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Understanding Grief in Adults Whose Sibling Died during Childhood: A Qualitative Study

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**UNDERSTANDING GRIEF IN ADULTS WHOSE SIBLING
DIED DURING CHILDHOOD: A QUALITATIVE STUDY**

A Master's Thesis

Presented to

The Graduate College of
Missouri State University

In Partial Fulfillment

Of the Requirements for the Degree
Master of Science, Child Life Studies

By

Amanda Marie McCarthy

December 2020

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UNDERSTANDING GRIEF IN ADULTS WHOSE SIBLING DIED DURING CHILDHOOD: A QUALITATIVE STUDY

Department of Child and Family Development

Missouri State University, December 2020

Master of Science, Child Life Studies

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ABSTRACT

This retrospective, phenomenological study investigated how bereaved siblings believe the death of their brother impacted their development. Through semi-structured interviews, five adults whose brother died during their adolescence discussed how their grief changed over time and the factors that influenced changes in grief. Participants experienced periods of lack of acceptance, independence and isolation, and finding contentment. Factors that influenced changes in grief include sibling's cause of death, family reaction, establishment of a support network, remembering the deceased, and milestones and dates. These findings provide a glimpse into how grief changes over time in the context of development. Furthermore, the results promote a need for family-centered grief support resources to better aid bereaved siblings.

KEYWORDS: bereavement, child life, sibling, grief, qualitative, retrospective, development

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In the interest of academic freedom and the principle of free speech, approval of this thesis indicates the format is acceptable and meets the academic criteria for the discipline as determined by the faculty that constitute the thesis committee. The content and views expressed in this thesis are those of the student-scholar and are not endorsed by Missouri State University, its Graduate College, or its employees.

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INTRODUCTION

Death can be complicated to understand and come to terms with, no matter the relationship to the deceased or the number of deaths experienced. An additional layer of complication is added when the bereaved is a child who is still developing physically, mentally, emotionally, and spiritually. Research often focuses on how children respond when one or both of their parents die, but what about when a sibling dies? It is important to consider the impact this broken bond has on the child's psyche and development. This study investigated how bereaved siblings believe the death of their brother or sister effected their childhood and how their grief has changed over time.

Statement of the Problem

Current literature outlines the importance of various support networks to best assist bereaved siblings. Studies have previously featured parental input about their child's grief or accounts from the children shortly after their sibling dies. This study observed the perceived impact having a brother or sister die during childhood from the perspective of bereaved adults. While it is beneficial to study the impact on bereaved siblings directly following death, this study instead interviewed participants years after the incident. How will the passage of time impact their ability to reflect about their experience? Additionally, this aims to provide insight to how bereaved siblings believe their grief has changed throughout childhood into adulthood. By being aware of how grief evolves in adulthood, both with and without professional supports, interventions can be adjusted to best support siblings throughout their mourning.

There have been several studies that interview bereaved siblings, both directly after and

years following death (Barrera, Alam, D'Agostino, Nicholas, & Schneiderman, 2013; Demmer & Rothschild, 2011; Foster, Gilmer, Davies, Dietrich, Barrera, Fairclough, & Gerhardt, 2011; Lovgren, Jalmsell, Wallin, Steineck, & Kriebelbergs, 2016; Lovgren, Sveen, Nyberg, Wallin, Prigerson, Steineck, & Kriebelbergs, 2018; Paris, Carter, Day, & Armsworth, 2009; Sveen, Eilegard, Steineck, & Kriebelbergs, 2014). While these studies make a start in providing an outlet for bereaved siblings to share their stories, the information provided requires expansion on demographic interviewed and geographic location. These studies focus on death due to cancer or AIDS and/or were not conducted in the United States. The pursual of this research study provides a glimpse into the American experience after losing a sibling to any type of death. The research currently available is limited and does not necessarily apply to the population interviewed.

Hearing the lived experiences of bereaved siblings is imperative to fill the gaps of grief research within the field of Child Life and health care overall. This study offers new information about precisely what intervention were and were not helpful towards the grieving process. This will inform the future implementation of support networks, interventions, and coping skills to bereaved siblings to aid in on-track development and emotional processing.

Purpose of the Study

The purpose of this retrospective phenomenological research study is to explore the lived experiences of adults who experienced the death of a sibling during childhood and how their grief has changed and evolved into adulthood.

Research Questions

1. How does an individual's grief following the death of their sibling during childhood change over developmental time?
2. What factors influence that change?

Research Design

A qualitative, phenomenological research approach was used for this study. Interviews allowed participants to speak openly about their experience while sharing their individual story as part of the overall phenomenon (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019). Open-ended questions prompted participants to think about the impact their sibling's death had and currently has on them. It was beneficial to have the participant responses guide the questions of the study, as opposed to asking predetermined survey questions. Considering the sensitive nature of the topic, participants were encouraged to discuss their lived experience as much or as little as they chose (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019). The qualitative research design provided the flexibility for respondents to speak from the heart.

Significance of the Study

This research study informs caregivers and health care professionals about the best interventions to assist siblings following the death of a brother or sister. With this information, siblings will be provided with the tools and support necessary to manage the lifelong grief experienced after their sibling dies.

The project identifies what factors influence grief and the many forms it takes across time. The responses of participants inform how to develop coping mechanisms in siblings through various channels. The current research primarily focuses on how childhood death impacts parents, while the impact on siblings remains less clear.

As the study interviewed bereaved siblings in adulthood, the information provided contains insight to grief levels and the establishment of coping mechanisms throughout development. Additionally, as adults were interviewed, the responses collected are expected to be well-informed and honest. If children had been interviewed instead, for example, the responses may not have been as fully articulated in terms of feelings and emotions. This study is significant because it evaluates how adults perceive their coping skills in the past as a child and in the present as an adult.

REVIEW OF RELATED LITERATURE

The majority of literature revolving around familial loss in children focuses on losing a parent (Foster, Gilmer, Davies, Dietrich, Barrera, Fairclough, & Gerhardt, 2011; Packman, Horsley, Davies, & Kramer, 2006; Paris, Carter, Day, & Armsworth, 2009). It is essential to research the impact the death of a sibling has on the child and the best interventions throughout the grieving process. Should proper grief and coping mechanisms be ignored, an individual may never heal from the emotional, physical, mental pain losing a sibling to death ensues (Funk, Jenkins, Astroth, Braswell, & Kerber, 2018). Research has found that several factors influence the length of bereavement, or the act of losing something, typically due to death, including parental intervention, the creation of a support network, cause of the sibling's death, and child's understanding of death and loss (Andrade, Mishima-Gomes, & Barbieri, 2018; Horsley & Patterson, 2006; Koblenz, 2016; Lovgren, Sveen, Nyberg, Wallin, Prigerson, Steineck, & Kreicbergs, 2018; Lovgren, Jalmsell, Wallin, Steineck, & Kreicbergs, 2016; Sveen, Eilegard, Steineck, & Kreicbergs, 2014). The following review of literature depicts how these variables promote or prolong healthy grieving. To date there are several theories that in some ways help depict the processes of grief individuals experience over time.

Theoretical Frameworks

To be conceptualize current research, it is imperative to consider the theories that lay the groundwork. There are many theoretical frameworks that can be applied to studying loss and grief, as well as development and time. For this particular study, Worden's four tasks of mourning and Erikson's psychosocial stages of development are utilized.

Worden's Tasks of Mourning. Grief work has been influenced by several theorists throughout the years. Popular theories include Freudian grief work, the Kübler-Ross stage theory, and the Stroebe and Schut Dual Process Model of Grief (Hall, 2011). In regard to analyzing grief over developmental time, the most fitting theoretical framework to use as a lens for this research is Worden's tasks of mourning. Worden (2009) outlines the four tasks individuals go through following the death of someone in their network. Worden notes that grief is not a linear process and, while the tasks are numbered in chronological order, the tasks can be visited and revisited in any order at any time (Worden, 2009).

The first task is an individual's ability "to accept the reality of the loss" (Worden, 2009, p. 39). This means that the individual must accept and confront the fact that this person has died and that their death is permanent. The second task is "to process the pain of grief" (Worden, 2009, p. 43). Processing death is an individualistic experience and varies depending on the person. It is important to face the grief however the bereaved believes is best for them, mentally, emotionally, spiritually, psychosocially, and physically. Next, is the third task "to adjust to a world without the deceased (Worden, 2009, p. 46). This task involves resuming life "as normal" and being able to find joy in new things. Lastly, the fourth task is "to find an enduring connection with the deceased in the midst of embarking on a new life" (Worden, 2009, p. 50). This includes progressing with life while still remembering the deceased individual. During this task, the bereaved person may move forward with day-to-day activities as their own person while holding a connection to the person who died (Worden, 2009).

Erikson's Psychosocial Stages of Development. Erik Erikson established the psychosocial stages of development, that highlight psychosocial crises one must resolve during a specific developmental period (Lightfoot, Cole, & Cole, 2018). In the context of this reach, the

most crucial developmental stages to examine are adolescence, young adulthood, and middle adulthood.

