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Loss of a Sibling: A Phenomenological Exploration of the Experiences of School-aged children

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Loss of a Sibling: A Phenomenological Exploration

of the Experiences of School-aged children

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Abstract

More than 50,000 child mortalities are recorded in the U.S. each year. As a result, almost 8% of the population experience the loss of a brother or sister before age 25 (Jacobs & Bovasso, 2000). This study was an open conversational exchange with ten Grief Counselors who worked with school-aged children, who had experienced the loss of a sibling, to identify the behaviors and expressions of this group of Disenfranchised Grievers. Three patterns were identified: *1) Grief in children takes different forms, 2) Sibling loss in childhood is a life-changing event* and *3) Childhood grief has its own time.* Each of the patterns were comprised of three themes. The themes for the first pattern were: *Children's grief differs, wide variety of atypical behaviors* and *developmental understandings of death.* The themes for the second were: *Loss of a life-long companion, new normal in the family unit* and *parents subsumed in grief.* The themes for the third pattern were: *Grieving periods in children, anniversaries, birthdays and holidays,* and *loss follows a child throughout life.* Based on this study, several changes were formulated for practice, research, education and policy that would benefit this population. It was concluded that early identification is the key to prevent misdiagnosis and assist these children with their grief journey.

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Keywords

Disenfranchised grief, sibling grief, childhood grief, characteristics of sibling grief

Chapter 1: Phenomenon

More than 50,000 children mortalities are recorded in the United States each year (National Center for Health Statistics, 2016). As a result, almost 8% of the population experiences the loss of a brother or sister before age 25 (Jacobs & Bovasso, 2009). These deaths create a void within the family involved, upending its entire experience. Whether an expected passing (such as a child with cancer) or a sudden occurrence, each family member is affected by this event. The parents are understandably shaken, (Foster, et al, 2011 & Riches & Dawson, 2002), but the surviving children experience their own type of grief (Conger & Kramer, 2010 & Cox 2010).

Sibling grief is a serious phenomenon that has not been adequately researched. While there have been studies on this topic, many were based on information parents provided (Barrera, Alam, D'Agostino, Nicholas & Schneiderman, 2013; Bugge, Darbyshire, Rokholt, Hangsredt & Helseth, 2014; deCinque, Monterosso, Dadd, Sidhu, Macpherson & Aoun, 2006; Erlandsson, Avelin, Saflund, Wredling & Radstad, 2010; Foster, et al, 2011; Lohan & Murphy, 2002; & Youngblut & Brooten, 2013). These parents described observations they had as well as topics their children discussed. Given their own state of mind, however, the accuracy of these recollections comes into question. Additionally, the surviving sibling's feelings may not be an experience they are able to convey with adequate specificity. These grieving siblings may feel guilty for turning to their parents for comfort when they observe the grief their mom and dad are experiencing over losing their child.

Sibling grief can be a life-changing event for the child who is experiencing this phenomenon. Depending upon their age, this may be the first experience with death this

child has encountered (Bonati, Leondari & Mastora, 2013; Hunter & Smith, 2008 Levine & Kline, 2007 & Willis, 2002). They may have lost a pet or observed a plant die, but their understanding of loss and the finality of death is limited. Due to the longevity of the lifespan in the U.S. today, all their grandparents, and possibly their great-grandparents, may still be alive (U.S. Department of Health & Human Services, 2017). Their sibling's death is something new to them.

Cox (2010) asserts that, "sibling relationships often involve strong emotional ties (p. 1)". Considering this idea, and the proximity with which siblings live, the death of a brother or sister is quite possibly the closest relationship a child has ever lost. Conger & Kramer (2010) advise that a sibling relationship could also be one of the longest relationships a child may have. Sibling relationships contribute to the honing of many development tasks throughout the life of the child (Cox, 2010).

The loss of a child is one of the worst experiences a parent can have. For most, it is all-consuming. Keesee, Currier & Niemeyer (2008) liken it to the loss of part of oneself. Gijzen, L'Hoir, Boere-Boonekamp & Need (2016) describe it as, "an enormous tragedy (p. 1)". They are unavailable for their other children despite that child's need for comfort. In Neimeyer (2001), the author discusses the concept of parental tasks after the death of a child, including, "reconstructing a personal world of meaning (p. 141)". Some parents must even be institutionalized or treated as an out-patient at a Mental Health Facility. In a study by Lichtenthal, et al (2015), forty-one percent of the 120 participating bereaved parents required mental health treatment. These parents are an inadequate source, and may not provide the breadth of information needed on their children's experience.

The grieving sibling may experience a variety of maladies. Some of the behaviors observed in those children grieving the death of a brother or sister include anxiety, depression, aggression, sleep disturbances, attention-seeking, withdrawn behavior, school difficulties, jealousy, guilt, enuresis, anti-social behavior, fearfulness of experiencing another death and somatic complaints, such as stomach ache or headache (Bolton, et al, 2016; Giovaanola, 2005; Hibbert, 2017; & Willis, 2002). Additionally, if their health care professional looks only at their symptoms and not the circumstances surrounding those symptoms, the child may be misdiagnosed (Stikkelbrock, Bodden, Reitz, Voliebergh & van Baar, 2014).

When a child with unresolved grief becomes an adult, he or she may have difficulties starting and maintaining a relationship (Magen & Kekel, 2008 & Sandler, Robinson & Carter, 2012). They may experience trust issues, making it difficult to display their vulnerability to another individual. Conversely, they may become codependent and "smother" a potential partner by clinging to them too tightly (Brandt, 2017 & White, 2014).

Unresolved issues as a child can carry on into parenting as well, and can continue to perpetuate throughout the generations (Kurtz, 2000 & Lerner, 2016). If, while growing up, a grieving sibling had parents that seemed distant due to working through their own angst, the possibility arises for that individual to project those feelings of neglect onto their own children. There also exists the opposite reaction. The individual may become overprotective and grow zealous with their affection toward their children, causing them to rebel due to feeling overwhelmed by their hovering parents (Florida

State University, 2016). Therefore, identifying the behaviors of grieving siblings is an important task to initiate.

Statement of the Purpose, Research Question & Specific Aims

The purpose of this study was to describe the behaviors of school-aged, sibling grievers using Husserlian descriptive phenomenology. This was accomplished via interviews of the Grief Counselors caring for these sibling grievers. These providers have a close relationship with these children, and identified new behaviors not previously reported as being displayed by a sibling griever. In addition, with their training, a more in-depth analysis was provided.

The research question that guided this study was, "From the experience of a Grief Counselor, what are the behaviors and expressions of school-aged children who have lost a sibling?" The specific aims were to identify the behaviors that were attributed to the grief the sibling is experiencing and to better identify a child that is dealing with grief. This knowledge would be very helpful to school nurses, counselors and teachers, in addition to health care providers. It can provide the tools to open dialogue or have a richer and deeper understanding of the subject to be able to notice, but also target, the issues a grieving sibling is facing.

Locating the Researcher in the Research

Husserlien phenomenology requires that the researcher "bracket" themselves, to put aside any previous knowledge or experiences they have had with the topic of interest, resulting in the ability to research it with an open mind (Moja-Strasser, 2010).

As a nurse on a medical-surgical unit in a children's hospital since 1996, I have witnessed the death of a child first-hand on a few occasions. To help the family as they watched their loved one slip away, and comfort them after the death, have been but a few of the duties I gladly performed to assist them in this phase of their life. I have participated in memorial services for those children and attended funerals. As a camp nurse, I witnessed children speak about the loved one they lost. I assisted them with their medical problems in addition to interacting with them directly and discussing their emotional well-being. In my current position as a Pediatric Nurse Educator for the last ten years, I have accompanied students to a Pediatric Hematology/Oncology floor to fulfill their pediatric clinical requirements. Direct experience with a child's death, however, is not a tragedy that has been specific to my professional life.

In April 1995, my husband and I experienced a parent's worst nightmare–the death of our three-year-old daughter. Throughout her short life, there were many traumatic incidents that led medical professionals to believe that she was close to death, but she always managed to recover. During her final hospitalization, however, she became septic and all her systems shut down. After hours of painful deliberation, we chose to remove her from life support, and she died in our arms. While it was a serious blow to us, I cannot imagine what it felt like to her three siblings.

Her sister and two brothers witnessed many events including grand mal seizures, ambulance rides and exchanging Christmas gifts in a hospital room. They were even there on her final day. They were 9, 11 and 14 years of age when their sister died. Since she was a special needs child, they observed, and assisted, in her care. It was not unusual for her eldest brother to assist with her tube feedings and nebulizer treatments. Like many parents of grieving siblings, we tried to aid with their grief, but I wonder if we could have done a more thorough job of tending to their needs.

In following the Husserlian methodology, I will remain conscious of these personal issues in analyzing my data and will use methodological techniques to both honor and separate my experiences from analytical findings in my research.

Sibling grief is an important subject to research due to the large number of childhood deaths in the United States each year and the impact those deaths have on the surviving children. The concept of death may be new to the surviving sibling, and, depending upon his or her relationship with the deceased, may be a serious hardship on them. The natural choice for them to turn to (their parent), however, is dealing with their own grief. Unresolved grief can wreak havoc on future relationships and into parenthood. In Chapter 2, documented accounts of the different aspects of sibling grief will be reviewed.

Definitions

Concepts	Definitions
Atheoretical	Not guided by one, particular theory (Speziale & Carpenter, 2007).
Coping	"The development of positive, constructive strategies for dealing with stressful situations" (Charles & Charles, 2006, p. 1).
Disenfranchised grief	"…occurs when one experiences a loss that cannot be openly acknowledged, publicly mourned or is socially acceptable" (Wlodarczyk, 2013, p. 1).
Epoche	"…to put aside our biases, assumptions, prejudices and focus on the immediate experience (Moja-Strasser, 2010, P. 50)".
Losses	Those instances that may provide a type of grief response – i. e. loss of employment, moving, divorce, etc. (Feldman, 2015).
Grief Counselor	Licensed or certified professionals who work with children who are experiencing grief.
Palliative care	"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention, relief of suffering by means of early intervention and impeccable assessment and treatment of pain and other problems, physical psychosocial and spiritual means" (WHO, 2017, p. 1).
School-aged children	Children aged 6-12 years of age (Feldman, 2015).
Siblings	All children having one or more of the adults living in the house-hold as their parent (Feldman, 2015).
Universal essences or eidetic structures	Certain aspects of an experience that are constant from one person to the next (Lopez & Willis, 2004).

Chapter 2: Review of the Literature

This chapter includes a discussion of theories that inform this research, as well as society's view of death, palliative care, grief, types of losses and adult versus childhood grief.

Theoretical Perspectives

The theories investigated include cognitive theories, psychosocial theories and grief theories. Cognitive and psychosocial theories are included to determine at what stage in a child's life they begin to understand more fully the meaning of concepts such as death. Several theorists have presented their ideas on grief, and this research will address the better known of them, as well as use their findings as a guide. The fear of death that is felt by a great deal of modern society adds to a child's confusion when confronted with the loss of a sibling. Palliative care has become an option over the past several years, with in-home hospice occurring more frequently in recent decades. It removes some of the harshness of death and allows for a more natural end of life for everyone involved. The severity of loss a child experiences has a direct effect on how well they cope. Each loss provides a new lesson on the topic. Adults experience death and grief in a different way than children do, as discussed further in this chapter. Therefore, previous research on grief needs to be aligned with the proper age group.

Most qualitative studies are not guided by a singular theory. Qualitative research is, essentially, an "atheoretical" discipline (Speziale & Carpenter, 2007). This is true of studies conducted in the early stages of the field, in which very little data exists. In a

literature review published by Wu & Volker (2009), four hundred qualitative studies were located that corresponded to their field of research. Three hundred and seventy-eight of those four hundred were not directed by a theory. The two researchers felt this was a typical outcome (Wu & Volker, 2009).

This research study followed along those lines in that it was not directed by a theory, but rather, several theories were consulted to work towards a clearer meaning of what a sibling griever is experiencing, and how that individual might behave. The criteria for selection of guiding theories for this study included the fact that it would either pertain to the age group being researched, or could be adapted to them, it explained the various cognitive levels and understanding of a young child, or it involved the subject matter of grief.

Piaget's Theory of Cognitive Development

A child's mind goes through various developmental states, as noted in Piaget's Theory of Cognitive Development. Piaget described stages that include: Sensorimotor, ages 0-2; Preoperational, 2-7 years of age; Concrete Operational, 7-11 years; and Formal Operational, 11 years of age and above (Feldman, 2015, Ojose, 2008).

Piaget labeled the third state the Concrete Operational Stage (Piaget, 1952). Children in this stage are starting to use logic to understand the world around them. Piaget is quick to caution that it takes a while to develop this skill, and that children may go back and forth between Preoperational and Concrete Operational until they finally achieve it (Feldman, 2015 & Piaget, 1952). Children in this age group have a hard time grasping abstract or hypothetical thought (Cherry, 2017). They have trouble when

attempting to problem-solve. For example, when observing a chemical reaction in science class, they experience difficulty in determining exactly what happened. They must hear or see the answer from someone older than them. This study is based on this age group.

