with the topic we discussed today, or if your participation in this study has caused you concerns, anxiety, or otherwise distressed you please contact Ohio University Counseling Services or Tri-County Mental Health & Counseling. The information for OU’s counseling services and Tri-County Mental Health & Counseling is listed below.

Ohio University Counseling and Psychological Services

Location: Third floor of Hudson Health Center, located on North Green
Hours: 8:00am-5:00pm, Monday-Friday
Drop-in hours being 9:45 am to 3:15 pm, Monday through Friday.
Contact Information: Phone: (740) 593-1616, Fax: (740) 593-0091
If you are trying to reach a counselor during an emergency or want to talk to someone immediately, please call CPS (740) 593-1616 or OUPD (740) 593-1911 at any time.

Tri-County Mental Health & Counseling

Location: 90 Hospital Drive, Athens Ohio 45701
Contact Information: 740-592-3091

If you have any questions or concerns, you are welcome to contact me, Erin Naumann, by email at en852013@ohio.edu or by phone at (216) 870-7723, or my researcher advisor Dr. Jenny Chabot by email at chabot@ohio.edu or by phone at (740) 593-2871. If you
have any questions regarding your rights as a research participant, please contact Chris Hayhow, Director of Research Compliance, Ohio University, at hayhow@ohio.edu or by phone at (740) 597-1267.

Thank you again for your participation and time. If you have any after thoughts or reflections about this interview, please do not hesitate to contact me at en852013@ohio.edu.
Appendix F: Clay Activity

CLAY ACTIVITY

Age Level: All

Time Required: 45 minutes

Materials Needed:
- Soft clay
- Plastic table cloths
- Small objects to put into clay (i.e., pencils, buttons, straws, etc.)

Description of Activity:

Frequently, our actions speak louder than our words. Grief is difficult to express at times, especially when dealing with anger and frustration.

Tell the group they don’t have to “make” anything we are just experimenting with the feel and shapes of the clay. Ask them to think of thoughts such as anger, frustration or sadness. Give the group time to get into their feelings quietly. As they think, encourage them to work with the clay – squeezing, shaping or pounding.

Have each person share his/her thoughts. As they share, be aware of their body language, especially their hands. See if their body language matches their words. If the two are different, share your observations and explore them with the individual. Example: Participant is pounding pencil into clay as he or she says they are experiencing no frustration or anger.

Some people make letters out of their clay. As an example, one girl spelled the word “AIDS” and then smashed it with the remainder of her clay. Others may make an object like a bottle and then destroy it, symbolizing their hatred of alcohol. Some may simply play with a ball of clay as they speak and feel no desire to create anything. Have them tell you how the clay feels – texture, temperature, etc. This helps the individual to really pay attention to what he/she is doing so that they are fully present in the moment.

This exercise is not meant to be analyzed in depth. It is simply an experiment in exploring new ways to get in touch with feelings. It is a very popular activity.
Appendix G: Future Fears Activity

FUTURE FEARS

When someone important in our life dies, we not only lose that person, but we lose the expectation of those things we would be doing with them in the future. As an example: If I am a 16 year old girl and my father dies, the expectation of having my father walk me down the aisle when I get married is not shattered. If I am a boy who loved to go fishing with my dad all the time, his death makes it impossible for me to fish with him ever again. If I am a girl who really enjoyed cooking with my mom, cooking now, without her, could be very painful. If I used to double-date with my brother or sister a lot, dating may feel very different now. If my grandmother was the safest person in my life to talk to, I may have trouble trusting anyone else with my private thoughts and feel like I have to now keep them all to myself.

With these thoughts in mind, please respond to the following:

Now that ___________________________ is no longer alive, I am afraid I will have
to experience ____________________________

____________________________________

____________________________________

_______________________________

without him/her.