During adolescence, an individual is involved in Erikson's *Identity versus Role Confusion* stage of development. In this stage of development, the question of "Who am I?" is posed and this age group is prompted to consider their role in life. This time period is crucial for adolescents to find themselves, identify their interests, and discover their purpose in life or else face confusion and crisis (Lightfoot, Cole, & Cole, 2018). Young adulthood's main task is establishing close bonds and intimate relationships in the psychosocial stage of *Intimacy versus Isolation*. Without these close bonds, an individual will enter crisis and establish feelings of isolation. Lastly, during middle adulthood, there is a great focus on finding one's purpose in life. In the psychosocial stage of development, *Generativity versus Stagnation*, an individual must find purpose throughout work and family. Without creating a meaningful mark on the world, one will face crisis through feelings of failure and hopelessness (Lightfoot, Cole, and Cole, 2018).

Factors Related to Grief Processes

Based on the current research, the primary factors related to grief processes are parental intervention, the creation of a support network, cause of the sibling's death, and child's understanding of death and loss.

Parental Intervention. It is imperative that siblings feel support by their parents following the death of their brother or sister (Andrade et al., 2018; Barrera, Alam, D'Agostino, Nicholas, & Schneiderman, 2013; Demmer & Rothschild, 2011; Funk et al., 2018; Horsley & Patterson, 2006; Koblenz, 2016; Packman et al., 2006; Thompson, Miller, Barrera, Davies, Foster, Gilmer & Gerhardt, 2011). Depending on the cause of death, the brother or sister may

have been in and out of the hospital or requiring a great amount of care. After potentially receiving unequal attention, the sibling must now face a new life without their sibling. Additionally, the child must adjust to how their sibling's death impacts the parents and family as a whole.

As a child copes, parents should be encouraged to let their children talk freely of the deceased. Children will mirror the response of the parents, so adults should not attempt to hide the situation. It is difficult for the surviving children to witness both extreme emotions and avoidance of the subject. While difficult to maintain a balance, siblings must be able to have normal conversations with parents about death and loss. How will the family dynamics shift without this sibling? This is a question that is difficult for both the sibling and parents, but important to continue with natural projection of life (Horsley & Patterson, 2006).

Some parents avoid discussing the deceased child as to not further upset their children. This good intentioned act ultimately displays to the surviving child that they should suppress their emotions and not talk about the death. The child then internalizes their grief and does not cope properly. Children especially want to discuss their emotions following their sibling's death if they helped care for their siblings. The complexity of the illness may prompt the child to have years of pent up stress, anxiety, and feelings about the situation. Interviews with bereaved siblings whose brother or sister died from AIDS shared that participants were encouraged to not talk about their emotions with their family (Demmer & Rothschild, 2011). By being prompted to not "[dwell] on their grief," bereaved siblings felt like they had no one to turn to (Demmer & Rothschild, 2011, p. 21). Parents should prompt their children to discuss how they feel in the present but also how their past has influenced them. In what ways did having a sick sibling impact their development?

Heightened anxiety and stress are also caused when siblings are not included in parental decision making after death. What will be done to the deceased child's room? Clothes? Pictures? Parents make decisions based on how they are feeling personally, such as not wanting to see pictures of their deceased child and then putting them away. On the other hand, the sibling may want visual reminders of their brother or sister and then become upset that their memory is being erased. Many times, the parents and surviving kin may grieve and cope differently. It is imperative for parents to include their remaining children in decision making to ensure their needs are met and to encourage healthy coping skills and processing (Funk et al., 2018).

Should a child be prevented from grieving properly, their emotions can become overwhelming and consequent into risky behaviors or extreme sadness (Demmer & Rothschild, 2011). If a parent is unable to support their surviving children after sibling death, extended familial communication is recommended. Other family members can connect to the bereaved child by relating to the death of a loved one while being one additional degree removed (Barrera et al., 2013). Children may want to avoid further upsetting their parent and seek a different human connection.

Still, parental connection following the death of a sibling is most important as it proves to the child that everything will eventually be okay. Parents may struggle to support their living children as they are grieving the loss of their child in addition to caring for their remaining kin. Despite the challenges of emotionally supporting the living children, parents must perform this task or else children face negative consequences such as fear of abandonment and stunted development (Andrade et al., 2018).

Parents must be cognizant that a bereaved sibling assuming normal activities does not mean they are not impacted by the death. Children are able to cope and process using play where

they may otherwise struggle to communicate verbally. It is developmentally appropriate, healthy, and expected for children to be granted the freedom to be their normal, playful self following death (Packman et al., 2006). Parents who become frustrated or hurt that a child plays after a traumatic event suggest that coping is not acceptable. Play is all that some children know and the ability to use this activity to display emotion is age-appropriate and normal.

Ultimately, parental support following the death of a sibling proves greatly complex. Parents seek support themselves while attempting to stay strong for their surviving children. It is helpful for the children to show appropriate emotion, allow open communication, include them in decision making, encourage play, and remember the deceased (Barrera, Alam, D'Agostino, Nicholas, & Schneiderman, 2013; Demmer & Rothschild, 2011; Funk et al., 2018; Horsley & Patterson, 2006; Packman et al., 2006; Thompson, Miller, Barrera, Davies, Foster, Gilmer & Gerhardt, 2011).

Establishing a Support Network. Considering the parents are also grieving, it is helpful for the siblings to have additional support networks. Support networks promote healthy coping skills and lessen the likelihood of anxiety and behavioral issues. Children without social support can face higher levels of unresolved grief and therefore higher levels of depression. Two of the larger identified supports that are easily accessible to bereaved siblings are friends and the school system (Sveen et al., 2014).

Friends are seen as a strong support system for adolescents who have lost a sibling. Risky behaviors are taken by grieving adolescents when they do not have a strong network. However, peers can serve as enablers in addition to supporters which can further complicate the grieving process (Barrera et al., 2013). Parental interviews indicated that, following the death of a brother or sister, 44% of bereaved siblings engaged in self-reported risk behaviors (Barrera et al., 2013).

Children, especially adolescents, can add further stress to themselves and families when pursuing risky behaviors after their sibling's death. Are these acts a call for attention? The support network can take it upon themselves to provide enhanced attention to the child immediately following sibling loss. This includes taking measures to ensure the sibling's peers are a positive influence and encouraging healthy growth.

Support groups for bereaved siblings are especially helpful. In this setting they are able to speak freely to other grieving siblings, without fear of triggering parental emotions or causing tension. Bereavement groups also show that they are not alone in their grief and that other children are on the journey to healing as well (Demmer & Rothschild, 2011; Packman et al., 2006). While the Koblenz (2016) study focused on parental loss, this retrospective cross-sectional study found that support from the surviving parent and group therapy were beneficial to bereaved children immediately following death of a parent. Participants completed a questionnaire and unstructured interviews in which 73% of bereaved siblings indicated having a support network aided in their grieving process. Individual therapy was looked favorably upon later in life when the child had the ability to elect this intervention on their own (Koblenz, 2016).

Support groups and grief support networks must be careful in the language used following death. As previously discussed, parents face complicated emotions that influence their surviving children. The implication by parents and support groups that children must be strong or brave for their parents deters their own grieving. This type of language discourages children from sharing their emotions and ultimately isolates them (Horsley & Patterson, 2006). This is especially damaging in bereaved sibling support groups considering children identify them as a safe space.

In a study conducted by Lovgren et al. (2018), bereaved siblings also emphasized the importance of a supportive healthcare team. Years after losing a sibling, Lovgren et al. (2018) reported that participants wished staff helped and supported them more, even when they had previously expressed not wanting attention. Siblings of children with long-term illness traditionally do not receive as much attention as their sick sibling and may form the habit of deflecting attention. Medical staff should encourage communication throughout the bereavement process to make sure siblings are included in conversations and physically, mentally, and emotionally well (Lovgren et al., 2018).

Overall, support networks are beneficial to bereaved siblings as it grants a safe and open space for children to share their feelings and cope. Children may not feel comfortable or allowed to talk about their sibling's death with their parents. A support network ensures children do not suppress their emotions and impact their development (Barrera et al., 2013; Demmer & Rothschild, 2011; Horsley & Patterson, 2006; Koblenz, 2016; Lovgren et al., 2018; Packman et al., 2006; Sveen et al., 2014).

Sibling's Cause of Death. While there is still more research to be conducted in this area, the sibling's cause of death has an effect on the grieving process. Unexpected or sudden death creates shock as the family is unable to prepare for death or services. Expected death, on the other hand, allows planning time but has had a long-term impact on family dynamics and sibling expectations (Eaton Russell et al., 2018; Paris et al., 2009).

If a sibling dies of cancer, for example, their brother or sister's battle may have lasted months or years. In this timespan, the sibling has grown accustomed to helping their brother or sister throughout their illness to the time of death. In this situation, grief is formed early on while watching the decline of their sibling through the helper role. The children recognize their sibling

cannot perform duties they once could or play in the same way as when they were healthy.

Before their sibling dies, they already begin to grieve who they used to be (Eaton Russell et al., 2018).

On the surface it may appear that serving as a helper for their sick sibling is a burden on the child. Instead, the role of helper positivity influences siblings by allowing them to contribute to their time and care, lessen parental stress, and assume a role of importance. Siblings receive support from their family and community when serving as a helper, where they otherwise could face lessened attention from being the healthy sibling (Eaton Russell et al., 2018). After the sibling dies, the attention shifts from being a helper to being a bereaved child and in some cases a new “only child.” This can be difficult to come to terms with, especially considering the age of the bereaved child.