According to Piaget, much of our understanding also originates with "two basic principles, assimilation and accommodation (Feldman, 2015, p. 17)". He explains that assimilation is our current understanding of the world that we draw upon to make sense of something new. When this process fails us, we use accommodation to help us develop a new angle or completely abandon our old way of thinking if it does not fit, devising an original explanation (Feldman, 2015). He believed these principles could be found in action in children from his first stage through adulthood.

An example of assimilation and accommodation would be when a child first sees a zebra. He or she calls the zebra a horse. This is because the child has seen horses before and notices some similarities. When a parent corrects them by saying that it is a zebra, that child then turns to accommodation. Now, he or she can note the differences and not make that mistake in the future (Pugetsound.edu).

Piaget's Concrete Operational Stage (7-11 years old) is applicable for this research. Children in this stage are starting to comprehend the world through the lens of logic, but still experience difficulties in fully understanding many concepts. They have, however, mastered the concepts of assimilation and accommodation. They are considered school-aged, and as a result, interact with teachers, counselors and school nurses. It is for this group the results of this project are intended.   In addition to

understanding cognitive theories in children, a working knowledge of psychosocial

theory is also necessary to fully understand their development.

Erikson's Psychosocial Theory

Erik Erikson covers the concept of psychosocial development extensively. He

addresses social interactions from birth to late adulthood. They are: birth to 12-18

months, Trust versus Mistrust; 12-18 months to 3 years, Autonomy versus Shame and

Doubt; 3 years to 5-6 years, Initiative versus Guilt; 5-6 years to adolescence, Industry

versus Inferiority; adolescence to adulthood, Identity versus Role Diffusion; early

adulthood, Intimacy versus Isolation; middle adulthood, Generativity versus Stagnation;

and late adulthood, Ego-Integrity versus Despair (Dinkle & Harbke, 2016).

To progress from one stage to the next, Mr. Erikson advises the individual must

undergo a "crisis" and resolve it (Feldman 2015, p. 14). Preschool children become

school-aged children and begin to solve problems and understand more complex

concepts. For purposes of this study, the stage directly relevant is that involving the

school-aged child (Ojose, 2008).

This study focused on Erikson's "Industry versus Inferiority" stage. During this

time in the child's life, they are becoming most capable of the task of sorting through

information and making sense of it. Prior to this stage, children have been focused on

trusting, autonomy and initiative (Dinkle & Harbke, 2016). After successfully clearing

those hurdles, they are ready to start taking on more complicated concepts, such as grief.

Grief Theories

Most grief theories apply to adult experience. Applications of these theories may aid in understanding children's grief. The theories most commonly recognized include: Kubler-Ross' 5 Stages of Grief, Freud's Psychoanalytic Theory on Grief, and Bowlby's Theory of Attachment (Buglass, 2010; Worden, Davies & McCown, 1999). One of the most familiar is Kubler Ross' 5 Stages of Grief, in which the stages are denial, anger, bargaining, depression and acceptance (Buglass, 2010, Corr, 1993 & Kubler-Ross, 1969). After interviewing the Grief counselors, these theories did not correspond to what the children were experiencing or have experienced. Past studies agreed with this. Most of the research seems to show that children's responses differ greatly from those of adults (Barrera, Alam, D'Agostino, Nicholas & Schneiderman, 2013 & Bonoti, Leondari & Mastora). Sigmund Freud also had a theory on grief.

Freud's Psychoanalytic Theory involved bereaved adults working on removing the deceased from their life by contemplating all their interactions and wiping them from their memory (Buglass, 2010). This process aligns with a study that directly interviewed grieving children. These children advised that remembering their loved one was a big help in working through their grief (Thompson, et al, 2011). Therefore, their interviews refute what Freud suggested. They wanted to remember their loved ones and not wipe them from their memory. The memories gave them comfort. Another researcher, John Bowlby, did include children in his studies.

Bowlby's Theory of Attachment shows promise in addressing sibling grief in a young child. He outlines the steps of grief as shock, yearning and protest, despair and recovery (Buglass, 2010). Flynn (2014), advises that separation anxiety, as explained by Bowlby, experienced due to separation from a child's mother, may be a precursor to

grief. The child experiences the separation as a "loss" and reacts by displaying some

signs of grief – protest and despair. Recovery is usually displayed after a time when

either the child calms down or is reunited with their mother. These same reactions are

displayed in the child who experiences the death of someone close to them (Flynn, 2014).

Society's View of Death

Society tends to avoid discussions of death despite there being a great deal of

literature on death and denial (Becker, 1973; Callahan 2000; Cozzolino, Blackie &

Meyers, 2014; Kastenbaum & Aisenberg, 1973; Kellehear, 1984; Kubler-Ross, 1969;

Seale, 1998; Vahrmeyer & Cassar, 2017; Weisman, 1972 & Zimmerman, 2007).

Whether we think we can circumvent it by not broaching the subject, or it is just

something we do not want to think about, the American consciousness is averse to the

idea. We will often soften the lexicon, using phrases such as "passed away" or "lost their

life," and grow shocked when a young person dies, no matter what the cause. The feeling

intensifies when we learn that the death might have been preventable–a drug overdose,

automobile accident or suicide, for example.

Ernest Becker received a Pulitzer prize for his book, "The Denial of Death"

(Cozzolino, Blackie & Meyers, 2014), which gave rise to Terror Management Theory.

The theory has been researched over the years and continues to appear in research

articles. Terror Management Theory highlights the conflict that continues with humans

desiring to avoid thoughts or talking about death, concentrating on things that do not die,

like cultural world views. There are scales specifically designed to measure an

individual's fear of death, such as Death-Attitude Profile, Revised, The Collett-Lester

Fear of Death Scale, the Lester Attitude Towards Death Scale and the Death Anxiety

Scale (Cozzolino, Blackie & Meyers, 2014; Larrabee, 1978; Lewis Espe-Pfeifer & Blair, 2000 & Vance, 2014). Rose & O'Sullivan (2002) even found that belief in an afterlife does not always reduce humankind's fear of death. There can be little surprise, then, that children are confused over the death of a loved one and how to cope with such an occurrence. Society has been in search of a way to ease into the subject of death. Palliative care strives to dispel the negativity of death and replace it with a more palatable approach to the subject.

Palliative Care

It was not until recently that Palliative Care pervaded the literature, and ways to have a "good death" were researched and pursued. In 1974, Connecticut Hospice, the first in the U.S., was opened (National Hospice & Palliative Care Organizations, 2016). In the beginning, services relied heavily on charity, foundations and volunteer nurses. Federal funds for hospice were not approved until almost a decade later. In 1986, Medicare hospice benefits were established (Buck, 2011). Since that time, many hospice organizations have opened programs.

> The WHO's (World Health Organization) definition of Palliative Care is an approach that improves the quality of life of patients and their families, who are facing life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other ailments, whether physical, psychosocial or spiritual (2017, p. 1).

Hospice care and palliative care usually are not offered until death is imminent and there is nothing more that medical science can do for someone. Palliative care may be offered when one has advanced cancer, for example, for which treatments are no longer effective or their systems are failing. Supportive care is provided by various health professionals, including nursing, social work, pastoral care, pharmacists and doctors. The dying patient receives pain medicines and anticholinergic meds (ones that dry up their secretions) through the combined efforts of nursing, pharmacy and physicians. Social workers order equipment such as oxygen and a hospital bed. Pastoral care looks after the spiritual needs of the patient and family, bringing a portable communion table to the bedside and administering communion.

Grief for a loved one may precede their actual death. Family from out of town are called and advised that the individual does not have long to live, and it would be a good time to come by and make a final visit and comfort them. If there are family members who have had disagreements with the soon to be deceased, it would be a good time to reconcile those disputes. The pastor from their church might also be called to provide communion, a song, some comforting words and possibly last rights. Some families try to make the dying individual as comfortable as possible by playing their favorite music, keeping the lights down low, having their favorite blanket and pillow on their bed and having a fan blowing to cool them (Mak & Clinton, 1999). Some palliative care/hospice organizations suggest that children are included in this dying process. The dying patient and their family still have a choice of where their death is to take place. It can occur at home or at a facility.

Even if the dying individual passes away in the hospital, provisions are usually made by personnel for a private room and allowing more than the two visitors per room stay with the patient. The hospital chaplain may also visit and offer assistance. Twenty-four-hour nursing care would be provided, and the bed, oxygen and other necessary supplies would be readily available. The doctors also periodically stop by the patient's room to offer what assistance they can. When the patient passes away, he/she is taken to the morgue to await personnel from the mortuary to come and claim the body (Teno, et al, 2004). Those eighteen and over can make their choices known well before the time comes by completing advance directive forms.

Palliative care is not solely for the elderly, pediatric palliative care is starting to appear more in the literature. The Pediatric Palliative Care Library has 56 articles listed on the subject since 2010 (pediatripalliative.com/publications & Spicer, Macdonald, Davies, Vadeboncoeur & Siden, 2015). Pediatric palliative care is still directed at creating a good end of life experience for the patient, but it also strives for a good experience for other family members as well (Bouri, Danai, Petros & Paraskevi, 2017; Brock, Cohen, Sourkes, Good & Halamek, 2017 & Brown, Nelson & Beuscher, 2017). At first, some parents may be resistant to this plan of care, but after they are fully informed about it and experience it first-hand, they readily recommend it to other families (Thrane, Mauerer, Cohen, May & Sereika, 2017).

The family's participation in each of these phases of their loved one's death can help to ease them into their grief a little less abruptly. If they are there comforting the individual and trying to make the transition as easy as possible, it may help them to feel

better about the situation. It also does not hide anything from the children in the family

that will also be grieving.

Grief and Types of Losses

Grief is the response an individual experiences from a personal loss. Personal

losses can take many forms. They can come in the form of material objects, such as a

home, job, divorce, or a pet, among others. Each of these experiences can be equally

upsetting to the individual, no matter what age. A home is more than a place to live, it is

a comfortable place with all a person's belongings and where he or she can feel at ease

(Fiorini & Mullen, 2006; & Smith, Robinson & Segla, 2017).

When a person moves from familiar surroundings, it may upset their entire way of

life. Several weeks may elapse before belongings are unpacked and in clear view once

again. In moving, there is a new address, new surroundings, and new neighbors and

friends. While this may be an exciting adventure to some, for others, it may prove

difficult to adapt. The familiar places and people are gone, and it is up to them to make

new friends and learn their way around. Losing a job involves similar adjustments in

social interaction and no longer having the familiarity of a steady income.

Another potential change may involve a parental layoff. With employment

terminated, there is no longer interaction with co-workers or daily reporting to

supervisors. The lack of income will also affect the downsized employee, with anxiety

rising as unemployment continues and a source of income remains unsure. Depending

upon the person's age, education and experience, obtaining a new job may not be an easy task. Gone are the days of stopping by the personnel department to complete an application; most employers use on-line applications and interviews. For someone that is not familiar with this process, it can be difficult. The job seeker may take turn downs personally and feel as though they are no longer a vital part of the work force. If there is a child in the home, they may be witnessing all of this and become confused.

For a child, a parents' divorce can also be a source of grief. What once was a single home with a mother and father has fractured, with, usually, one parent remaining in the home full time and the other having a separate residence. The children naturally miss their parents both being around them daily. Going to the other residence may be a difficult thing to do, as well as leaving one of their parents behind to spend time with the other. One parent may malign the other, try to get the children to take sides, or bring a new "dad" or "mom" into the picture. Seeking comfort from a pet can be a good alternative.

Over 69 million households in the U.S. owned a dog, and over 74 million a cat, in 2012 (AVMA, 2013). Most pet owners feel their animals are part of the family, even considering them one of the kids (Coren, 2011). Owners will oftentimes have pictures of their pets displayed in addition to ones of their children and grandchildren. Coren (2011) reports, "On average, dog owners have about seven photos of their dogs displayed in their homes or offices and … a photo album dedicated to only pictures of their dogs (p.3)". Families do not just live with their pets; the pets accompany them most places they go. Their pets go camping, to concerts, to the store and wherever else they may be allowed. Children, too, tend to spend a great deal of time with the family pet. The care of the pet

may be their responsibility. The child may even encourage the pet to sleep in their bed.

With the pet's inevitable death, the loss may cause a child great sadness.

While the above-mentioned losses may not all directly affect the child, they do

see what it is doing to their family. The experience of these losses may provide a

foundation for grief. The child begins to understand what a loss entails by observing

their family member's sorrow and dealing with their own grief of a loss first hand. Thus,

when a family member passes away, they use that foundation to begin their grief journey.

Adult Grief

Adults have usually experienced many losses and have a good understanding of

death. As young adults, they may grieve the death of a grandparent, as well as other

elderly relatives. In middle age, it may be their parents who pass away. As they reach

their sixties and beyond, they may lose many friends and acquaintances. This leads to

thoughts of their own impending death. In preparing for their death, Feldman (2015),

advises many adults complete a "Life Review." This review looks back at their

accomplishments in life and assigns worth. This evaluation is a form of coping with their

loss of life.