Now that ___________________________ is no longer alive, I know I will be
expected to ____________________________

____________________________________

____________________________________

_______________________________

After responding to the above, please share what options you might have to make the experiences described above less painful.
Appendix H: Letter to the Deceased Activity

LETTER TO THE DECEASED

When someone dies, we do not always have the opportunity to say “goodbye” Perhaps we are left feeling as though we should have said what was in our hearts and didn’t, or we are feeling guilty for things we wish we had not said. Writing a letter to the person who died can be helpful in expressing unresolved feelings. Below is a letter written by grandson to his grandmother after her death.

After reading this letter to your teens, it is important to let them know that this letter was written by a boy who was saying goodbye to his grandmother for the first time. This is a man who finds it extremely difficult visiting friends in hospitals or attending funerals. He has suffered from insomnia most of his life. His grandmother died when he was eight years old and he went on to share that, when he was 17, his girlfriend was “mysteriously killed” in a hunting accident. Writing this letter was his first opportunity to acknowledge painful feelings he had carried with him for a lifetime. The point to this is that grief does not just go away in time. If we do not actively acknowledge our feelings of loss and take care of ourselves in the process, our unresolved and confused feelings will continue to enter into other areas of our life without our realizing it. This man experienced tremendous relief after writing this letter. He had only wished that someone had been there for him years ago!

Dear Grandma,

I always liked going to see you. I felt so at home there. It just seemed you and Grandpa were the way grandparents should be. Your death confused me, Grandma. Now you’re my Grandma and now you’re gone. You didn’t even say goodbye. All of a sudden, you get pneumonia and then we get a call telling us you’re dead. I felt an immediate loss. I felt empty. I felt betrayed and abandoned. I needed to talk to someone, but I had no listeners. I was on my own to figure this out myself. Aunt Ruth helped me the most when she told me your spirit would be with me forever. That helped.

The funeral was the topper. I remember sitting there watching you lie in that coffin. The smell of the flowers remains with me. I would sit and stare at you, so frail, so peaked, so peaceful, so dead and gone. Then I would swear I could see you move. Mom shook her head “no” when I would tell her I saw you move. Then the soft organ music. Why that tear-jerking music? Did you really want that Grandma? That just made it worse. I really felt crummy and empty. Is that normal? Did that have to be? I still see you there, gone! This confuses me. I never said good-bye to you. I never knew how.

The procession to the cemetery was a real gem, too. I remember the long, winding road. It seemed we were never going to get there. I did feel privileged though, riding in the family car. I never saw Dad cry before. That left an impression on me. I remember sniffling and he looked at me with disapproval. When we finally reached the cemetery, they opened the coffin again. Why? Why more torture?

Grandma, I needed to talk to someone. I needed to talk to someone that understood these things. So much confusion. Grandma! I’m angry still. Grandma. I still feel the tears. Grandma. I would love to know where you are with all this. Do you approve? There has to be a better way.
If you are finding it difficult to write your letter to the person who has died, feel free to use this outline to help you.

Dear...

I remember when you...

The hardest part about your death for me is...

It would have been nice if...

I’m really sorry for...

My best time with you was...

If you were here right now, I would...

Thank you for...
Appendix I: Memorial Quilt Activity

MEMORIAL QUILT

Age Level:

Time Required:

Materials Needed: White cotton fabric 9" x 9" square
Fabric paints
Markers
Applique items
Decorative glitter

Goals:

• Memorialize.
• Facilitate talking about the person who died while working on their square.
• Unify group and sense of belonging

Description of Activity:

1. Each child is given a blank square of fabric to decorate with the name of the sibling or parent who died. The squares don't have to be washable so there is a lot of leeway in how they are decorated.

2. A seam allowance of 1/2" should be allowed all around the square so it can be seam or sashed together.

3. The group can vote on a favorite fabric to sash together.

4. A sleeve can be sewn on the back so the piece can be hung.

Variation: Using squares or circles of colored paper, design a block to represent the deceased family member. Hole punch corners or circle quadrants and tie them together with colored yarn.