Still, it is difficult to truly distinguish if sudden or expected death influences the length of the grieving process for siblings. While hypothesized that sudden death increases trauma, there is no clear evidence at this time to prove this with certainty (Paris et al., 2009). Paris et al. (2009) suspects that there may be no difference at all in levels of grief and trauma found in children following expected and unexpected deaths. Children may not be developmentally able to process what an “expected death” is. Have they reached the point of development to understand the permanence of death? If not, emotions of grief and trauma will not change based on expected or unexpected death because all deaths will be viewed as “unexpected” (Paris et al., 2009).

Understanding of Death and Loss. Age and development of the bereaved sibling greatly impacts how death is perceived. Do they understand death is permanent? Have their parents appropriately explained death? A child who believes their sibling is “sleeping forever” will grieve differently than a child who has been given a truthful account of the situation. Parents

must be willing and able to explain death to their surviving children to avoid confusion, concern, and anxiety (Barrera et al., 2013; Foster et al., 2011; Funk et al., 2018).

The understanding of death and loss greatly varies depending on child development. Infants do not have any grasp on the concept of death. At the time of death, the biggest impact comes from however the people around them respond. Then, as the child ages, so does their knowledge about loss. Toddlers and pre-school aged children still have a hard time grasping the concept of death but begin to understand time. There are often misconceptions about the irreversibility of death which can enhance or instill feelings of separation anxiety. Next, school-aged children start to grasp and understand death and its relation to life. Additionally, this age group starts utilizing coping strategies and outwardly processing the loss. Finally, adolescents understand death, the consequences, and the fact that death can happen to anyone at any time. This age group is the most likely to engage with peers for support, but also the most likely to engage in risky behavior and withdraw (Crowe & Murray, 2005).

No matter the age, as a child, the sibling may not have a strong grasp about death merely due to age and cognition. Siblings attempt to process death at the same time they are developing themselves. It is natural for a child to focus on their own development, even considering an unfortunate event (Foster et al., 2011). We can expect children to grieve but cannot expect them to pause their own development while they grieve a sibling.

Children do face further halt in their development and well-being when losing a parent as opposed to a sibling, however. This could be due to attention levels received by the various parties. When losing a parent, a child also loses significant attention. When losing a sibling, a child likely receives more attention since parents can provide more care to their remaining kin.

The sibling no longer “fights” for the support that predominantly centralized around medical needs of a long-term, sick child (Foster et al., 2011).

In addition to developmental age and understanding, grief is also influenced by “degree of sibling suffering, how the sibling was told about the death, being present at the moment of death, and ability to view the body” (Funk et al., 2018, p. 6) Some parents do not know how to explain death to a child and avoid the topic entirely. This complicates a child’s ability to process loss and death and follows them into adulthood (Barrera et al., 2013).

This is especially the case for sudden death, which is difficult to explain to a child who had never encountered death. They begin to wonder “Will I die suddenly, too?” It then becomes the job of the parent to explain that occasionally bad instances occur and you cannot always worry about it happening again. There is time to prepare for the death of a child when they face a long-term, chronic condition, should they be at a certain developmental age. Unexpected death does not allow for parents to prep their child for the loss of a sibling. In addition to personal grief, siblings must then take on the emotions and uneasiness of watching their parents grieve (Funk et al., 2018).

Summary

The death of a sibling is extremely complicated for both the parents and surviving children. Siblings may not be at a developmental age to understand the certainty and seriousness of death. Still, it is imperative to be honest and inclusive of the siblings before, if applicable, and after death to allow for proper coping (Barrera et al., 2013; Foster et al., 2011; Funk et al., 2018). Death can have an especially hard impact on siblings who lost a brother or sister to a long-term illness as their job of helper has been replaced with bereaved sibling. Activities should be

implemented for children to give them a job or responsibility after their sibling dies. Otherwise, the child could feel lost and without purpose (Eaton Russell et al., 2018; Paris et al., 2009).

Similarly, parents must continuously engage their bereaved children with appropriate attention and display of emotion. Children should not be encouraged to “be strong,” but instead taught how to release emotion in a healthy way. Parents can teach children healthy coping mechanisms by using them personally. Siblings will otherwise bottle their emotions into adulthood and develop unhealthy coping skills. It is also recommended that children play, even shortly after the loss of a sibling. Play is a developmentally appropriate coping mechanism for children, and even allows them to display or discuss feelings that were previously suppressed (Andrade et al., 2018; Barrera et al., 2013; Demmer & Rothschild, 2011; Funk et al., 2018; Horsley & Patterson, 2006; Koblenz, 2016; Packman et al., 2006; Thompson, et al., 2011).

In addition to parents, bereaved siblings should also have an established support network after losing a brother or sister. This can be comprised of peers, the school system, extended family, and support groups for bereaved siblings. Children may put on a façade for their parents to portray themselves as brave. Outside support networks allow siblings to let their guard down and be honest about their emotions without judgement (Barrera et al., 2013; Demmer & Rothschild, 2011; Horsley & Patterson, 2006; Koblenz, 2016; Lovgren et al., 2018; Packman et al., 2006; Sveen et al., 2014).

Though the research revolving around grief in general is plentiful, there are several limitations to the collection of related articles. The selected studies are the relevant articles found when searching EBSCOhost with the following criteria-- Grief or loss or bereavement or mourning AND children or adolescents or youth or child or teenager AND death AND sibling. Articles were requested to be full text, from between the years 2004-2019 and in English

academic journals. The search results produced 99 articles of which The researcher selected 14 as related.

Many of the studies filtered through were about bereaved children following a parental death as opposed to sibling death. Several themes overlap between the two topics but losing a sibling is a unique experience that requires further study. This research aims to expand the literature and collect responses about sibling grief directly from siblings. Parent accounts of sibling grief are helpful to the field but lack the personal connection a direct interview with the sibling holds.

Additionally, six of the studies selected were not conducted in America. Culture has a great influence on grief and death and therefore results may differ from country to country. Do certain cultures discourage grieving? Are siblings always able to attend services? What influence does this have on the siblings? These are important questions to consider as death has many spiritual and religious connotations.

As a result, research findings may also vary from state to state within America, as well, due to differing religious, educational, and political values. None of the studies were conducted in the state of Massachusetts where the researcher and majority of participants currently reside. As such, there was an anticipation of a fresh perspective to the literature by surveying Massachusetts residents.

Most studies focus on long-term illness that results in death, such as cancer. This research increases the span of literature to include siblings who lost a brother or sister in a sudden or unexpected death. The experiences of these two populations likely differ greatly as expected death allows time to prepare and educate prior to death.

The available literature offers a glimpse into the lived experience of bereaved siblings. Additionally, in the lens of grief theories, there is a depiction of how grief changes over time, but not how grief changes based on developmental factors. As an individual ages, their awareness of death, loss, and permanence develop and change. Using a qualitative research study, this study aims to assess how development and grief interact when loss is experienced in childhood. This research plans to expand on the current research and fill the gaps created by the outlined limitations.

METHODOLOGY

A phenomenological approach is helpful to share and discuss the experiences of others who share a common attribute—in this case being a bereaved sibling. Qualitative data was collected through various means, such as interviews, field notes, and journals. This research study retells the stories of participants who experienced the death of their sibling during childhood through a phenomenological approach. The selected methodology allowed for emotion to be articulated in addition to words and numerical data (Hendricks, 2017, Mills & Gay, 2019). The study was overseen by the Missouri State University Institutional Review Board on October 12, 2020 with an approval number of IRB-FY2021-33 (see Appendix A for the Institutional Review Board approval letter).

Research Design

To study current grief in bereaved siblings, a qualitative study was conducted. The approach selected was used to collect data through participant interviews which are ultimately compiled and summarized into one shared story about this phenomenon. Common themes in the words and language of the participants were identified to highlight commonalities in the experience of a sibling dying. The aim of this qualitative study was to determine how grief changes over time in the context of development and what factors influence that change (Hendricks, 2017, Mills & Gay, 2019).

A qualitative research design is imperative for this study to truly hear and interpret the participants' experiences having a brother or sister die during their childhood. In this context, a survey could certainly pinpoint levels of grief, but this data collection method would not be able

to document feelings, emotions, and body language like qualitative data can (Hendricks, 2017, Mills & Gay, 2019). Death is an extremely sensitive and traumatic time for many individuals. It is important to learn from the participants about what they experienced and how to provide optimal care to other bereaved siblings in the future.

Site of the Study

The study was conducted via online interviews. This allowed for individuals to participate across the country and in the comfort and privacy of their own homes.

Participants

The goal recruitment number was six to ten individuals, while five participants were ultimately recruited. This number was selected to create a “collective story” of bereaved siblings as opposed to a single account (Creswell, 2007). The varied number of participants initially selected was decided based on data saturation which was reached at five participants. Table 1 demonstrates the demographic breakdown of the five participants.