Coping with grief can take many forms for an adult. Some may cry and want to

be alone, while others may desire the love and companionship of others. A grieving adult

may reminisce about all the interactions they had with the deceased, both happy and sad.

They may feel it is their obligation to create some type of memorial in honor of the

individual who has passed away. Support group meetings offer another outlet for an

adult griever to express and understand their feelings. These groups are made up of

people who have shared life experiences. Visiting the grave of the deceased and keeping

it adorned with flowers is comforting to some. Others find burying themselves in work or

projects helps with managing their loss. Many of these coping tasks are not something

one would observe in children.

Childhood Grief

Much of the literature written on childhood grief focuses on complicated,

traumatic grief and disenfranchised grief. The grieving child may experience a variety of

maladies. Some of the behaviors observed include anxiety, depression, aggression, sleep

disturbances, attention-seeking, withdrawn behavior, school difficulties, jealousy, guilt,

enuresis, anti-social behavior, fearfulness of experiencing another death and somatic

complaints, such as stomach ache or headache (Bolton, et al 2016; Giovaanola, 2005;

Hibbert, 2017 & Willis, 2002). Some important aspects to consider when studying

childhood grief are how it differs from the adult grief, children's understanding of death,

how children cope with grief, and assistance that is currently offered to childhood

grievers.

How children's grief Differs from adult grief

A child's grief does not necessarily look like, or follow the patterns of, adult grief.

While a child may appear sad or tearful over the loss of something or someone, that may

be short-lived. Children usually do not take the time to actively reminisce about their

relationship with the deceased, nor do they partake in many of the other grief tasks that

adults do unless an adult includes them in their plans (Cohen, Mannarino, 2004; Eppler,

2008 & Webb, 2003 & 2011).

Despite their age and mental development, children are still capable of experiencing some degree of grief (Black, 1998). Whatever their loss may be, to discount or overlook their feelings would prove a great disservice to them. Children may relive their grief each time they attain a new developmental level. They look at the loss in a different way based on their experience and how they understand it (Biank & Werner-Lin, 2011).

How children cope with grief

Children may begin to understand grief, but how do they cope with it? Bugge, Darbyshire, Rokhold, Harystvedt & Helseth (2014) concluded that children need their parent's help to understand and cope with their grief. In their study, parents reported that their grieving children "asked a lot of tough questions" as they were trying to make sense of the death. Also, children in the study liked to look at pictures of the family member who had died (Bugge, Darbyshire, Rokholt, Hayshedt & Helseth, 2014). Not only do these children have a lot of questions, they also report seeing their dead family member in dreams.

Dreaming about the deceased and interacting with them can be comforting for the grieving child (Adams & Hyde, 2008). Writing and drawing pictures helps children with their grief, as well (McClanahan, 1998). One child spoke of remembering something their brother or sister did for them, or having something that belonged to their brother or sister. (Thompson, et al 2011). In another study, a grieving sibling spoke of a teddy bear that sits in the seat where his brother once sat (Foster, et al, 2011). A few siblings spoke of taking possession of his or her deceased brother's or sister's toys to remember them. Still another child spoke of wearing the dog tags that belonged to his brother. These

children remarked that remembering the deceased child in some way helped them to deal

with the loss. This differs from Freud's conclusion that grievers need to wipe their loved

ones from their memory to go through the healing process.

Religion was reported as a big part of the way families coped in the Thompson, et

al (2011) studies. Two sets of parents told their surviving child that their brother was

now a star in the sky. The children took comfort in seeing a particular star shining and

believing their brother was doing ok (Dowden, 1995). Several children also reported to

their parents that they would one day be rejoined with their brother or sister in heaven.

One child spoke of needing to pray more and read the Bible for comfort. And lastly, one

child spoke of a memorial service their family held in the backyard (Thompson, et al,

2011). Despite needing an outlet to assist in dealing with their pain, however, the grief of

these children can sometimes go unrecognized.

Walter & McCoyd (2009) define disenfranchised grief as "grief that is not

recognized, validated, or supported by the social world of the mourner (p. 18)".

Disenfranchised grief can affect many different groups of people, including healthcare

workers who lose their patients (Crowe, 2017; Lathrop, 2017; MacDermott & Keenana,

2014; Mortell, 2015; and Spidell, et al, 2011), family mourning the loss of an inmate

(Beck & Jones, 2007; Long, 2011; & Metzler, 2015), grief of same sex partners (Jenkins,

Edmundson, Averett & Yoon, 2014: & McNutt Oksana, 2013), or the loss of a child at

birth (Lang et al, 2011; & Milvihill & Walsh, 2014). Sibling grief is now also included

under the heading of disenfranchised grief (Godfrey, 2016; & Robson & Walter, 2012).

The suffering of a brother or sister is often overlooked. Condolences are offered the

child's parents, but very little is said to the siblings of the deceased child, further

devaluing their grief. Sibling loss, however, occurs on a daily basis, and with that loss

comes grief.

Children's understanding of death

One of the biggest differences between an adult's and a child's grief has to do

with their understanding of death. It is not until children reach school-age that they begin

to comprehend the meaning of death (Hunter & Smith, 2008). Bonoti, Leondari &

Mastora (2013) also concluded that children who had experienced a death(s) were more

advanced in their understanding than their inexperienced counterparts.

The first studies of children understanding death were conducted in the 1940s-

1960s (Slaughter, 2005). One such study consisted of having children draw pictures or

tell stores of their experiences of death (McGowan & Davies, 1995). After her study,

Nagy determined that death was "personified" in the 5-9-year-old group (Nagy, 1948).

Carefully analyzing the pictures these children drew assisted her in coming to this

conclusion. The next group of childhood grief researchers trying to determine children's

understanding of death incorporated cognitive developmental concepts in their studies to

get a clearer picture of what was going on in the mind of the child witnessing the death of

someone close to them.

In 1960-1970, researchers of childhood grief borrowed concepts from Piaget on

Cognitive Development (Kane, 1979; Koocher, 1973; Safier, 1964; Speece & Brent,

1984; &White, et al, 1978). They constructed interview questions based on the stage

Piaget reported that a child was in. These studies helped the researchers begin to

comprehend the understanding children had at different ages and at what age death understanding starts to take place.

Slaughter (2005) asserts that between 4-6 years of age, children reported that, in humans, the functioning of organs, such as the heart and lungs, were necessary for life. She concludes that grasping this idea gives rise to the understanding that death occurs when these organs no longer function (Slaughter, 2005). While the definitive pronouncing of death is when the brain ceases activity, if a child starts to realize that the heart stops beating, and the individual is no longer taking breaths, when they die, it is a great accomplishment. While this may be a first step in determining at what age death starts to make sense to the child, still other researchers assert that their understanding involves four main parts.

Bonoti, Leondari and Mastora (2013) and Machajewski & Kronk, (2013), discuss four parts that make up the young child's comprehension of death. The first is the "irreversibility factor (Machajewski & Kronk, 2013, p. 221)". Children believe that everything that breaks can be fixed. Their favorite toy breaks and dad glues it back together. They have a cut on their finger, and, with a band aid and time, the cut heals. Thus, when the child is told that grandma was sick and has gone to heaven, he or she does not understand. They believe the doctors should be able to fix her. Children who understand the irreversibility factor acknowledge the fact that grandma cannot be brought back and there is nothing the doctors can do to change it (Machajewski & Kronk, 2013).

The "irreversibility factor" is closely related to the next concept that children have a difficult time understanding, the finality of death (Willis, 2002). Grade school children and younger are still struggling to understand time and permanence. They do not grasp

how long a week is, much less the meaning of forever (Willis, 2002). Never seeing grandpa again does not make sense. Grandpa may not live with them, but they still go to visit him. Understanding that grandpa will no longer be living at the location where they always went to visit him must be explained to them. This leads to the next factor, inevitability.

The concept of inevitability is another that children struggle to fathom (Willis, 2002). The idea that we are born, and, someday, we will all die, is hard for them to comprehend. Death occurs in different people at different times. They begin to observe this when they attend funerals of children and middle-aged adults.

Yet another difficult issue for children to understand is the idea of "causability," as per Willis (2002). That their grandparent's death may be due to old age is hard for them; it may not make sense. They may play with toys that belonged to their dad when he was little. They are old, and yet they do not die. They see stories about some people living to 100 years of age or older. They may not recognize why these people live that long and grandpa cannot. Based on the aforementioned factors, researchers have determined a general age for understanding death.

The researchers concluded that it is not until around 5-6 years old that children can understand that everyone dies and that, once they have died, they cannot come back to life (Kastenbaum& Aisenberg 1967; Koocher, 1973; & Spencer & Brent, 1992). Recognition of these two facts represent an important step towards a full understanding of death.

Children between the ages of 5-6 years old fall into the end of Piaget's

Preoperational Stage and the beginning of the Concrete Operational Stage (Piaget, 1952).

At this age, they are beginning concrete thinking, which involves logical thought. Less is

left to the imagination. More things are thought through and analyzed, resulting in a

conclusion. Most of what research we have on children's understanding of death shows

very little individual differences in children. While children may start to understand

death by age 5-6, the level of their coping skills may be called into question.

Sibling grief

Sibling relationships are unique; the loss of a sibling is profound. Eighty to

eighty-five percent of children grow up as a sibling worldwide (Conger & Kramer, 2010).

These children share their entire lives with their brothers and sisters As Buist &

Vermande (2014) advise, "sibling relationships are usually the longest lasting of one's

life (p. 529)". Positive sibling relationships can contribute to the overall mental health of

the individual. Whether they are good or bad, many things can be learned from the

sibling relationships, such as conflict resolution, emotional regulation, negotiation,

persuasion, problem-solving, comforting another person and providing security. Positive

sibling relationships can even lower the risk of anxiety, depression and aggressive

behaviors (Buist, Devkovic & Prinzie, 2013; Davies, 2014; Gass, et al, 2007; & McHale,

et al, 2012).

Sibling attachment

Grief may be affected by the degree of closeness the surviving sibling

experienced with the deceased child. If the deceased was an older brother or sister that

provided guidance and direction to the younger surviving sibling, the grieving sibling

may be at a total loss. If the surviving child was the big brother or sister to the child that

has passed away, they may feel as though they have lost one of their purposes in life, to

assist in their care. Several researchers have concluded that the closest siblings are twins

(Gass, Jenkins & Dunn, 2007).

Several studies have been done focusing on the topic of twins. The extreme

closeness of these individuals has been well documented. One research study advised

that possibly the twins share some of the same genes, causing a high degree of emotional

closeness (Mark, Pike, Latham & Oliver, 2017). The death of one invariably forces an

unwanted separation.

The grief of losing a sibling

Siblings find it hard to imagine life without their brother or sister. When their

sibling dies, however, that is exactly what they must do. To successfully recover from

this loss, they must go through the processes of grieving and coping. Depending upon

their age, they may have a very good understanding of what happened or may require

assistance in grasping the situation. The psychosocial aspect of the grief may best be

understood through the developmental theories of individuals such as Erikson.

Preschool and school-aged children are much more aware of their surroundings

and what is going on with their family and all that they interact with. At approximately

age 5, they begin to comprehend what death means. Understanding that they will never

again see their family member may be hard for them to handle (Buist, Devkovic &

Prinzie, 2013 & Huner & Smith, 2008).

As discovered in this literature search on the topic of sibling grief, very little has been written on helping children get through the early stages of grief. Interventions seem to be utilized only when symptoms become severe. Suggestions for parents in assisting their grieving children by paraprofessionals comprise the bulk of the literature. Experts in the field seem to reserve their studies and interventions for extreme cases. If these professionals would intervene earlier, the grief a child experiences may not have the opportunity to reach the advanced stages that require more invasive measures (Cohen & Mannarino, 2004).

Whether the eldest child in the family, the youngest, or one in between, to lose a brother or sister can have a tremendous and devastating effect. It may show up as a physical disorder or more of a mental ailment. With this more cognitive affectation, there is the very real possibility that the grieving sibling may be misdiagnosed with a disorder they do not have and treated unnecessarily.

Unresolved sibling grief may follow the child into adulthood and affect relationships they have with others. The sibling griever, who has now become an adult, may not be able to express themselves to others since he or she has kept their feelings to themselves for many years. This grief may also play a big role in how they raise their children. They may be domineering, or unavailable, depending upon how their grief affected them as a child (Magen & Kekel, 2006).

Sibling grief has many factors that play into it. Parents are experiencing the biggest hardship in their life–the loss of a child. They may not be available to help the surviving children deal with their grief. The children may also want to keep from placing another burden on their parents, so they do not voice their feelings. The sibling griever

may not even feel they have a right to experience grief. Few, if any, adults have openly

expressed their condolences to them. If the sibling griever has not lived through many

losses so far in their life, they may not fully understand what this event means.

Depending on the circumstances of the death, the sibling may even feel responsible for it.

The loss of their brother or sister may mean the loss of their best friend.

To fully understand this concept, we need to rely on several theories to guide us,

as well as ascertain what developmental stage the child is in, to help us determine what

their understanding of death is. If the child has witnessed other deaths or losses, the

events surrounding the death may not be as much of a surprise. Another aspect to

consider is if the death is a planned death, such as the soon to be deceased is a cancer

patient in hospice care. Some researchers believe this helps the individual better cope

with the loss, while others do not feel that this makes a big difference. How close are the

siblings? The closer they are, the harder the loss may be.

In the next chapter, the methodology that was used will be discussed as well as

the methods that were used to carry out the research. Details on descriptive

phenomenology, the method best suited for this study, will be provided. The sample,

sample size and setting will be discussed. Data collection will be explained as well as the

steps of Giorgi's Data Analysis reported. Rigor will be accomplished via Lincoln &

Guba's techniques.

Chapter 3: Methodology and Methods

The literature on sibling grief includes a wide range of methodologies, but there is not adequate attention to this problem. A qualitative approach was used to explore the experiences of children's loss of a sibling, as viewed by the grief counselors that work with them. This chapter includes a discussion of the methodological approach and the methods, or procedural steps, which were used in this study.

Methodology

Phenomenology was the best method to use for this study as the questions to be answered required a complete description of lived experience. The experience of sibling grievers was elicited through the storied accounts of counselors who work with them. These specialists had close access to the experiences of the children who are the subject of this inquiry.

Husserl – the founder of descriptive phenomenology

A descriptive phenomenological approach was used. Descriptive phenomenology was founded by Edmund Husserl (Abalos, Rivera, Locsin & Schoenhofer, 2016). Husserl (1859-1958), was a mathematician and philosopher. In blending those two disciplines, he was able to rigorously investigate the meaning of a person's "lived experience" (Abalos, Rivera, Locsin, & Schoenhufer, 2016 & Behnke, 2018). His math background helped him to formulate the steps he followed in research. He also borrowed mathematical

terminology to describe various aspects he believed to be necessary in his type of

research, such as bracketing (Behnke, 2018; Hill, 2013 & Sawicki, 2018). In philosophy,

he was able to explore the deeper meaning of his findings. His mentor was Franz

Bretano, a former priest and philosophy instructor in Vienna. Bretano is credited with

introducing Husserl to the history of philosophy, descriptive psychology and phenomenal

intentionality (Dewalque, 2013). On this foundation, Husserl went on to research,

describe and practice descriptive phenomenology.

Husserl's research opposed the Cartesian model of his day, mind-body dualism,

which is the belief that the mind and body are separate entities (Mehta, 2011). Husserl

felt that one method humans learned was through sensual encounters and those

encounters of seeing, hearing, tasting and touching objects were imprinted on the brain

(Behnke, 2018). Those experiences could not leave their mark on the brain if there was

no connection between the mind and the body. Therefore, mind-body dualism was not an

accurate depiction of how humans experience things, according to Husserl.

Husserl's description of the relationship between the mind and body in human

beings led to the "lived-body" Merleau-Ponty speaks of. Merleau-Ponty stated that the

body is not an object, but, rather, it is part of the mind-body connection that we all have

(Mehta, 2011). In addition to this connection, the human being's mind also has a vast

memory. This memory is part of the consciousness Husserl writes about (Lopez &

Willis, 2004).

There are certain aspects of an experience that are constant from one person to the

next, according to Husserl. He calls these aspects, "universal essences or eidetic

structures" (Lopez & Willis, 2004, p. 728).   In analyzing the interviews of participants,

these essences were discovered, as they were repeated by most, if not all, of them. Some

interviewees discussed aspects of an experience. Husserl, however, believed that there is

a "central core" that can be teased out of the interviews to get a better description of the

subject at hand (Husserl, 1982, p. 221-222). Yaw (2015) used the analogy of a door to

describe the distinction. Some participants may recall certain aspects about the door,

such as the color, door handle or design on it. However, their focus will always return to

the door itself–the "central core" (Husserl, 1982). Another aspect of descriptive

phenomenology involves a practice called "epoche" (Dowling, 2007; Englander, 2016:

Hamill & Sinclair, 20910; Reiners, 2012; Sousa, 2014 & Yaw, 2015).

In descriptive phenomenology, a researcher employs *Epoche* (Dowlling, 2007;

Englander, 2016; Hamill & Sinclair, 2010; Reiners, 2012; Sousa, 2014 & Yaw, 2015).

Epoche is the practice of putting aside any previous knowledge and experiences he or she

has with the subject matter when they are interviewing the participants (Hamill &

Sinclair, 2010). As a researcher begins his or her study, they will disregard any prior

knowledge of the subject they are investigating. Thus, the published research study

includes only that information revealed by the subjects, and not any presuppositions by

the researcher. Past experiences were also noted and discounted, to avoid influencing

questioning of the participants or analyzing the data and drawing conclusions. In

following this practice, a researcher will discover what the participant experienced.

Descriptive phenomenology

This type of research involves four important concepts – bracketing, intuiting,

analyzing and describing (Hamill & Sinclair, 2010). Husserl felt it was very important to

bracket one's knowledge and beliefs to see more clearly what the participant is reporting

to the researcher–intuiting. In analyzing, the researcher can arrive at "the core" that Husserl spoke of, with describing the findings as the ultimate goal (Hamill & Sinclair, 2010).

In bracketing, or *Epoche*, the researcher looks at concepts anew through the eyes of the participant without involving any preconceptions of the subject being studied. Putting aside past knowledge and experience is necessary, according to Husserl. He believed the best way to understand something is by analyzing descriptions of first-hand observers, those who have "lived it." Those individuals had experienced something and committed that something to memory (Dowling, 2007; Englander, 2016; Hamill & Sinclair, 2010; Reiners, 2012; Sousa, 2014 & Yaw, 2015).

In drawing that memory out of the participant in an interview, the researcher can get a clear picture of what it feels like to experience this phenomenon (Husserl, 1982). He or she can then continue to gather information on the topic by questioning the participant more, to gain further insight into every aspect possible. This will provide an unobstructed view of the concept being studied and provide much needed information.

Husserl recommends that the researcher continually evaluate their ability to bracket their knowledge, experiences and biases during the entire process of the research. Should the researcher fall short of this requirement, it is then up to him or her to redouble their efforts and resume the study with greater objectivity. This process is called "transcendental subjectivity" (Lopez & Willis, 2004; Reiners, 2012 & Sloan & Bowe, 2013). Hamill & Sinclair (2010) advise that bracketing is not complete until the study is complete; therefore, a researcher must continue to bracket through information gathering and beyond.

Information gathered from each participant was analyzed to get at "the core" of the data, as Husserl described it (1982). This core is a central item that occurs in each of the interviews. It helps to build a definition that has been shared by all those who have experienced this phenomenon. Once defined, all will know what a particular experience is composed of by the researcher presenting his or her description of the experience.

This description should be a full report of every aspect the researcher discovered through interviewing the participants. It should not only involve "the core," but all the subcategories that presented as a recurring theme in the interview. To get a full understanding of the subject matter, the reader will need to be provided all the details. Not only is the researcher providing information, he or she is providing opportunity for future research (Hamill & Sinclair, 2010). Martin Heidegger, a student of Husserl's, built upon Husserl's method of research and created his own type of phenomenological research–interpretive phenomenology.

Descriptive versus interpretive phenomenology

Interpretive phenomenology, or hermeneutic inquiry, created by Martin Heidegger (1889-1976), was developed in response to Husserl's descriptive phenomenology. Heidegger did not believe the researcher, or the subject, could bracket the knowledge and experiences he or she had with the phenomenon. He described this as "being in the world" (Lopez & Willis, 2004, p. 729). Heidegger felt that the true meaning of things was hidden to the participant, and that it was up to the researcher to interpret that meaning. He felt that expert knowledge on the subject being studied was helpful in doing research, as it could be used as a guide. The researcher's expertise,

according to Heidegger, was also a valuable tool in analyzing and interpreting the

findings (Lopez & Willis, 2004 & Sloan & Bowe, 2013).

Methods

Identifying the behaviors that sibling grievers exhibit due to the loss of a brother

or sister was one of the aims of this study. These children have been misdiagnosed in the

past and placed on medicine protocols that may have been unnecessary. School-aged

sibling grievers experience a variety of behaviors that are not often observed in the adult

population. To identify grief behaviors in these children, it is important that we identify

the wide variety that have been observed by Grief Counselors that have worked with

them. If teachers, counselors, healthcare professionals and school nurses understand

what behaviors to look for, these sibling grievers may be identified early on and

assistance provided before it becomes an invasive issue.

For purposes of this research, a descriptive approach was appropriate, as little had

been published on the topic from a child's perspective, and this description was needed.

Much of the studies had been from the parent's viewpoint. As a result, we have little

first-hand knowledge of what it is like to be a child who has lost a sibling. In this study,

an indirect approach to eliciting the child's perspective was used. The professionals who

work with them served as a substitute to directly interviewing the children involved. In

interviewing these professionals, they were asked to put aside any previous first-hand

experience they have on the subject, as the researcher did. The results can be described

as the "essence" of what the sibling griever is experiencing (Lloyd, Sailor & Carney, 2014 & Sloan & Bowe, 2014, p. 1293).

Human Subject Research training was completed via the NIH Office of Extramural Research. On completion of that training, an IRB application was electronically submitted via IRB Net. Internal Review Board (IRB) approval was obtained prior to data collection

Sample and Setting

Grief Counselors, having worked with at least three or more children, 6-12 years of age, who have experienced the loss of a sibling within the last year, were interviewed. Phone calls were made to organizations that provide individual grief counseling to children who have lost a brother or sister.   Follow-up e-mails were sent with the attached recruitment flyer (See Appendix A – Solicitation flyer). The researcher conducted one-on-one interviews with qualifying and consenting individuals. All interviews were conducted via a recorded telephone conversation.

Sample

In researching the question of an appropriate sample size in a qualitative study, there seems to be no hard and fast rule. In fact, the response by most qualitative researchers is, "it depends" (Albert, O'Connor & Below, 2012; Baker & Edwards, 2012; Braun & Clarke, 2013; Creswell, 2013; & Munhall, 2012). Some justification for this reply includes the fact that in qualitative studies, much more information is gathered from each participant, and as a result, requires much more in-depth data analysis. Detailed interviews are examined, at great length, to obtain commonalities. These commonalities

are further subdivided and regrouped to get at the core of what a certain phenomenon means, and to identify the various characteristics that are also attributable to it. Interviews are conducted until "saturation" (the point at which no new information is forthcoming) is achieved (Baker & Edwards, 2012; Creswell, 2013 & Munhall, 2012).

Since no definitive number has been established for cases needed in a qualitative study, this research enlisted ten participants who have counseled three children or more regarding sibling grief. The result was at least 30 children's behaviors and expressions to analyze. Additional input provided by each of the grief counselors was also be included in the analysis of this phenomenon.

Data Collection

A semi-structured interview was used to gather data about the behaviors of grieving siblings from the individuals who are assisting them to work through their grief, followed by an elicitation of their stories (Kallio Pietila, Johnson & Kangasniemi, 2016). The researcher provided some redirection to gather as much rich data as possible (Interview Questions – Appendix B). The interviews were audio recorded and transcribed by the researcher. All names and identifying features were removed from the transcript so that neither the grief counselors nor the children were identifiable.

Confidentiality was further maintained on the sibling grievers via deidentification. They were assigned a code number, as several researchers advised to do (Clay, Ozanne-Smith, Watson, Congiu & Fox, 2006; Johnson & Bridge 2015 & Petrova, Dewing & Camilleri, 2016). All "direct identifiers" were removed at the suggestion of researchers such as Rothstein (2010). Data was stored in secure electronic files.

Ten Grief Counselors were recruited and interviewed for this study. The criteria used to determine participants involved Grief Counselors who worked with at least one school-aged sibling griever during their career. The primary investigator in this study constructed a list of potential participants from an internet search of Pediatric Grief Counselors. These individuals were contacted by either e-mail or phone. Three attempts were made at contacting each Grief Counselor. If the investigator was unable to speak with them by phone or e-mail, no further attempt was made. Two Grief Counselors recommended additional individuals, who were then added to the contact list. The Counselors were assigned a number for identification purposes based on where they were on the list of potential participants.

For those that agreed to participate in the study, demographic and consent forms were sent via e-mail and the completed forms were returned to the primary investigator. Dates and times for phone interviews were mutually agreed upon. Participants were advised that they would receive a $10 Amazon gift card in appreciation of their participation. The gift card was sent by e-mail. Once the gift card had been delivered, e-mail addresses were destroyed. The initial list of potential participants was also shredded.