Participants were recruited using the convenience and criterion methods. The criterion method is necessary for the phenomenological approach to guarantee participants are bereaved siblings whose brother or sister died during their childhood. The criteria to participate guaranteed participants were the correct age and had a sibling or siblings who died during their childhood, (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019). Table 2 depicts participant specific information, including age at the time of death, age at the time of interview, and sibling’s age at time of death. Additionally, the table denotes whether or not the sibling’s death was anticipated (expected or not). One participant’s brother died from cancer, in which death became expected

when he no longer responded to treatment. In terms of unanticipated deaths, one participant's brother died from suicide, one died from an unknown cause, and two died from surgery complications. To select participants, flyers were posted on social media through the researcher's personal profiles and shares from family and peers (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019).

Table 1. Demographic profile of research participants.

Demographic variable	Category	Frequency	Percent
Age	20-30	3	60
	50-60	1	20
	60-70	1	20
	Total	5	100
Gender	Female	5	100
	Total	5	100
Religion	Buddhist	1	20
	Catholic	1	20
	None	3	60
	Total	5	100
Sexuality	Heterosexual	4	80
	Prefer not to respond	1	20
	Total	5	100
Location	Maine	1	20
	Massachusetts	4	80
	Total	5	100
Ethnicity	Asian	1	20
	White	4	80
	Total	5	100

Ethical Considerations

While there are no evident physical risks, potential emotional and psychological risks are present. Since the topic of death is personal and potentially traumatic, privacy and confidentiality must be especially maintained. Participants were provided with a pseudonym to provide confidentiality.

Table 2. Participant specific categorization of pseudonym, ages, and death anticipation.

Participant Pseudonym	Age at time of sibling's death	Age at time of interview	Age of sibling at time of death	Death anticipation
Erin	13	24	24	Unanticipated
Jane	12	57	6	Unanticipated
Rachael	12	63	12	Unanticipated
Sarah	17	25	27	Anticipated
Tina	18	26	9	Unanticipated

At the beginning of each interview, participants were reminded that they should not feel pressured to answer any question they were not comfortable answering. Additionally, the researcher emphasized the option to immediately conclude the interview for the personal well-being of the participants. At the end of every interview, resources were sent to each participant including information about online grief support groups.

Informed consent was obtained from all participants prior to the research beginning (see Appendix B for the informed consent letter). This document and an Institutional Review Board (IRB) application were reviewed and approved by the Missouri State University Institutional Review Board before the start of the study. The study remained overseen by the Missouri State University Institutional Review Board until its completion.

Data Collection Procedures

Approximately one-hour long interviews with each participant were conducted online via Zoom. This allowed for the interviews to be conducted in a private location of the participant's choosing. The researcher remained alone in her apartment to ensure participant confidentiality and privacy during conversations. Interviews were also recorded to allow for a transcription period. Interviews were transcribed by listening to the recordings on file as many times as needed and keying the conversation in a Word Processor.

Instrumentation. With a phenomenological research approach, interviews are essential to hear the stories of the participants in an honest, in-depth fashion. As such, semi-structured interviews were conducted because the research focuses on a specific period in the participants' lives. Semi-structured interviews guided the participants in their answers but allowed them to share their story openly (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019). The interview questions took the participants from past experience to present with specific questions about their experiences as a bereaved sibling. Questions focused on themes such as family dynamics, personal and emotional well-being, coping skills, growth and development, and grief (see Appendix C for interview questions).

Additionally, field notes and journals were utilized to document body language and behavior during interviews. The field notes acted as a reference to the participants' moods and how the conversation affected them.

Role of the Researcher. As the researcher, the aim was to establish a trusting relationship with all of the participants. This research study resurfaces a traumatic and sensitive experience the participants have gone through and there was no intention to extend or inhibit the grieving process. While it was important to maintain a professional front, in the context of

qualitative research, it was also important to make a connection. There was then the assumption without trust and empathy interviews would run short and provide insufficient data.

There was also thought put into the great value of pausing and listening. Especially in semi-structured interviews, it was necessary to leave several moments of silence to allow the participant to collect their thoughts and for the researcher to process what was said. It was important for interviews to not be rushed and instead let the process occur naturally.

Additionally, it was important to be cognizant of the population being studied and their religious and spiritual beliefs. With an open recruitment method, recruitment of a diverse group of participants and cultural considerations was paramount. Depending on the lived culture and religion, siblings and their families might not believe in mourning for extended periods of time. On the other hand, another religion may utilize a multi-year grieving process. As such, it was imperative to not guide participants to answer one way or another about their experiences with death.

Data Analysis

Research was conducted through field notes, journals, and interviews. The first step of data analysis was reading and summarizing field notes and journals. Interviews were listened to repeatedly to accurately transcribe the data verbatim. Interviews, journals, and field notes were reviewed to highlight main takeaways amongst the themes and codes. Large scale themes and codes were identified from the main takeaways highlighted in the interview transcripts and summarized journals and field notes. A codebook kept track of themes and codes throughout the research (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019).

The findings were outlined regarding the lived experiences of the participants written in

sections influenced by the themes. Based on a review of current literature, projected themes before data collection included parental intervention, the creation of a support network, cause of the sibling's death, and child's understanding of death and loss. Transcribed interviews were ultimately quoted in the phenomenological story to highlight noteworthy statements and to determine how the grief changes over time and the factors that influence these changes (Creswell, 2007; Hendricks, 2017, Mills & Gay, 2019; Worden, 2009).

RESULTS

All participants were recruited online using social media through original posting and word-of-mouth. Each participant was assigned a pseudonym to protect their identity and maintain anonymity. Results were analyzed under the lens of grief changes over developmental time and the factors that influence changes in grief.

Grief Change Over Developmental Time

Changes in grief were analyzed under the lenses of development and time. Based on the ages of the participants studied, development was categorized into adolescence, young adulthood, and middle adulthood. Time influenced grief in three chronological experiences: lack of acceptance, independence and isolation, and finding contentment.

Development. An individual's developmental stage determines how they interact with others, one's self, and the world. This applies to how an individual understands and copes with death and loss (Lightfoot, Cole, & Cole, 2018). Differences in grief experiences were noted in adolescence, young adulthood, and middle adulthood.

Adolescence. After her brother's suicide, Erin took it upon herself to find the role of caretaker and helper at age 13. She began hanging out with more friends who needed guidance after feeling weighed down from the guilt of not being able to help her brother.

It made it really difficult for me to be okay with people who are not happy around me. Like knowing someone is going through something very difficult. Like knowing somebody is depressed made me feel like I needed to like save them in some ways. Always...Because there was a lot of guilt and regret that surrounded the event with really everybody in my family. Regret and guilt was a very major theme. And it wasn't always but whenever that topic came up it was definitely this sense of what it was. Yeah.

Jane also assumed the role of helper in her family, but not by choice. After her brother died, her parents began to care less for themselves, for Jane, and for the household.

When I was 12, everything flipped. I took over the family basically out of necessity. I made sure the bills were paid...I made sure we did groceries. Mom was there. She cooked, she cleaned but not really...I was confused. I was scared. I did not want to be the parent, but I had to. Somebody had to. Our electricity was turned off because they had just checked out. It was a lot.

Rachael, on the other hand, did not know what her role or identity was after her twin passed away.

I don't know. I think on some level when you're 12-years-old you appreciate the attention that having a death in the family brings to the whole family. You know, neighbors are coming over. People are bringing good food...But I didn't really suffer any emotional. I was a teenager when I think it really hit me. I know this is gonna sound crazy, but I saw the movie *Ordinary People*...It's all about survivor guilt and that just shook me to the core for whatever reason and I did, I went to see a psychiatrist about it because I was really, I was rocked by it. You know, why did I survive, and he didn't? ...Where is my place now that...You know, you're always looking for the other shoe. Twins are a totally different animal as far as a connection.

Tina felt internal conflict over whether it was appropriate to assume the role of excited high school senior and grieving sibling simultaneously.

I fell into depression and isolation...So, he passed away the summer right before my senior year of high school. He passed away about 11 days or less before the first day of school. So, you can imagine everybody like, you know the feeling, too, you know your senior year, you're super excited. You're gonna get you, you know, your college notice. It's the most exciting time of your life and one of the biggest milestones. But I was still grieving. And, when you go to school, you have so many distractions and so many things

that go on. You fall into it and you don't think consciously of all these distractions and you forget that you're still grieving.

Young Adulthood. Coming to terms with grief in young adulthood was common the participants. Rachael stated, "It took me...I was probably 20 years old...8 years before I really and truly dealt with the trauma." For Erin, she felt a shift when turned 24—the age that her brother died. She shared "I'm getting closer and closer to his age and...Yeah. There's huge turning points now in my life that he's not here."

Sarah faced a turning point in young adulthood when her depression worsened. She had to contemplate the various ways her mental health was being impacted.

And I remember being on this one medication that just I feel like really made my depression and mental health so much worse. And I didn't know how to like explain that...And I remember a lot of like back and forth where they were like well, is that because of the medication or is it because your brother passed away? Is it because of things with school? Like, why are you actually feeling this way? And it's like trying to identify like why do I feel suicidal in this moment?

Tina found ways to cope and grieve in young adulthood through practicing mindfulness.