At the assigned time, the interviewer initiated the phone call to the participant. Upon verbal consent, the interview was started. Using a digital recorder with an earpiece that picked up both the interviewer and the interviewee, the conversation was recorded. Once the interview was completed, the investigator transcribed it and stored the transcripts in a protected database. These transcripts were then uploaded to a google drive. An analysis team consisting of a fellow PhD student, the primary investigator's

mentor and the primary investigator was formed for data analysis. Accessibility to the google drive was provided solely to the members of the data analysis team. The team reviewed Giorgi's steps of data analysis prior to beginning the analysis of the transcripts, as this was the method that was chosen, and, beginning with Step One, the process was begun.

The first step of Giorgi's method consisted of reading the transcripts, with the second being to re-read them. Each of the team members accomplished the first and second task prior to meeting. Step Three involves, "Identifying the transition units of the experience." To accomplish this task, each team member extracted meanings of what was reported by the Grief Counselors from their meeting with the sibling grievers. These meanings were supported by direct quotes from the transcripts. The committee met and discussed their take on the interviews with supporting quotes. The fourth step is to clarify and elaborate the meaning by relating constituents to each other and to the whole. The committee completed this step by determining units (patterns) that helped to describe the experience. These units were derived by locating them in several transcripts. To clarify the meaning, the units/patterns were dissected to come up with the themes that, when joined together, explained the patterns. The next two steps involve reporting findings in the language of the participants and converting the terminology into the concepts or language of science. Since the Grief Counselors already had provided their accounts in scientific language, we were able to use their quotes. The final step is to integrate and synthesize the insight into a descriptive structure of the meaning of the experience. The committee found that by integrating these patterns, and the themes that made up the patterns, the meaning of the experience began to emerge.

One to two transcripts were chosen each week. Committee members presented their analysis to the group, and, after discussing it thoroughly, a final decision was made on the content of the interview and how it related to the research question: "From the experience of a Grief Counselor, what are the behaviors and expressions of school-aged children who have lost a sibling?" The participant's interviews included substantial amounts of rich data for the committee to analyze. After examining approximately half of the transcripts, several patterns began to emerge.

The counselors provided storied accounts, as they recalled them, from sessions they conducted with these sibling grievers. Some of the children had experienced the loss of their sibling through sudden tragedy—crushed by a dresser, a fall off a cruise ship—while others involved brothers or sisters who had a chronic illness. A semi-structured interview was utilized. However, more valuable information was gleaned by allowing the counselors to take the lead in the conversation. Participants were urged to provide details of individuals they worked with in the past.

Data Analysis

Several researchers use Giorgi's (Giorgi, 1985) steps of data analysis (Han, Han, Lee, Kwon & Choe, 2016; Ntlale & Durma, 2012 & Russell & Smith, 1999; Speziale & Carpenter, 2007), which are outlined below.

Giorgi's Steps of Data Analysis

1. Read the entire description of the experience to get a sense of the whole.

2. Reread the description.

3. Identify the transition units of the experience.

4. Clarify and elaborate the meaning by relating constituents to each other and to the whole.

5. Reflect on the constituents in the concrete language of the participant.

6. Transform concrete language into the language or concepts of science.

7. Integrate and synthesize the insight into a descriptive structure of the meaning of the experience.

A team of researchers analyzed the data in this fashion, including my Chairperson, and a student of phenomenology.

Rigor

Determining the validity of a study is considerably different in a quantitative study versus a qualitative study. Often this is referred to as trustworthiness and credibility (Cope, 2014**). Lincoln and Guba's Trustworthiness in a Research Study** has been used by many researchers. The four parts are: credibility, transferability, dependability and confirmability (Lincoln and Guba, 1985). Techniques for achieving credibility–the first of these four important aspects of trustworthiness include prolonged engagement (spending an appropriate amount of time with the participants), persistent observation (obtaining as much information as possible regarding the subject being researched), triangulation (one method involves using several people to analyze data), peer debriefing (having an uninterested peer review the findings), negative case analysis (looking at potential solutions that are contrary to what appears to the researcher), referential adequacy (putting some of the data aside, reviewing the data that is left, then pulling up the data that was set aside to see if the same conclusions are arrived at with

both data sets), and member-checking (having participants review conclusions to see if

they make sense to them).

Further, Lincoln and Guba (Lincoln and Guba, 1985) described techniques for

establishing transferability, including thick description, techniques for establishing

dependability (having another researcher not involved in the study evaluate the accuracy)

and techniques for establishing confirmability (audit trails), triangulation, and reflexivity

(involving the researcher constantly evaluating himself or herself and the process he or

she is using) (Cohen & Crabtree, 2006).

To achieve prolonged engagement, the first step in establishing credibility, a

thirty-minute initial time frame was established with each of the participants. This

amount of time was sufficient to gather enough information. Additional meetings were

not required. Along those lines, it was important to allow each participant enough time to

tell the full story of the individuals they have counseled. The researcher also needed to

pay close attention to items such as the vocal intonation, the participant's choice of words

and any additional information they gave regarding the counseling sessions. These steps

provided for the persistent observation that Lincoln & Guba (1985) note as their next step

for establishing credibility.

The third step under this category involves triangulation. Triangulation was

achieved by having the analysis conducted by a team of researchers. Different

researchers will, undoubtedly, analyze the data from different angles. When similar

conclusions about the data are determined by each of the researchers, successful

triangulation will have occurred. In addition to the team of researchers analyzing the

data, a fellow PhD student also reviewed the findings to provide peer debriefing (Step

four).

Step four involves negative case analysis. In analyzing the data, all potential

avenues were explored, including opposite conclusions to those already determined. By

reviewing these opposing outcomes, they were ruled out and previously accepted

conclusions were more strongly supported. The next step in establishing credibility

involves dividing the data. In step six, referential adequacy, data is divided into two

separate sets. One of the sets is analyzed and then the other. Both sets are then compared

to determine if the same conclusions are reached of them separately as together.

The final step in establishing credibility is using a technique called member

checking. In member checking, participants are contacted and provided the conclusions

arrived at by the team of researchers in the data analysis. In this study, we reached out to

one to two participants who were advised of this in advance and agreed to it, to determine

if they agree with the conclusions that have been drawn by the researchers. Lincoln &

Guba (1985) believe that credibility will be proven if all of these steps have been taken

and positive results have been achieved.

Transferability is another part of Lincoln & Guba's (1985) process for

establishing trustworthiness. This technique requires the researcher to provide as much

detail as possible. That detail was gathered from dialogues with the participants. The

researcher allowed adequate time for the participant to tell their entire story, encouraging

them to elaborate whenever possible, thus achieving a thick description of the

phenomenon. Dependability is another feature that Lincoln & Guba (1985) feel is

necessary to prove rigor.

The plan to show dependability rests with another researcher from the committee reviewing all aspects of the study for accuracy. Volunteers were solicited early on so, as the pieces of the study were completed, that individual began the task of reviewing them and reporting back on anything that did not appear to be correct or needed repairing. The final technique, according to Lincoln & Guba (1985) is confirmability.

Confirmability starts with reviewing the results of the external audit completed by the volunteer committee member when establishing accuracy. It then goes on to advise an audit trail is necessary. A table was constructed outlining all steps of the research. This table provided all the data needed for this step. Another aspect reviewed for this technique was the triangulation previously completed by the committee members in analyzing the data. The final step under confirmability involves Reflexivity.

Entire papers have been written on Reflexivity. Lincoln & Guba (1985) condense this task down to having the researcher remain transparent throughout the entire study. Reporting on each of the steps that were accomplished in the study and what the findings were are very important to divulge. In the process, the researcher should be evaluating themselves and the process being used. Several descriptive phenomenologists have used this method (Cheng, Chen, Liou, Wang & Mu, 2010; Cope, 2014; Kissorio & Langley, 2016 & Locsin & Kongsuwan, 2013).

Conclusion

This chapter discussed the methods that were used in this research on sibling grief. First, an internal review board approval was obtained. Upon that approval, organizations, as well as individual grief counselors, were contacted to locate an adequate

number of participants to provide enough information on the phenomenon of sibling grief

for a thick description. A semi-structured interview was used in the gathering of this

data. Confidentiality was accomplished via de-identification–participants were assigned

a code number and data was stored in secure electronic files. Data analysis was

accomplished using Giorgi's Steps of Data Analysis (Speziale & Carpenter, 2007).

Lincoln & Guba's (1985) techniques for trustworthiness were used to establish rigor.

Upon conclusion of this study, an answer to the research question of "From the

experience of a grief counselor, what are the behaviors and expressions of school-aged

children who have lost a sibling?" was determined.

RESULTS

Patterns & Themes

Pattern 1: Grief in children takes different forms

<u>Themes</u>

- Children's grief differs
- Wide variety of atypical behaviors (i.e. aggression, school difficulties and hyperactivity)
- Developmental understandings of death

Pattern 2: Sibling loss in childhood is a life-changing event

<u>Themes</u>

- Loss of a life-long companion
- New normal in the family unit
- Parents subsumed in grief

Pattern 3: Child grief has its own time

<u>Themes</u>

- Grieving periods in children (1 year – adulthood)
- Anniversaries, birthdays and holidays
- Loss follows a child throughout life

Chapter 4: Results & Discussion

Results from this study answered the research question: From the experience of a

Grief Counselor, what are the behaviors and expressions of school-aged children who

have lost a sibling?

Interviews with ten Grief Counselors revealed rich descriptions and patterns that

describe the profound experience of children who have lost a sibling. The Grief

Counselors who were interviewed provided detailed information on school-aged sibling

grievers via storied accounts of children they worked with in their many years of grief

counseling. Not only were we able to construct a detailed list of their patient's behaviors

(See Appendix D), we went a step further and could actually "see and feel" what the life

of a school-aged sibling griever was like. Based on the interviews with these Grief

Counselors, three distinct patterns were identified that included two to three sub-patterns

or themes. These patterns are: 1) *Grief in children takes different forms*, which included

the following themes: *Children's grief differs, wide variety of atypical behaviors,* and

developmental understandings of death; and 2) *Sibling loss in childhood is a life-

changing event,* including these themes: *Loss of a life-long companion, new normal in

the family unit* and *parents subsumed in grief;* 3) *Childhood grief has its own time,*

comprised of these themes: *Grieving periods in children, anniversaries, birthdays and

holidays* and *Loss follows a child throughout life.*

The participants in this study were ten experienced Grief Counselors, two male

and eight females. Two participants did not return a completed demographic form.

Seven of the participants had Master's degrees–five had Masters in Social Work degrees

with licenses in Social Work & Family Therapy, one had a Master's in Family

Counseling and one a Master's in Thanatology Counseling. Another had a Bachelor of

Arts in Counseling with a Certification in Thanatology. The years that they had been

Grief Counselors ranged from nine years to 30 plus years. None worked exclusively with

children; however, they all advised that children and their families were their primary

clients. Various types of counseling methods were utilized by the participants, including

group, family and individual counseling, talk therapy, art therapy, writing therapy and

play therapy; CBT and EBT were also utilized. The ages of children that they counseled

varied from preschool to 20 years of age. The interviews with these participants provided

the valuable information that led to the results of what it is like to be a grieving school-

aged sibling.

Results

The three patterns followed Husserl's description of "universal essences" in that

these same patterns were identified by the Grief Counselors, which led us to believe that

the beginnings of what it is like to lose a sibling as a school-aged child were starting to

emerge. The patterns identified were: *Grief in children takes different forms, Sibling loss*

in childhood is a life-changing event, and *Childhood grief has its own time.* Themes

within the patterns are exemplified below.

The following statement from one Grief Counselor summed up the overall phenomenon:

> Parents may be kind of absent from this child . . . it is something [sibling grievers]
>
> are going to carry. I think my colleague calls it their shadow. It's something that
>
> can follow these young people throughout their life (Participant #36, l. 9 & 31-
>
> 32).

Grief in children takes different forms

The first of the patterns, *Grief in children takes different forms*, was broken down into the following themes: Children's grief differs, wide variety of atypical behaviors, and developmental understandings of death. Many examples of these themes were identified by the committee members from the Grief Counselor's transcripts. (See Appendix D)

Children's grief differs

Adults that are grieving usually present with depression, a tearful state that may include a lack of concentration. Most health care professionals, and rightly so, will prescribe anti-depressants for grieving adults who are unable to cope without some assistance. Adults are not new to grief; they may have experienced the loss of grandparents, other older adults, and maybe even their parents. They possess a developmental understanding of what death means. They have learned to utilize various coping methods that are usually not observed in childhood grievers. While it is true that some sibling school-aged grievers can display some of these reactions, not all do, and it is usually short-lived with the childhood griever. Depending on the age of the child, their grief experience may be rather limited. As a result, their reactions to the loss of their sibling may not be what we would expect to see.

Participant #51 gave a poignant account of the experience of children's grief. He/she described it as unique, different from adult grief, and having profound pressures. His/her first, and summarizing, comment was related to the link to parents.

My first interaction with the siblings is with the parents also, so we do like a

family intake and [sibling grievers] are so hyperaware of the parent's emotional

reactions to the loss as well. That would be my first thing I notice is that they are

so tuned to the parents, about not wanting to get their parents upset. They will

limit their responses to me based on the parent's initial responses. And, it is a

reaction I first notice with a sibling loss, because this child lost their parents also

(Participant #51, l. 5-12).

The grieving parent is unique to the situation of a childhood sibling griever, and

unaware of their surviving children's needs.

If the child needs to be comforted, they cannot go directly to their parents,

because the parents may be deeply involved in their own grief and unavailable to their

grieving children. Another aspect of grief that is unique to this population is that they are

not in a continuous state of grief. Children cannot sustain a prolonged period of sadness,

and, as one Grief Counselor put it, "they have to do it in small dosages" (Participant #3A,

l. 34). The counselor suggested the reason for this is that "they only have a certain ability

to go to that bad part because it is so difficult for them. (l. 33)". What might be observed

in children is a short period of sadness, followed by running around and playing with

other children. Some school-aged sibling grievers may try to ignore and hide their

feelings to protect their parents. Others may act out, become angry or present behaviors

that are opposite of their usual ones.

The conduct of the parent has an effect on the child, according to one counselor

(Participant #3A). He/she believes that adults try to hide their grief from their children

and, thus, model composure rather than expression. Further, children "feel that loss of a

parent, too, [who are] not emotionally available" (l. 126-127). In this case, a mother did

not seem to recognize the possibility of grief in her daughter–

Mom was always constantly frustrated with the five-year-old because at home she

had a big temper tantrum and she was just difficult. Mom just didn't have a lot of

patience or energy because of everything she was going through. But I think that

was just an expression of her world being turned upside down. And, Mom had a

really hard time getting her head around that or being curious enough about it.

She just saw her as a difficult girl that was not cooperative (Participant# 3A, l.

133-137).

Another participant, when discussing school-aged sibling grievers, remarked, "You

cannot put all of them in the same category if you want to talk about the way siblings

grieve" (Participant #75, l. 10-11). So, as the next theme under this pattern suggests, "a

wide variety of atypical behaviors are observed in these siblings."

Wide variety of atypical behaviors

Many different behaviors were extracted from the accounts provided by the Grief

Counselors when describing the children they worked with. Some of the behaviors and

observations noted tend to be uncharacteristic of someone who is grieving. Participant

#36 advised, "they might have nightmares and it might last six months" (l. 51). And, "I

think the other thing you have to be aware of is impulsivity and inability to concentrate.

This is common for grieving children" (l. 56-57). Participant #12 advised, "A lot of

times, there may just be some anger that they are having difficulties with (l. 10-11).

Further, they have a lot of anxiety" (line 21). Participant #63 reports, "So, with the

brother, the older brother, he became angry, aggressive, shut down. He was fighting, and

he was a very bright young man" (l. 22-25).

Aggression and hyperactivity are not usually associated with grief in the adult world. The literature search revealed behaviors such as anxiety, depression, sleep disturbances, attention-seeking, withdrawn behavior, school difficulties, aggression and hyperactivity in children (Bolton, et al, 2016, Giovanola, 2005, Hibbert, 2017 & Willis, 2002). The symptom list (Appendix D) shows many more symptoms were observed and reported by the Grief Counselors. As previously mentioned in other studies cited, some grieving siblings can even be misdiagnosed with disorders such as ADD & ADHD.

This therapist, Participant #12, like others, has recognized that the experiences and behaviors of grieving children may lead to misdiagnosis and this is described clearly in his/her account. In the process of managing manifestations of behavior, he/she advises:

1. Recognize that feelings due to the loss are normal (l. 32-33).

2. Children need attention because families cannot usually give it (l. 47-48).

3. Children may need individual time (l. 84).

4. Children need supportive friends, peer support groups (l. 97-98, 125 & 179).

5. Others must look at "softer emotions," what's underneath behavior (l. 103).

6. Be aware of subtle changes (l. 127).

7. Be a cheerleader: "It's going to be OK" (l. 120).

Symptoms range from acting out to withdrawal, and several steps in between. Those children that display behaviors akin to their general demeanor are at greater risk of not receiving therapy early enough, or not at all. For example, if an introverted child quietly grieves the loss of their brother or sister, no one may notice. When a quiet child acts aggressive, however, because it is not the type response one would expect from this

child, they may be the first to get counseling. Similarly, if an extroverted child becomes

unusually quiet or does not get together with their friends, parents may get them into

counseling right away. Whatever the reaction, there will be some type of response at one

time or another after the loss of their sibling (Black, 1998).

> Participant #63 shared, so you had one that was extroverted and the younger one
>
> was introverted. And, for the teacher, the quiet child is not going to be so much
>
> of a problem. But, production of work decreased, his focus was affected, and it
>
> wasn't because he had ADD. It was because he was traumatized and grieving (l.
>
> 33-38)

Luckily, the teacher picked up on this child's grief and he was able to get the assistance

he needed. That is not always the case.

Developmental understandings of death

Another theme under this pattern is that grief reactions are based on

developmental understanding. As Nagy reported, children do not start to understand the

concept of death until around age five (Nagy, 1948). While that is a chronological age, it

represents the time in a child's life that Piaget labels preoperational (Feldman, 2015). By

experimenting with this age group, he concluded that they are beginning to grasp basic

implications, but do not yet have a full understanding of death. Erikson advised that

children in the stage of Industry vs. Inferiority can start to sort through things and come

up with some conclusions (Dunkle, Harbke, Marcia & Josselson, 2012). During this

stage, children are more prepared to start grasping the meaning of death.

As Bonoti, Leondar and Mastora (2013) and Machajewski & Kronk (2013)

reported, there are four parts to death that children must also have some knowledge about

to begin to make sense of it. Those are the "irreversibility factor," the fact that those who die will not come back–grandma is not sleeping in the coffin, she is dead; "the finality of death," knowing the concept of "never" is involved with this factor–you will never see grandpa again; "inevitability," understanding that everyone is going to die someday–grandparents, aunts, uncles and even parents will pass away; and the fourth factor is "causability," that the illness their chronically ill brother or sister has can actually cause his or her death, or that a person can die in a car accident. As one Grief Counselor put it, "I think it's age. I think it's what they, themselves, experienced" (Participant #12, line 94). Even if the sibling griever fully understands all these concepts and achieves the developmental steps that Piaget and Erikson list, the loss of their brother or sister is still a "life-changing event," as the second pattern suggests.

Sibling loss in childhood is a life-changing event

The second pattern describes how all-encompassing this loss is. Specifically, the pattern identified, "Sibling loss in childhood is a life-changing event." The themes within this pattern include, "Loss of a life-long companion," "New normal in the family unit" and "Parents are subsumed in their own grief." One participant, #7A, provided some detail of what the family dynamics are, realistically, when a child dies–

> The children are confused because their parents are either right on top of them, or they are absent because they are so caught up in their own grief for the child who died. So, the parental response to the child's has a huge impact on how the sibling will react. The parents are learning how to deal without the child who has died and how to work with the children who are still in the house. And we have a lot of conversations with the parents how to handle these relationships.

Sometimes, there may be arguments or behaviors when the parents start re-

investing in the children (lines 21-27).

These children have lost someone who quite possibly helped them make sense of things,

their brother or sister.

Loss of a life-long companion

Conger & Kramer (2010) reported, 80-85% of children grow up with a sibling

worldwide. Their brothers or sisters become their "life-long companions." As one of the

Grief Counselors commented–

"Lots of time, the brothers and sisters share a room, and their brother or sister is

not there anymore. It makes it just that much more painful, and it is a constant

reminder that their sibling isn't there for them" (Participant #36, l. 6-8).

They experience much of their life with their brothers beside them, their shared

experiences forming a bond that, for some, is stronger than any outside of the parent-

child relationship.

Participant #7A states–Depending on the relationship, I notice the companionship

and it has to do with their age. I remember a twin I had, they had lost a major

companion when they lost their twin (l. 3-5).

Twins are very close, and the loss of their counterpart is very traumatic for the

surviving twin. One of the Grief Counselors explained the twin relationship–

I think a lot of times I am talking about grief generally, but once again, when we

talk about relationships of the siblings. Because when we talk about twins, they

are very, very close, kind of joined at the hip (Participant #7A, l. 67-69).

Whether they are younger or older, losing them is a difficult experience. One

Grief Counselor brought up another angle, "Do I still have a brother or sister?

What do I say when people ask me?" His/her advice was to give the grieving

sibling a choice, i.e. "I had a sister Kate and a brother Dan, who died," or if they

are not comfortable with that, decide what would work for them (Participant #36,

l. 63-67).

It can all be rather confusing for them; how do they describe their family?

New normal in the family unit

There is a new normal in the family unit, as the next theme reports. One Grief

Counselor, Participant #38, describes it as:

The consistent, persistent grieving of the family. You know when Mom walks

into the room where the child was, she cried. And you know, this is all normal.

You know it's normal, but you can't even look at the child's room for a while.

But if you are the sibling, you don't even know what is going to happen next.

How is Mom going to feel today? Where am I going today? Are they putting me

in another grief group? Or, is my teacher going to ask me to draw another picture

again? Or, you know, it's just a constant barrage of grief, I think (l. 87-94).

Each family member must deal with all the aspects of grief in their own way. For

the inexperienced child, however, without anyone to guide them, this may be

overwhelming.

Parents subsumed in grief

One theme we arrived at to cover this aspect of the sibling grief scenario is, "Parents are subsumed in their own grief." One participant spoke of one situation he/she encountered: "The parents were having a really hard time. We actually counseled the parents. Both parents. The parent's reactions affected how she grieved" (Participant#75, l. 27-28). Another Grief Counselor remarked, "I think oftentimes, with the death of a child . . . with this kind of grief, parents may be kind of absent from the child, not physically, but emotionally. Often siblings take a back seat to grief" (Participant #36, l. 9-10).

As is often said, the loss of a child is one of the worst things a parent can experience. As a result, they become lost in their grief. The children see this and try very hard not to bother their parents with their own grief. In fact, they may tend to cater to their parents, and even take on additional responsibilities–parent their parents, so to speak. For some grievers, the grief process lasts a very long time. This is a new experience for these children, and they may be overwhelmed with this new role and the length of time it lasts.

Childhood grief has its own time

"Childhood grief has its own time" seemed to sum up the other patterns identified from analyzing the transcripts of the Counselors interviewed and provided a pattern of its own. "Length of grieving periods differ in children," "anniversaries, birthdays and holidays are difficult" and "Loss can follow a child throughout their life" were the themes that emerged in this pattern. This is illustrated by one Grief Counselor, who discussed working on the grief too early after the sibling death.

A lot of parents will bring their children in immediately after the death, and what

we find is that they are still in that shock place . . . "I don't know how I feel," and

"Why are you wanting me to talk about this experience that I don't even have my

head around yet?" So, what we find is if we can talk to the parents about creating

a safe routine, you know, let's create a good steady home life for them right now,

and then down the road, you will be able to see if there are issues that come up

(Participant #7A, l. 38-44).

Participant #12 advised–It tends to be sort of a time limited thing. So, this loss

was a month ago, or six months ago, so it is time to move on. And, grief, as you

know, is very personal and individualized to each person (l. 68-70).

What may have worked for one child, may not work for another. The length of

time should not be a factor.

Grieving periods in children

Children's grief journeys may be stalled for many reasons, including catering to

their parents, hiding their grief so as not to upset anyone, or because it appears theirs is

not as important as their parents' grief. As one of the participants reported:

They take their cues from the adults. And, so a couple of things happen. If the

parents are a basket case over the loss of their child, which is natural, the child is

going to try to work really hard to stay composed and not express or show their

grief because they are afraid of what that would do. Or, that they may lose that

parent. So, they try to hold it together (Participant #3A, l. 41-46).

Other aspects are highlighted by another Grief Counselor–

> With grieving children, you might not notice anything for three weeks. You have
> to create a time and space, because every child grieves differently . . . And, if it
> was a tragedy, it may take them a year to just grieve the trauma. . . You are
> talking about a complication that freezes grief and so that trauma takes time to
> grieve (Participant #36, l. 24-26 & l. 38-40).

Still another participant had this to say–

> I had this one family in which the child died at home. So, the room the child died
> in stayed the same for as long as I worked with them. The room stayed untouched.
> So, over two years, they didn't do anything with the room. They would go into
> the room and clean it and kind of touch things to feel his presence. The child was
> exposed to that . . . And, that happens a lot of the time. It takes a really long time
> to go through the things and be able to part with them (Participant #75, l. 65-72).

> Similar scenarios were reported by just about every one of the Grief Counselors.

Some children never do attend to their grief as a child, and in adulthood, when trying to

work through other situations, it shows up again. This is reflected in one participant's

words, "Some adults never had the opportunity to grieve the loss of their sibling"

(Participant #75, l. 129-131). So, it is no surprise that these adults suddenly have a

difficult time when the anniversary of their sibling's death is upon them.