For me, it's starting to...reading about...Buddhism. And specifically, about open mindedness. And, that really helped me a lot because it taught me how to accept myself but also...forgive yourself. And, when you practice mindfulness, you learn how to emphasize with yourself... It's almost like meditating. You learn how to pause. You learn how to focus. Not just yourself, but your surroundings...I feel more balanced. I'm not as short tempered. I'm not as irrational...I don't think how I used to think a few years ago or a couple years ago.

Middle Adulthood. Two of the participants, Jane and Rachael, are currently in middle adulthood. While they admit to progressing through the grieving process over time, they state the impacts of their sibling's death linger today. Jane's coping mechanism of stress eating was only recently resolved. She states, "Stress eating has always been in my life. It's been the past seven months that I've, well the past year and a half I've figured out how to deal with it."

Rachael noted an emotional response to certain events in middle adulthood that began after her brother's death.

But even to this day, I remember, "Leaving on a Jet Plane" was the song that was playing on the stereo and when he went to go to the hospital. And I just never thought anything would happen so, you know, I didn't make a big deal about it. I'm like yeah, see you when you get home. You know, that kind of thing...and even now, I switch the channel on the radio if it comes on. It just rips my heart out as an opportunity lost.

She shared a change in perspective in middle adulthood following a loss of her own child.

It was very cathartic for me. You know, I...I have become the keeper of the grave. You know, my whole family is down the street at a local cemetery and, you know, I'm the one that does the wreaths and the flowers and all that. And I remember many times I would go to the cemetery for my brother's grave and I would see her [my mother] sitting in her car doing the rosary. And she was never a particularly holy woman, you know, she made us go to church cause that's what the Catholic church demanded, but you know, she wasn't a roller by any means...But I really understood what she had gone through when I lost my son. Cause you can't understand that until you're a mom. I mean, you sympathize, you emphasize, but you don't know. You can't know.

Time. Over time, feelings of grief changed and were universally experienced by participants. The trajectory of grief over time included lack of acceptance, independence and isolation, and feelings of contentment.

Lack of Acceptance. The five participants all expressed difficulty accepting the death immediately following the death. Erin noted denial that her brother was truly gone.

For a while, for a long time...For weeks and weeks and weeks, I would wake up and I really would think that I would go downstairs, and he would be there. Like that he was gonna come home.... He's coming back. Like this is just a weird game that people are playing or something. Like, this didn't actually happen. He's just, like, sick.

Jane shared "The reality of it is our lives revolved around him and then he wasn't there. So, the reality was everybody was at a loss, so we knew he wasn't there. There was nothing to focus on and it was hard to accept that we couldn't interact, be, feel." Tina also could not accept the reality of the loss in adolescence.

I didn't fully accept the reality and I felt like I tried to accept it by making all these decisions and doing all these things that I think it was necessary. And it was necessary at the time. Like, trying to go to school that was far away knowing I wasn't ready to leave my mom...I wasn't ready to mourn. I wasn't finished grieving...When you try to escape something...you haven't fully coped from, you fall into a darker hole.

Rachael shared the sentiment that accepting the loss was difficult in adolescence. She stated, "I couldn't accept it. I couldn't...Adjusting was hard...We were in the same grade. That was hard for me." Sarah noted, "It definitely took a while to accept that he wasn't there because my family has this really unfortunate history of just not telling us when things are happening."

Independence and Isolation. Four of the participants noted feelings of isolation after their sibling died. For Rachael, this happened quickly after accepting the death had occurred.

I grew up in a close-knit Italian family, if you know what that means...But, everyone just sort of scattered. Everyone, people grieve in their own way...My mother just completely withdrew into herself...When he was gone, she figured, well none of you need me...That was really...my first experience of death within the family so to speak.

Some of the participants found that their grief and mourning continued for years and into young adulthood. Tina recognized her grief became noticeable when leaving for college.

I didn't realize that I wasn't ready to leave my mom. I wasn't done mourning. I wasn't done grieving...I was okay but being alone and feeling alone. And I was in the stage of a really deep depression and anxiety and I didn't know that, that, that was what I was going through. Like I didn't know that I was going through depression. I didn't know that I was okay with being alone and it had gotten so bad that I was alone and to be honest with you, I was alone in my dorm just getting high and really being in that state of isolation. And I was comfortable in that darkness. So, I started missing out on classes and I eventually failed and lost my scholarship. My full ride.

Jane felt similar feelings as she entered the early stages of young adulthood and garnered more independence.

When I was 18, I joined the Marines. It was my way of running away...I had applied to colleges and my mother basically said to me you're on your own because we can't afford to get you through college. And I weighed my options...I surprised everyone. I signed up. I went to bootcamp. I did four years in the Marine Corps. I should have stayed, but my mom got sick, my grandmother got sick, and I came home. But when I was 18 and I went away, I felt that first bit of freedom. I felt, like I could be me. But then I felt sad because I was starting to feel and deal.

For Sarah, isolation occurred when returning to college and discovering her roommate had moved out without notice. Unable to trust her parents, she felt like she had no one to turn to.

I obviously did not want to go back to school. And I really felt like I couldn't trust my parents...But I also didn't have anyone else to talk to...When I went home after my brother died my roommate in college thought I wasn't coming back because that seems like a rational thing. So she had arranged to move into a different room with one of her friends...And she was gonna tell me she had moved out, but it's again figuring out when to say something like that...I didn't really know that I was going back until it was happening. And so, I just remember we go back to my dorm and it was half empty and...my dad started yelling at me because I didn't tell him that my roommate had moved out...So, I explained I didn't know.

Finding Contentment. Tina found peace in knowing that her brother would be happy with how far she's come personally and in her grieving.

I think I'm done grieving and mourning. It's just now understanding that he's in a better place and what I'm doing today, I know that if he was here, he'd be so proud. He would be so proud if he was here today, seeing what I'm doing, seeing how I'm doing, how I'm living. I think he would be a proud brother and say, you know, this is how I wanted you to grow up and how you should grow up.

While Sarah admits to still accepting the death of her brother, she has found comfort in incorporating him into her new reality post-loss. She stated, "I mean, I do feel like I've kind of figured out...this is how I incorporate [my brother] into my everyday life." Rachael recognized the difficulty of the situation, but that through time and processing the situation she found contentment.

You'll never forget but you will process it and be okay. But you have to give yourself time and allow yourself to feel whatever you have to feel because that's the way it is...And, you know, it's trite, and it's old, and it's boring, but you got to be tough. Because, if you're not, the world's gonna eat you and spit you out and not even think about it. And that's sad but, it's the way it is.

Jane can now reflect back onto her brother's death and acknowledge how she was able to grow from all she experienced. She shared, "I wonder how it's impacted my life because it made me a caretaker and some of the choices I've made later on in my life weren't necessarily the greatest...But I am a very strong person because of everything I went through."

Factors Influencing Change in Grief Over Time

After content and data analysis, five major themes emerged in determining factors that influence feelings of grief over time in bereaved siblings: sibling's cause of death, family reaction, establishing a support network, remembering the deceased, and milestones and dates. Table 3 outlines during what developmental stage these factors were experienced.

Sibling's Cause of Death. All five participants experienced the loss of their sibling in a different way though, coincidentally, they were all adolescents at the time and each lost a brother. Additional themes emerged related to death anticipation (expected or not).

Adolescence. Sarah had a younger brother who was diagnosed with cancer as a toddler and passed away from this condition after 6 years of treatment. To her, death had become imminent several months before he died.

He was diagnosed with stage four, high risk, neuroblastoma when he was 3 ½. And that was in 2007...We did the standard protocol treatment at the time...He was in remission for about like 4 months and then he relapsed for the first time and after that first relapse he never cleared again and was in treatment solidly for like, total he was in treatment for 6 years...It was the rest of his life he was in treatment. In, so he passed away in March of 2013. The prior September, October we found that...his neuroblastoma had become refractory and wasn't responding to anything...At that point his doctors were kind of just hoping to get him into a vaccine trial and we were waiting for that and then a few months after that we found out he had a secondary cancer from treatment and at that point we couldn't do anything.

Table 3. Developmental stage in which factors influencing change in grief over time were experienced.

Factors influencing change in grief	Adolescence	Young Adulthood	Middle Adulthood
Sibling's cause of death	X	-	-
Family reaction	X	X	X
Establishing a support network	X	X	-
Remembering the deceased	-	X	X
Milestones and dates	X	X	X

Participants who experienced a sibling death that was unexpected often described factors contributing to their grief including missing out on special moments. Rachael had a twin brother who was born with a congenital heart defect.

He was born with a hole in his heart...And he had open heart surgery when he was 12, when we were 12, and he made it through the surgery fine, but the machine that was pumping his blood failed for 90 seconds and he passed. Because the machine failed...I knew, you know, any surgery is risky and even at 12-years-old, they say, they tell you, you know, it's dangerous. But in a million years I never. I mean we were all pretty... You know my brother went to football practice. My sister went out wherever she goes. I was across the street. And I remember...my parents' car pulling into the driveway. Cause I said I was across the street at the time and my mother getting out of the car and just collapsing on the front steps. And I'm like oh shit this isn't good.

Another participant, Tina shared a similar sentiment in the shock of having her brother die unexpectedly.