Anniversaries, birthdays and holidays

One theme that appeared in several of the transcripts was that "anniversaries,

birthdays and holidays are difficult." It can be challenging for the family to determine if

they should celebrate the deceased child's birthday or not. They must determine if it

would be harder to deal with the event without much fanfare or memorializing the

deceased child by celebrating his or her birthday in some manner. Several of the Grief

Counselors interviewed advised that they offered options to families and let them decide.

Many family members report that the anniversary of the child's death is particularly hard.

In working with the Hispanic population, one Grief Counselor reported:

> Sometimes in our Hispanic/Latino population, too, especially around the age of
>
> Quinquennia, sometimes those big events bring about some grief waves for
>
> families, especially for some families that have lost children around that age
>
> (Participant #80, l. 93-95).

Additional counselling sessions may be needed when celebration decisions become

overwhelming. It is not unheard of for sibling grievers to visit Grief Counselors several

periods in their lifetime for their loss.

Loss follow a child throughout life

As previously alluded to, "Loss can follow a child throughout their life," which is

the last theme in the final pattern. One Grief Counselor advised that:

> I have seen it happen when there is something else that happens, maybe Grandma
>
> dies later on, or their dog dies, or there is some other type of loss in their life, and
>
> then, if the grieving hasn't been "completed," like the grieving of their sibling,
>
> then it can happen all over again. It's like a scab comes off that wound and it is
>
> very fresh again. Very often I will see young adults, who never got to grieve their
>
> loss as a child, have difficulties again (Participant #60, l. 91-95).

Another Grief Counselor reported that:

Each time they reach a new developmental milestone, they will re-grieve it. So,

like a 5-year-old whose brother died in a car accident, all of a sudden at 7 years

old, realizes that death is permanent . . . will kind of re-grieve that death. Or a 12-

year-old whose sister dies from, you know, cancer, will, on her sibling's birthday,

re-grieve that death. And, so there is an on-going process, but, in my experience,

there is no time line for it, and we kind of cater our programs to that (Participant

#51, l. 118-123).

The re-grieving experience can still occur when this child reaches adulthood. This same

Participant who works with the adult population on a regular basis, in addition to

school-aged sibling grievers, stated it like this:

There are adults who lost a brother or sister when they were young, and it was all

about the parent. And, their grief over the sibling was not at the forefront and so

it was not dealt with. So, yeah, Disenfranchised Grief (l. 47-49).

Discussion

Disenfranchised Grief, as previously mentioned, now includes sibling grief.

These grievers have lost someone close to them, but the focus is more on the parents of

the deceased. One aspect of sibling grief that qualifies it to fall under Disenfranchised

Grief is that some people do not recognize children who lose a sibling as true grievers.

Whether these individuals don't believe children grieve, may outgrow their grief, or that

condolences should be reserved for the parents who have suffered the greatest loss of all

is not known. The above Grief Counselor proceeds to elaborate a bit more on this topic:

Some adults have never had the opportunity to grieve the loss of their sibling. For

some of my adults, we had to go back to that loss. You know, go back and kind

of reprocess through all of that. They had to put it in a box and put it on a shelf

somewhere, and so it never got processed through (l. 129-133).

The means of death also matters. Circumstances surrounding the death are

uniquely traumatic to children. This participant describes a family who lost child in a

pool accident:

A seven-year-old lost her two-year-old sister in their backyard pool and her

inability to understand the drowning event along with some previous affective

problems complicated her grief. A year later, she continues to have problems

with peers and emotional reactions (Participant #60, l. 34-50).

The results of this study represent the experiences of children as told through the

stories of their grief counselors. This was the purpose for this phenomenological analysis.

Data analysis revealed some aspects of school-aged sibling grief were consistent with the

Grief Counselors interviewed. As a result, we can report that grief in children takes

different forms and the themes of that finding, as well as sibling loss in childhood is a

life-changing event and the themes that support it, and, finally, that childhood grief has

its own time and those themes.

Grief Counselors' advice

The grief counselors, additionally, made direct suggestions for others' consideration and are briefly outlined below with detailed information provided in Appendix E.

Grief Counselor #63 stated that it was beneficial for siblings to attend counseling sessions together so they can better understand why their surviving brother or sister is acting a certain way. Having an explanation for behaviors that do not make sense to the child directly from their sibling may help them with their own grief.

Grief Counselor #80 felt it was important to get good histories on each child to discover what their baseline is and to assist them to return to that norm. He/she felt that knowing their interests, school performance, etc., could help identify how their grief had affected them.

While it may be difficult "to see children in distress" (Participant #63, l. 140-145), things are going to take some time to return to normal. Some Grief Counselors spoke of the length of time it took just to have the children they were counseling feel comfortable with discussing their feelings with them. Peeling the layers off and getting to the heart of what is going on with the child may also be a time-consuming undertaking.

Participant #12 was not the only Grief Counselor that reported the importance of sibling grievers taking part in a peer support group. Meeting with other children that have had the same experiences provides an outlet for these children to discuss feelings with someone who really understands and helps them to discover they are not alone in their grief journeys.

Putting a plan together for these children when they become overwhelmed at

school was the suggestion of Participant #36. This would involve cooperation of their

teacher and a "safe person" they could go to for assistance. He/she advised it was very

helpful for a sibling they counseled.

Keeping children and their parents separate in their counselling sessions was a

method that Grief Counselor #38 advised. He/she stated, "it kind of defeats the purpose"

to have children discussing their grief in the same room as their parents. A majority of

the Grief Counselors interviewed discovered that children were hesitant to upset

their grieving parents with their needs, as they witnessed how overwhelmed their parents

were with their own grief and did not want to add to it.

Almost every Grief Counselor interviewed, reported that if the sibling death

involved a trauma, the counselling session had to first deal with the trauma, and then

work on the grief the child was experiencing. This, then, extended the amount of

sessions that were required. This was illustrated in Participant #51's comments.

Implications

Based on the findings of this research study, several ideas were formulated on

how to better identify and serve the vulnerable population of school-aged sibling

grievers. As noted by several of the Grief Counselors, these children fit under the label

of Disenfranchised Grievers; their grief is rarely identified. When a child dies, the

parents are perceived as suffering the greatest loss, that need the most assistance in

dealing with their grief. The grief of the deceased child's brothers and sisters is, for the

most part, not openly acknowledged. Whether the sibling grievers are covering up their

feelings to keep from causing any more problems for their parents, or we do not know

what symptoms to look for in these children, their grief is not obvious. To provide the most assistance, we need to set up procedures to better identify and assist them in their grief journey. Four main areas to focus on in putting such procedures into place are practice, research, education and policy.

Practice

For the area of practice, one of the Grief Counselors suggested that caregivers need to add an item to all intake forms for children: a question to determine if they have ever experienced sibling grief. While this might seem rather drastic at first, one caveat is that incoming patients have all become accustomed to the questions regarding abuse, drug use, alcohol use and the practice of safe sex that are currently found on many healthcare providers' intake forms. As noted above, some childhood sibling grievers cannot be easily identified and need to be asked directly. This applies to any aged child. While younger children may not have a true comprehension of what the death of their sibling meant, it might be a good time to assist in clearing up some of their confusion. Most school-aged children should have some grasp on what the event represented; however, they may not have received the assistance they needed to help them on their grief journey. One Grief Counselor pointed out that children can re-grieve as they progress through future developmental stages. It is important to assess how the child is currently coping. There may be some sibling grievers that never addressed their grief and "put it on a shelf" as one Grief Counselor advised. If they do not work through their grief issues as a child, it can follow them through their adult life and reappear when they least expect it. Therefore, it is important to determine who is a part of the sibling griever population to assist them with whatever issues they may have.

Upon identification, the next step would be to perform a thorough evaluation. This would be both physical and psychological. A surviving sibling's grief may have been overlooked, and the symptoms these children presented with in the past misdiagnosed as something other than the loss of a brother or sister. As the participants of this study revealed, many of the symptoms of a school-aged grieving sibling may not typically be seen in someone who is grieving the loss of a loved one. The symptoms can range from aggression to hyperactivity and even stomach aches. If a healthcare professional was not aware of their loss, and instead treated what they saw in the child exclusively, the plan of care may need to be revised.

Referrals should be initiated for anyone having difficulty with this experience, no matter how long after the loss it is. This action can prevent future complications. One participant in this study told of adults he/she worked with that did not address their grief as a child, which resulted in a more severe reaction to losses they experienced as an adult. To assist his/her adult clients with this dilemma, he/she had to go back with them and work through the grief they did not fully address as a child. If these practice steps are put in place, and we identify grieving siblings not long after their brother's or sister's death, their grief journey might be a little easier.

Research

Under the topic of research, the study helped to formulate the idea that it would be beneficial, using a mixed-method study, to create and test a tool to identify sibling grievers who may need assistance. Based on many of the behaviors, observations and assessments gleaned from the Grief Counselors, a questionnaire could be constructed to determine if the individuals are experiencing any of these maladies. Open-ended

questions can be included that would allow the researcher to gain further insight into

exactly what the person is dealing with. Utilizing a group of sibling grievers and

contrasting with a control group might be one way to test the reliability of this tool.

Another research study helpful to sibling grievers would be a qualitative study

that addresses what helped these individuals the most when going through their grief

journey. The use of a Descriptive Phenomenological method would help ascertain what

was helpful when dealing with their grief. A semi-structured interview could be

conducted with each individual. Transcribing their interviews and identifying the

patterns and themes, as this study did, would be useful to this population and the Grief

Counselors that work with them.

Education

According to this study's findings, the third area to concentrate efforts is

education. Creating a seminar or course outlining the signs and symptoms that a sibling

griever may exhibit, and making it available to school nurses, counselors, Nurse

Practitioners, Physicians and Physician Assistants, would be the most useful undertaking

as far as an educational intervention. More individuals may be attracted to this type of

course if continuing education units (CEUs) were offered in exchange for taking it and

completing a brief posttest. These healthcare professionals would then be able to identify

those individuals that should be evaluated for assistance.

School counselors and school nurses are frontline individuals who need to gain a

thorough understanding of the entire grieving process of a surviving sibling so that they

can provide much needed assistance. They should be able to recognize and refer those

that need additional help early on to get them the best treatment as soon as possible. One

step in making sure the school nurses and school counselors gain considerable knowledge

on sibling grief is to include this topic in their coursework curriculum for their degree.

Policy

The final area in which it is possible to make a difference in the life of a sibling

griever is under the topic of policy. One area to address specifically is health insurance

coverage for grief counseling. Many insurance companies do not cover mental health

services, or only pay a small portion of the cost of this service, which is the division that

counseling is generally assigned to. Lobbying health insurance companies to provide

coverage for this counseling would assist many families that could not otherwise utilize

these services.

Sibling grievers may be part of the group of Disenfranchised Grievers, but, based

upon the storied accounts of the ten Grief Counselors we interviewed, they can be

identified. If we can implement the practice changes, complete the research studies

mentioned, provide the education listed and work towards making policy changes as

outlined, we can make a real difference in the lives of sibling grievers.

Summary

These early findings are just the beginning in identifying the characteristics of

sibling grief and how to identify a sibling that is having difficulty dealing with their grief.

Follow-up studies of this type are needed, as well as interviews with the children directly.

The sibling grievers, themselves, were not interviewed. Interviewing the Grief

Counselors was the next best step, as they had established a rapport with the sibling grievers and their families and could also provide their expert observations and advice.

The difficulty in interviewing the sibling grievers themselves would be that a relationship would have to be established with these siblings to get valid information. Developing such a relationship would be a time-consuming task but would be well worth the effort in discovering if the Grief Counselors' observations, and our data analysis of the transcripts, is accurate.

Based on our findings, several implications for practice, research, education and policy have been identified. Following up with those implications would go far to assist these sibling grievers to get the assistance they need.

Sibling grievers may be part of the group of Disenfranchised Grievers, but, based on the accounts of the ten Grief Counselors we interviewed, they can be identified. If we can implement the practice changes, complete the research studies mentioned, provide the education listed and work towards making policy changes as outlined, we can make a difference in the lives of sibling grievers.

Chapter 5: Summary and Conclusions

Young sibling grievers are a unique population. Disenfranchised Grievers is a good description of them. These children have lost someone dear to them, but they cannot share their grief with anyone. They may not fully understand death, due to their developmental level, or their previous experience with loss. They tend to hide their feelings from their parents. Many sibling grievers "stuff" their feelings until some unrelated event may bring those raw emotions to the surface once again. To resolve the current situation, their past loss may have to be revisited and worked through.

There tends to be a degree of ambiguity to children's grief. On the one hand, there is the desire to keep the memory alive, especially on their sibling's birthdays. There is a zealotry to remember and honor their sibling, to preserve their memory. This desire usually wins out over the other factor, which is that it can be a painful experience to do all that remembering. There is an empty seat and it is the elephant in the room. There is a sadness that every holiday is tinged with after the loss. No matter how joyful it is, there's always that small dose of sorrow that sits in the corner. If the grieving child receives therapy, they may be able to work through most of their future problems surrounding this loss. Ultimately, the grief fades with time. That fading memory may cause the sibling griever to feel some guilt. That is where parents and those close to the young sibling griever, if given the proper guidance, can assist them through this difficult journey.