So...according to his death certificate, the cause of death is unknown. But...really, he suffered from seizures...He, he fell a Saturday afternoon with a seizure and from then on, he was hospitalized all throughout the summer of 2012...And he was transferred, he was in two hospitals. Both facilities, they weren't able to identify the root causes of the seizures. So, while they were, you know, trying to control his seizures he had to be sedated. Since he was sedated for such a long period of time his other organs and body parts started to break down because he was in a coma for well over two months. He, you

know, wasn't physically awake so a lot of the feeding had to be done through a tube...that was put in surgically to his throat. So, as you can imagine, a human body that's laying there for over two months, they're not doing anything over time. His kidney starts to fail, his liver wasn't working, and while they were still trying to control his seizing, but he was continuously seizing so much he ended up having brain damage.

Family Reaction. Familial reaction played a large part in how bereaved siblings identified feelings of grief throughout their life since the passing of their brother. This varied from parental reaction to other siblings and extended family members.

Adolescence. Immediately after the death of her brother, Jane noted the withdrawal of her parents.

I was 12 when he passed away but there was, when he was born, I was 6 and back in 1969 there wasn't a lot know about epilepsy and he had a severe form of epilepsy. So, his coming in to being was very traumatic for everyone. So, he was 6 and it was December 27th. He went in to have his tonsils taken out and they left him alone, had a seizure, and despite them trying to revive him, he didn't make it...It was...weird...Life was difficult because the world centered around him because he had so many seizures and then there was nothing. And the family, I wouldn't say fell apart, but they checked out. My mom and dad definitely checked out.

Rachael noticed the same about her mother specifically, in regard to losing her twin brother.

I think on some level it was kind of painful for her [my mom] to look at me. I was part of a set. And, you know, you lost one sneaker, what good is the other one? And not that, you know, not that she dismissed me, but she definitely withdrew from everyone. She just, I don't think she could process it on any level.

Erin similarly felt reservation from her mother in addition to her older brother after her 24-year-old brother committed suicide.

A lot. There's a ton of guilt. With my dad it doesn't seem as much so. But my.... Everybody blames themselves for what happened...and it, my mom certainly got a lot more reserved about more... Like I don't even remember what my family was like before the incident and that's kind of the problem, I think. Yeah...My brother the first few weeks after drank heavily of course. He was always kind of drinking heavily, nothing kind of changed in that way...[My brother] probably got more to himself. Cause that was just like...He was kind of distraught secretly. He kind of, he wanted to make the whole thing go away kind of, so he immediately just started renovating the whole apartment downstairs to like forget that it even happened so that he didn't even have to be around the memories of it kind of. It was a lot of trying not to remember until he got drunk and then he really wanted to talk about it.

She notes now that it would have been better to approach her family to talk about how she was feeling at the time, suspecting they felt a similar way.

I think not being afraid to go and like initiate the conversations about it. Like telling someone, like don't be afraid to all of the sudden go talk to your mom about this thing you're thinking about with your brother. Like, chances are your mom wants to talk about it, too. Like, it's helpful to talk about it, not to just be afraid that saying those things are going to upset the people that were affected by it just because you said it...It's better to share that feeling and cope with it together as opposed to alone.

Tina felt the impact of her mother's reaction to the death when her brother was being taken off of life support.

And I remember so clearly, like, one morning it was like six in the morning we were all waiting in the hospital cause...the night before we received a call from the doctors saying, you know, his body is not accepting any of the medicines we're giving him...They said at that point it's just the machine keeping him alive...So the hardest decision for my mom was to decide whether to pull the plug or not. He was on life

support...My mom said she couldn't just keep him suffering anymore...So, we were in the room and that's when they shut off his life support. So, when they shut off his life support, they have to shut off every other machine. And as soon as they shut off his dialysis machine you can see his blood that's cleaning through the tube like red like normal blood color, and as soon as they shut it off like split second you can see the blood turn dark black...So everybody is crying and we're sobbing, but my mom is just so strong. She just stood there and held his hand. Not a tear down her cheek.

One participant, Sarah, stated that her parents reacted to her brother's illness and death to the point of withholding information.

And when he died, I was at school. I was in college it was my first year. So, it was my second semester and in February...it was on Valentine's Day. My dad had called me and told me that I needed to come home because [my brother] was declining and he was declining very fast...And he said I don't know how long you're gonna be home but you should probably just pack a lot of your stuff and come home...And so, I was home for like a month basically and he kind of like declined but plateaued with medications and everything. So, my parents decided that I needed to go back to school. And they drove me back to school. And...two days later he died, and they didn't tell me. So, they asked my academic advisor to tell me...So he did tell me the day that he died, but he was not for being an emotionally intelligent man. I was in a lab and he walked into my lab and he said "Hey, [last name]. Your brother died." And then my parents didn't pick up the phone when I tried to call them and...there was a blizzard and I was stuck at the school. So, I was finally able to get in touch with my parents the next day and their neighbor came to get me because she felt like I shouldn't be at school alone.

Young Adulthood. The impacts of Erin's brother's suicide on the family linger still into young adulthood. She states, "They definitely, my mom is...My mom is very, even now 12 years later, she is still like very regretful about it. And every once and a while it still, we won't talk about it a lot, but it blows up in situations when we're upset about something." Eight years later, Tina similarly sees a lasting effect on her mother.

You could see it in my mom that she had to be the bigger person. That she had to be this, the leader. The leader of the pack.... I think 'til this day I think she still goes to sleep by herself crying. And it sucks cause no one is there to care to her. To hug her.

To this day, Sarah and her sister discuss the lasting implications of their brother's death on their parents. They recognized their parents' need for additional support, as well as the unlikelihood that this would occur. She noted, "We've had a few like more extensive conversations just where we actively kind of acknowledge that our parents' mental health is really unhealthy and not well. Things like different things that they should do, but we'll probably never get them to do."

Middle Adulthood. During middle adulthood, Rachael began to understand her mother's reaction and better empathize when her own son passed away at two weeks old. Recognizing her own emotions and similar experience, she stated, "No one should know cause it's not natural to bury a child. And I think she was just overwhelmed with it when my brother passed. It's hard to counsel someone else when you're internally falling apart."

Jane reflected on how her father with dementia still talks about her brother and now deceased mother occasionally, many years later.

My dad is 84 and he's well into dementia. But my dad will...and my mom passed away 20 years ago. It's kind of weird because my dad will talk about them. In January, my dad said to me 'Why don't you bake me bread pudding anymore?' And I'm like, 'Dad, that was always mom that made bread pudding. I don't have the recipe.' And my dad gave me the recipe. Like, 'Your mom's here. She's visiting with me.' And, it was weird because I made it and it was just like hers. So, it's kind of, interesting to think that maybe he is visiting with them cause dad never cooked. So, it's kind of a comfort.

Establishing a Support Network. Bereaved siblings were also influenced by the availability of supports throughout their grieving process in their adolescence and young adulthood.

Adolescence. Of the five participants, only one felt truly supported following the death of her brother.

It was just friends. Friends and family... Yeah I just kinda two weeks afterwards started going to school and just kind of treated it like it was just a normal thing that had happened... Just pretending like it didn't happen was a way to cope with it kind of... It is an awful terrible thing, but for me feeling bad for someone and kind of being awkward around them because of it and not knowing how to really interact with the person after they lose someone like that makes it harder. Cause then you're like oh, am I acting weird? I just want this to feel kind of normal.

On the other hand, Jane felt that her situation was far from normal and, until recently, was utilizing stress eating as a coping mechanism.

There was no support. The one thing that I wish now looking back as if there was something at the school that could have helped out, a neighbor... There was nothing. I stress ate. That was my coping mechanism. It's a hard habit to break... I had no support whatsoever. And neither did they.

With the death of her sibling was unexpected, Rachael felt that supports were never put into place to prepare for this type of situation.

We never expected to, for it to end that way. So, it's hard to put things in place when you don't think you're gonna need them. But no, with the exception of the people across the street, you know, and my family and my friends. No. Nobody did [have support]. Of course, my father would rather open a vein than go talk to a professional. I know my mother went to her doctor's several times... Because they were friends as well as doctor-

patient, or well, doctor-parent of patient. But as far as...I'm trying to think if she ever went to talk to anybody professionally. I don't think she did. That generation didn't.

Young Adulthood. Soon after their sibling's death, two participants entered young adulthood. While grieving, they attended college and engaged in on-campus counselling services. Sarah found that on-campus counseling was not helpful towards her grieving process.

I spent a lot of time going to the on-campus counseling center and the on-campus counseling center did not know what to do with me because I was a very newly bereaved sibling. And they felt very strongly that I should go home, and the Dean of Students felt very strongly that I should go home...And it felt a lot like everyone thought I should go home except for my parents. But the deal breaker was that I would not get reimbursed for that semester at all if I were to withdraw at that point and my parents couldn't rationalize losing that amount of money. But, I...they weren't paying for it. It was all scholarships and grants. And...I paid like a few thousand dollars out of my own money. So, that was their argument was that I would lose all that money. But, I kind of lost it anyway because I did not do well that semester...I did not feel that it [on-campus counseling] was helpful...Because they just kept telling me, you know, we really don't think that you should be here. We really think you should go home. We really can't support you the way that you need to be supported here.