This study has increased awareness that sibling grievers exhibit identifiable behaviors. While the list prepared from the transcripts of the participants is not exhaustive, it does reference several maladies that could easily be mistaken for separate disorders. Healthcare professionals must act quickly to recognize these symptoms. Treatment is available, but if a referral is not made, which is dependent on the ability to identify this specific population, sibling grievers cannot get the help they need.

Many different signs and symptoms can be attributed to sibling grief. It can surface as a withdrawn, depressed reaction or take a more volatile form, such as anger or aggression. In most aspects, childhood grief is very different from adult grief. Adults tend to present as depressed individuals. Children may also show some signs of depression at one time or another, but their grief reactions are experienced in short, recurring intervals. As one Grief Counselor advised, children do not have the capacity to dwell in that depressed state for any extended period.

A common misconception that then arises is that not all children grieve losses. Regardless of how much time they spent with their sibling, when that sibling passes away, the living child will grieve. This ubiquitous experience affects not only their present life, but how they respond to certain happenings in the future, as well. It may occur to a child how life may have been different had their brother or sister not died or seeing a boy or girl the same age as their sibling may cause some of the grief to resurface. Specific dates, such as birthdays and death anniversaries, may trigger reminders, and the closeness of the relationship is also a factor. The adjustment may be greatest if they were twins.

The child's developmental level has a definite bearing on their understanding of the death of their brother or sister and what it can mean for them moving forward. Children can grasp partial meanings of death at an early age, but until they can fully understand the implications, it may not make much sense to them. If the death was experienced while they're young, a child may grieve the loss at several developmental stages as it begins to make more sense. The sooner the sibling griever is identified, the

earlier assistance can be provided to them. (A list of sample resources is provided in

Appendix F).

Early identification is instrumental in assisting sibling grievers. This early

recognition can prevent misdiagnosis of their grief, keeping them from taking

unnecessary medication and following protocols that are not beneficial. It also assists

these individuals in following a healthy grief trajectory, thereby preventing unhealthy

coping mechanisms. Once the child is identified as a sibling griever, an evaluation by an

expert would be the next step. Many of these trained individuals have worked with this

population for several years and know which children need a more invasive approach and

which may just need a small amount of professional guidance.

This study did not exclude any type of childhood death, but some of the

participants mentioned that death caused by a trauma may have a bearing on the type of

counselling the child needs. If the death was the result of a trauma, it can affect the grief

process of the surviving sibling and cause their grief journey to continue longer than if

the child who died was chronically ill. These counselors advised that the trauma aspect

of the death must be dealt with first, and then the actual grief process can take place.

Many methods and recommendations can be made by counselors to help alleviate

the responding grief. Support groups are frequently mentioned to assist children in

feeling a sense of solidarity in their mourning. They provide an opportunity to meet with

other children, who have experienced similar losses, on a regular basis. Many of these

meetings involve completing craft projects centered around the deceased brother or sister.

One Grief Counselor suggested play time using various toys to assist children in acting

out what is bothering them. Some organizations that have support group meetings for the

grieving children also conduct a parent's meeting at the same time to assist them in

working with their surviving children. Parents may be preoccupied with their own grief,

so counselors can help them be more aware of indicators that their children need help.

These children may also tend to hide their grief to avoid upsetting their parents.

Burying their feelings to keep their parents from any further complications was an

observation made quite frequently by the Grief Counselors interviewed. As one

counselor, who also works with adults, found, it follows the grieving individual the rest

of their life until they deal with it. "Stuffed" grief can amplify future losses that could

have been overcome easier had the past grief not resurfaced and complicated the

situation. The counselor must then work with the adult on resolving their childhood grief

prior to addressing the current issue.

Holidays may be very difficult as the loss is amplified during those times of the

year. Some individuals may not even feel like celebrating them, or their celebrations may

be rather somber. Thoughts of how the deceased brother or sister would have enjoyed the

holiday, or that their sibling is no longer able to partake in the festivities with them, may

preoccupy their thoughts.

The deceased child's birthday poses additional dilemmas, should it be celebrated

or not chief among them. Some families choose to memorialize the child who has died

either on their birthday or the anniversary of their death. One such suggestion was to

purchase a brick with the deceased child's birthday and death date engraved on it to be

placed by an angel memorial designed specifically for that purpose. Including the sibling

grievers in these memorial services may alleviate some of the symptoms that might be

present had they been excluded from this remembrance.

While there has been much research on sibling grief, addressing exactly what a sibling griever looks and acts like is long overdue. All professionals working with children must be able to identify all the possible reactions they may observe in this group. It may become essential to ask all children directly if they have ever experienced the loss of a brother or sister to be sure we identify all such grievers. Once a child has been identified as a sibling griever, professionals can perform a full examination of that individual to be certain that they are receiving the proper intervention and guidance. Interviewing Sibling Grievers to ascertain what interventions may have helped them the most would be a good step in setting up a plan of care.

More research needs to be pursued on sibling grief to provide the assistance these individuals desperately need. As was mentioned, sibling grievers are Disenfranchised Grievers. Their grief may not be recognized, understood or acknowledged. Their parent's grief tends to overshadow that of their child's and may be given more attention. Grief doesn't go away on its own, however. The surviving siblings need to be, at the very least, directed towards the correct path for their grief journey. Grieving siblings who have underwent therapy and counseling can provide valuable information on what worked best for them. That would be a great follow-up to this research study.

Epilogue

In Chapter 1, I discussed the death of our daughter, and the three siblings she left behind. After completing this study, I wish I would have known all this information at the time of Natalie's death. I may have better understood some of the odd behaviors her siblings displayed. Instead of scolding them for running around at Natalie's wake with their cousins, I would have known that they could not handle long periods of grief due to their age and developmental understanding. When her sister, who shared a room with her, spoke of missing her baby sister so much, I may have better realized the void the death of her sister left in her life.

Although I am not sure I could have taken time away from my grief to better understand the grief her siblings were experiencing, this research has opened my eyes to see how my surviving children may have been trying to spare me from additional worries by not openly showing how difficult this situation was for them. Even though we did provide some counseling and peer support group time for them, they may have needed more, but did not want to voice that request.

As I have worked on this study, I have discussed it with my now adult children to find out if any aspects of their sister's death still linger with them. Her oldest brother has provided me with some of his thoughts and I find that we may not have done enough to attend to his grief. I sincerely hope health providers assist with, and make sure that, parents in this same situation take heed of the findings of this study and provide as much help for their Sibling Grievers as possible.

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Appendix A

ATTENTION GRIEF COUNSELORS

We need your help to identify behaviors and expressions of school-aged children who

have recently lost a brother or sister (within the last year).

This will be an audio-taped interview either in person or via Skype.

The interview will take approximately 30 minutes.

For additional information, please contact: bastori@siue.edu.

Appendix B

Questions

1. In what capacity do you interact with grieving siblings?

2. About how many of these children do you think you have seen?

3. What are some of the first things you notice about these children?

4. Can you please tell us about some children you have worked with?

5. Why were you seeing these children?

6. Are there any similarities you noticed in this population?

7. What are some important things we should know about these grieving siblings?

8. Do you have any suggestions in working with this population?

9. Is there anything else you would like to add?

Appendix C

STEPS OF RESEARCH

1.	Literature search conducted on Sibling Grief.
2.	Phenomenology chosen as the method to use for this study.
3.	Descriptive phenomenology chosen as the approach to use
4.	Husserl's plan of performing Descriptive Phenomenology was followed.
5.	IRB approval was obtained.
6.	A list of potential participants was compiled based on the criteria determined.
7.	Recruitment phone calls were made, and e-mails were sent to everyone on the list of potential participants.
9.	Demographic forms and consent forms were sent and returned via e-mail.
10.	Data was collected via a semi-structured audio-recorded interview from ten Grief Counselors.
11.	Interviews were transcribed by the primary investigator and uploaded to a private google drive location.
12.	A committee was formed for data analysis consisting of the primary investigator, a fellow PhD student and an expert qualitative researcher.
13.	Transcripts were viewed on the Google Drive site and Giorgi's methods of Data Analysis were followed.
14.	Lincoln & Guba's techniques for establishing creditability were used.
15.	Results and implications were reported, as well as the Grief Counselors' suggestions.

Appendix D

SIGNS & SYMPTOMS OF SCHOOL-AGED SIBLING GRIEF PER GRIEF COUNSELORS

Behaviors	
acting out	difficult to talk about
Aggressive	cut off from emotions
anger	temper tantrums
anxiety	numbness
blurt out	sadness
can't sit still	crying
flat affect	frustration
Nightmares	bedwetting
Don't want to be around friend's	impulsivity
hyperactivity	unable to concentrate
stomach ache	
Observations	
confusion	clingy behavior
cut off from emotions	sudden increase in energy
don't talk a lot about their grief	motor functions slowed
don't want to go to school	low energy
guilt	monotone speech
inability to regulate emotions	lack of interest
may look like they are doing fine	idolize deceased sibling
oppositional interactions	blaming
preoccupied with parents	starts caring for siblings
question existence & mortality	trying to be a perfectionist
relief	they can't measure up to dead sib
take cues from adults	harm themselves, others or animals
traumatized	overly responsible
wise beyond their years	regress
withdrawal	survivor guilt
won't talk	I don't belong
Assessments	
feel alone	Preoccupation on parents
extended family may be important	Shock
physical ailments	
some kids don't have the words to express what they are feeling	
they can only deal with grief in small doses – they grieve in "spurts"	

Appendix E

GRIEF COUNSELORS ADVICE

Advice	Quote
Siblings should be able to attend counseling together.	Well, I think they should have the opportunity to be together, so they can understand, between them, why one might be reacting differently than the other and that that is normal . . . So, if you are three, it might be one thing, if you are five, seven or fifteen, you know, seeing why each of them react the way they do (Participant #63, l. 88-93).
It's important to gather good histories.	I think the best thing is to get good histories and understanding of how each one of them was behaving before it happened. What was their norm? How did they perform at school? What were their interests? What have they withdrawn from? What are they still interested in? (Participant #80, l. 88-98)
Therapy may take some time	Well, I think you have to understand, we can't force them to feel better right away, you know. I think it is very uncomfortable to see children in distress. I mean, it's normal. You just want them to be happy again and playing and want to right everything. But, again, it is a process and it is going to take some time. I think you should, you know, still provide children with fun experiences, but also be there when they need something, and it is not traditional therapy. They are not going to go into an office and sit down and talk about what happened like an adult would (Participant #63, l. 140-145).

Peer support groups help.	I would suggest, if we can, try to get them into a peer support group. Oftentimes, they don't feel ok talking about their feelings, and it is interesting. Again, it is interesting. Looking at my referrals, I usually don't get doctors, or teachers, or even parents, say that I want you to see a child who lost a, you know, a brother or sister. I, again, get the diagnosis that they are angry, or depressed, or acting out. They need to be evaluated or get counseling. And, the grief is almost something, you know, that is an afterthought (participant #12, l. 183-188).
It's important to attend to a grieving child's needs.	I think it is important to know that kids are hurting inside in a way they have never felt before. And they are feeling an overwhelming feeling of responsibility that they don't know what to do with . . . It is important to have procedures set up at school, so when a child is in a reading group and they are triggered by a story of someone's sister, they know they can leave the room without having to ask the teacher, and they have an agreement that there is a safe person they can go to (Participant #36, l. 138-146).
Should parents and children attend counseling together?	There is no hard and fast rule about whether to work with the kids individually or with parents … but you tend to find you can't say a whole lot with your parents in the room. You know, it kind of defeats the purpose, because it is going back to the way I'm living

	with my parents and I don't want to ruffle any feathers (Participant #38, l.153-156).
Trauma deaths of siblings may be more difficult.	I think that any child that has trauma associated with the grief just has more difficulty. We always recommend to parents that you need to heal the trauma before you can start processing the grief, because the trauma takes over (Participant #51, l. 173-175).

Appendix F

Sample Resources

Catholic Family Services

Lutheran Family & Child Services of MO

Barr Harris Children's Grief Center. Chicago, IL

Grief Counseling for Children, Boulder, CO

Samaritan Counseling Centers, Memphis, TN

Hope in Healing at IU Health

Children's Home Society, Warm Spring, ID

The Amelia Center, Birmingham, AL

Total Life Counseling, Orlando, FL

Children's Bereavement Center, San Antonio, TX

True Vine Christian Services

Boulder Psychological Services, Boulder, CO

Children's Home Society, Warm Springs, ID

Better help – on-line Counseling

Info Counseling St. Louis.net

The Sibling Connection

Dougy Center

Group Dynamics, St. Louis, MO

Wellness Alley, St. Louis, MO

Kidsgriefmatters@annieshope.org

Kaleo, Cottleville, MO

Bereaved Parents of the USA, St. Peters, MO