Tina also shared that sentiment that her on-campus counseling had no solutions or supports available.

I don't think I shared much with people. I was holding it very close to me. I was very personal about it...There was no support, there was no group therapy, or any of that. I tried therapy a few times when I was in college, but I didn't think it was helpful. I felt like the conversation that I was having with this therapist that was provided by the school...So they assigned me to this one therapist when I was at [college], to this one therapist that was also Asian because they felt like by sticking with someone with a similar background she could relate, or I can relate, and you know. And I met with her a few times and we did talk about my brother. But I felt like every time we connected, it feels like I'm just being reminded and having the same conversation over the same subject. And there was nothing being done, and there was no solution.

Remembering the Deceased. Beginning in young adulthood, finding ways to remember and commemorate the deceased became prevalent in the lives of bereaved siblings.

Young Adulthood. In adulthood, the participants noted the importance of continuing their sibling's legacy. They shared the sentiment that over time, they are able to live their lives remembering their brothers and think fondly of the time they had together.

Sharing more stories about him so we didn't like...Over the years, like years and years later, I would hear these awesome stories about him, and it made it feel like better. It just felt like he had like a good legacy...I used to always want to, in high school less so cause I didn't really drink but like for years later after I kind of processed it and wanted to kind of get back to feeling close to him, I would, I would go and do some of the things that he liked to do. Like I would go drink an iced coffee. Like a medium French vanilla iced coffee extra-extra. Or I'd go to the bar and I would drink Jameson shots and like kind of and like just doing little things that I'd be like I know you're not here but I know that if you were here it'd be pretty cool if we were doing it together.

For Rachael and Sarah, there is an importance in saying the deceased's name. Sarah states, "I do...I say his name all the time. And...I kind of encourage other people to, too. I guess maybe that. Like, don't be afraid to say your sibling's name. They're still your sibling even if they're not physically here anymore." She also emphasizes not being afraid to say she has three siblings, though her younger brother died when he was young. Sarah notes this was particularly difficult at first, but soon found confidence in being able to tell others about her brother's journey. Rachael does the same, to affirm that he had and continues to have an impact.

I think saying his name out loud. You know, he really did exist. He was a good kid. He was a funny kid. He was part of the neighborhood dynamic...As I said, we went out, there were 40 kids...But being able to say, oh, [my brother] used to like to play this game or... [My brother] would have thought that was funny. Just acknowledging that he was

here, and he did make a difference, and he did have an impact on our lives in whatever way. That was comforting.

Sarah also created a legacy for her brother by becoming involved in a foundation that provides funding for pediatric cancer research.

I somehow got connected with the Saint Baldrick's Foundation after [my brother] passed away...And they are like the largest, non-governmental funder of pediatric cancer research in the country....And they kind of gave me a platform where I could tell his story and my own if I felt comfortable with it. And where they, just really wanted to honor him and what we'd been through. And at first I was really skeptical and I really didn't, I didn't give them a lot...And I went to this event and it was people I had never met before, but they knew about [my brother] from newspapers articles or something on the Internet or I don't know. A friend-of-a-friend told them about this kid and his family and all the shit that they went through. And people I had no idea, were shaving their head and raising money for research while holding his picture with the hope that they'd be able to make something better for the next kid...So after that I said, alright, like let's do this. And their staff kind of helped me like how to tell my story and [my brother]'s and how to make a difference with it. So...They have helped me tell his story and they have brought me to D.C. several times to testify to Congress just to figure out like, or help with research and like getting money for it.

Middle Adulthood. Now 63, Rachael noted that every day she still feels the presence and remembers loss of her brother.

I was out with my daughter once when she was little...I'm a very spiritual person. I'm not a very...Catholic person. I don't go to mass. I don't put money in the basket. And I don't believe they have all the answers because I know they don't...But I was walking with my daughter and I had a dog at the time and she was walking behind me...I turned around and I would swear on a stack of Bibles it was my brother...coming up the hill...I would swear to this day. It's still so vivid to me...So he's always with me. Always...I know I'm always connected in every way and every day.

Milestones and Dates. Throughout the grief process, siblings noted how their grief was influenced by significant milestones and dates, pertaining to their own lives and the lives of their deceased siblings.

Adolescence. In Rachael's assessment, the first year after her brother died was complicated—"Everyday you'd get up, it was a different thing. Yeah, I still don't believe he's gone. The next day... Yeah, I wish he was here. Well, he's not here but I'm going anyway. For a full year...everyday was a different day...Until you come full circle and, you know, this is my life now without him."

Sarah also noted the expectation of difficulty during the first-year post-death considering special dates and milestones. To her, the second year was also hard to get through.

People will say, well, I don't know everyone always told us like the first year is the hardest. And so, we expect that first year was hard. But, no one told us how hard it was going to be to do it a second time...I feel like my life is kind of split up into these time periods of like, before [my brother] got sick, and while he got sick, and before he died, and after he died.

Young Adulthood. Erin shared she still has a difficult time 12 years later, especially around the anniversary of his death. She stated, "Around those days I kind of try to like, around those specific days of March 28th or like the week that we lost him that typically, often is a hard month for me for some reason. Recently less so but it used to be."

Tina experienced strong feelings of grief during the milestone of going to college and not having her brother to rely on.

I think of having my brother. If he was there, could I experience it more differently? And, if he was alive and I'm going through all these stages of life, would I have a better

outcome? And would he be there to say don't do this, don't do that, and to guide me more clearly and put me on a better path? But it was just me. And as a first-generation college student, you have a parent that is very reliant on you. They don't know what you're going through. They don't know the college experience.

Sarah shared that sometimes random memories and moments will spark feelings and emotions. Her sister recently began sending messages to Sarah reminiscing on their brother.

She'll just send me random texts every once in a while, that will be like 'You know, I just remembered how like [our brother] used to always give you...' He used to always give me sour patch watermelons before...we would do a port flush because the saline would taste so bad. So, we 'd always like. That was our thing. We would just chew them. She was just like, 'I was just walking through like Walgreens or something' and she's like, 'I saw them, and I just remembered that.' And her question was like 'Did that help?'...Or sometimes I'll get texts at like, I don't know, two in the morning, middle of the night and she'll just be like 'I really miss [our brother].' And that'll be it.

Middle Adulthood. Jane especially feels moments of loss and longing on special dates, such as her brother's birthday. Now, 45 years later after his death, she shared, "He was so young when he died. In July on his birthday I wonder what he would be like, what he would look like." Rachael also commented on how hard it remains to be on her brother's birthday. As twins, she once wished to have a more exclusive birthday. She stated, "It's still hard on my birthday when, you know, I was always like, I want my own cake. I want my own party. And, of course, we never did any of those things cause we were poor. You're gonna have one cake and you're gonna have one party and you're gonna shut up about it. Okay, there you go. And I did."

DISCUSSION

In conversations with all participants, a clear pattern of grief was displayed. First, a period of lack of acceptance occurred in which each participant had difficulty accepting their sibling was truly gone. Second, the participants faced heightened grief as they gained more independence and time to think. Finally, through time and processing their grief, each participant found contentment and a way to integrate the deceased into their everyday life.

Worden's four tasks of mourning similarly highlights the initial period of shock, denial, and lack of acceptance (Worden, 2009). The participants all agreed that there was, and in some cases continues to be, an acceptance period to grasp this new reality before they were able to process the grief itself. In terms of the period of independence and isolation, Worden (2009) denotes the second task of mourning as "to process the pain of the grief" (p. 43). Once the participants accepted the reality of loss, and typically years later into young adulthood, they began to acknowledge their pain, grief, loneliness, and depression. The participants ultimately found a way to mitigate these feelings and find contentment after the loss of their sibling. Worden's final task of mourning best identifies this phenomenon as the ability "to find an enduring connection with the deceased in the midst of embarking on a new life" (Worden, 2009, p. 50). This was noted especially during specific milestones, dates, and anniversaries associated with the deceased.

In terms of current stage of development, all bereaved siblings who participated in the study were 12 years old or older when their sibling died. From this, they all had a grasp of the permanence of death and its implications on themselves and their family (Crowe & Murray, 2005). Utilizing Erikson's psychosocial stages of development, the participants were each

involved in the stage *Identity versus Role Confusion*. From this, it is noted that the participants were seeking to find who they are as an individual. The inability to accept the death could tie into the notion that the participants could also not accept who they were without their sibling. However, this reaction and period of grief may also simply be a factor of time considering Kübler-Ross and Worden denote shock, denial, and lack of acceptance as part of the mourning process across age groups (Hall, 2011; Worden, 2009).

Participants also established a self-proclaimed identity of “helper” in adolescence that continued into adulthood. One participant sought friendships in which she would be able to help others after her brother’s suicide. She shared that her assumed role of helper remains to this day. Additionally, she remarked that she tries to help people as much as she can to get through difficult times. Another participant similarly assumed the role of helper, but not by choice. Instead, she took on this role out of necessity since her parents were not caring for the home. This aligns with Erikson’s psychosocial stage of development again, in that participants established this life role as a direct result of their sibling’s death.

In young adulthood, the majority of the participants began grappling with their grief and its impacts. This often occurred when participants left their family home for college or another reason and were “alone” with their thoughts. It was at this time that they began to process the grief but were also newly alone. One participant tried to push away her mourning in adolescence by utilizing distractions. It was not until her freshman year of college that she understood how drastic this change in self was. She found that she was not ready to assume the role of a college student and “move on” from what had happened. This ultimately had a negative impact on her mental health and led to her dropping out of college. Research by Taub and Servaty-Seib (2008) shows that difficulty in college following the death of a family member is common due to mental

health issues. This participant recognizes now that this experience helped shape her journey into finding her identity years later. Though initially failing to find a set identity she was happy with, she found a way to establish healthy behaviors and re-enrolled in college.

Now, eight years after the death of her brother, she found support and comfort through practicing Buddhism and mindfulness. During this time, she has taught herself how to accept and forgive herself, to pause and focus, see other's perspective, and became more Zen. This coping mechanism was established after years of drug and substance use. Eventually, she did not like who she saw in the mirror and made strides towards more healthy and mindful living.

Four participants pursued therapy in young adulthood, however, they described variances in effectiveness. It is possible that the participants attended therapy in young adulthood as they grew in independence. Especially of note that none of their parents attended therapy, once the decision laid in their hands to receive additional support, they acted upon it. The overall lack of therapy attendance in bereaved adolescents should be tended to, considering heightened feelings of grief in young adulthood. Parents and family should be encouraged to send their bereaved children to therapy after the death of their sibling regardless of how they believe their child is coping at the time.

While attending college in young adulthood, two attended on-campus counseling and neither found the supports of on-campus counseling helpful. This could be due to the fact that the on-campus counsellors did not feel equipped to handle grief work as opposed to more common on-campus happenings. Research suggests that colleges and universities should make a continued effort to improving training and supports for bereaved students (Taub and Servaty-Seib, 2008). The remaining two participants, who attended non-collegiate affiliated therapists, found their therapy supports to be beneficial. One participant noted a betterment of her mental

health after seeing a psychiatrist and now counsels others who are undergoing cancer treatment being a survivor herself. This has been a therapeutic process for her helping others get through a difficult journey.

In congruence with Erikson's psychosocial stage of development for young adults, *Intimacy versus Isolation*, it is imperative to form close bonds or else feel isolated (Lightfoot, Cole, and Cole, 2018). This was the experience for three of the five participants in that they felt alone and separated from family and friends in early young adulthood. Feelings of loneliness were stated by participants to be directly linked to their sibling's death and coming to terms with grief. As such, it could be speculated that this period of independence and isolation in grief is specific and related to the development of the participants.

Assessing grief in middle adulthood was only applicable for two of the participants who are not 57 and 63. For one, the implications of grief spanned into her middle adulthood. After the death of her brother, she coped by stress eating. This habit remained throughout her entire life, until close to two years ago. Eventually, she garnered the support of her current spouse to break this difficult habit. She noted that lack of support was a product of the times and the generation she grew up in. Again, she did ultimately seek counseling for herself in adulthood after her additional family members passed away. The second participant in middle adulthood, on the other hand, noted the most difficult loss for her was when her own son passed away. From this, she was able to retrospectively reflect on past experiences and family reactions in middle adulthood.

Developmentally, middle adulthood is a period where individuals find purpose through work and family in Erikson's stage of *Generativity versus Stagnation* (Lightfoot, Cole, and Cole, 2018). In the case of these two participants, the challenges faced in this stage of development are

likely due to a compilation of loss over time. Both participants noted lingering feelings of loss from their sibling, but also from deceased parents, children, grandparents, aunts, and uncles. As such, it would be difficult to state that their continued grief is isolated. Instead, it has been compounded upon for years since the death of their siblings.

The findings were also interesting to assess on an individualized basis in regard to participant-sibling relationship. For example, two participants had siblings die who were younger than them, two had siblings die who were older than them, and one had a twin die. For those who had an older sibling die, grief intensified as the individual approached the age their sibling died. It appeared that they felt a closer connection to them at this time and sought ways to strengthen their bond. In regard to those who had a younger sibling die, there was a level of caretaker that was established and lost when their sibling passed away. This appeared to contribute to feelings of confusion after their sibling's death. Without their sibling to take care of, what was their role? Lastly, in regard to the participant who lost a twin brother, there was a sense of lost identity. One's upbringing is so closely intertwined as a twin and the sudden loss of this connection is startling for the individual and their entire familial unit. All this considered, the age difference between the bereaved individual and their sibling should be noted when assessing one's grief experience.

In terms of factors that influence grief over time, the five themes identified are closely aligned to current literature, with sibling's cause of death and establishing a support network present in the findings. While similar in nature, the current literature's theme of parental intervention has been expanded upon to encompass the reaction of other family members and living siblings in addition to parents. Understanding of loss and death was altered to a theme of current stage of development, noting that development as a whole includes understanding the

permanence and impact of death. Lastly, new themes of remembering the deceased and milestones and dates emerged to highlight the participants' ability to live in Worden's fourth task of mourning, "to find an enduring connection with the deceased in the midst of embarking on a new life" (Worden, 2009, p. 50).

These findings are unique compared to Worden (2009) in that development is considered as opposed to time alone. Certainly, there are similarities in the grieving process regardless of age, but it seems apparent that development plays a crucial role, especially young adulthood. During this time period, individuals are seeking intimate relationships and the bereaved siblings are missing out on a lost sibling bond. After processing the loss in adolescence, the young adult is finally able to confront the loss of their sibling and the relationship they could have had if their sibling was still alive.

Sibling's cause of death as expected and unexpected did have an effect on how a bereaved sibling copes due to a change in family dynamics. Three participants had siblings with chronic health conditions, though only one knew their sibling would soon pass away. Their sibling's cause of death had an impact on them for a variety of reasons, such as whether or not the event was "expected." A chronic health condition established early on in the sibling's life had begun to alter the family's dynamics prior to their passing (Eaton Russell et al., 2018; Paris et al., 2009).

In regard to one participant, at the time of her brother's diagnosis, she was 12 years old and had just moved to a new state. The stress inflicted upon her family seemed apparent throughout his 6 years of treatment, especially as she entered her freshman year of college. As the oldest, she continued on her academic journey while her parents and three siblings stayed home. An anticipated death from a chronic health condition can pose internal conflict for a

sibling as they pursue new experiences, such as moving away from home. This can feel like one is missing out on time with their sibling, though the weight of expectations to keep going push the sibling to continue forward. This can lead to feelings of regret later in life depending on the decision made either way in terms of “pausing” other activities or pursuing them be (Eaton Russell et al., 2018).

Additionally, during his diagnosis, she did not note a significant burden placed upon her with a sick brother which contrasts the findings of current literature. Instead, she willingly tried to assist as a T-cell donor for her brother and, during testing of her cells, doctors found she also had cancer and was ineligible. This further complicated her grief and feelings of sorrow after he passed away, especially during her relapse after his death (Eaton Russell et al., 2018). In contrast, another participant did describe having to take care of her brother and watch over him when he would have seizures. She noted how challenging of a responsibility this was as a child (Eaton Russell et al., 2018).

In death incidents where a sibling passes without notice, one does not have the opportunity to say goodbye or know it will be their last moment together (Funk et al., 2018; Paris et al., 2009). Thinking back on these final moments can be painful and cause a flood of emotions in present day. 51 years later, this still happens to one participant when she recalls her final moments with her twin. While he had a chronic health condition, she had not been anticipating his death and therefore did not have the opportunity to have a final moment of closure.

Another participant felt similarly, as she did not realize when her brother entered his two-month-long coma that he would not wake up. Right before entering his coma, she heard her brother state his name and recognize that he was in the hospital. This was the last time she remembers him being conscious in her presence. Tina remarked the difficulty of this encounter

not knowing this would be her “last moment” with her brother. While he was alive for an additional few months, she also did not receive the closure of having an official goodbye.

Unexpected sibling deaths experienced by two participants also changed their family dynamics. Tina noted her grandmother became more bitter and Erin’s family became reserved and regretful. The inability to distinguish a true difference in how expected and unexpected deaths impact grief is closely aligned to the current literature (Paris et al., 2009).

Differences arose in how death anticipation influences grief in the participants for various reasons. In terms of the anticipated death, the foundation for how the family would react to the death was laid out before the event. This participant’s parents typically withheld information and followed a similar pattern when the sibling died. While it did not necessarily make grieving any easier for the participant, she did have an expectation for the reaction. Additionally, this participant knew her brother’s health was declining and was presented with the opportunity to be with him for most of his final days.

The participants who did not anticipate the death of their sibling has no baseline for how their family would respond to such an event and were not presented with any opportunity for closure. The lead to an abrupt shift in family dynamics, as opposed to a gradual shift over years of a chronic diagnosis where death became more anticipated. Still, regardless of these noted differences, the trajectory of grief experience remained the same for all participants.

In terms of family reaction, the participants unanimously shared that their parents withdrew after the death of their sibling. The current literature suggests that parents mostly do not talk about death with their children for fear of upsetting them (Demmer & Rothschild, 2011; Funk et al., 2018). In the instances of these participants, it appeared that parents did not talk to

their children about the event because they were overwhelmed with grief and sadness themselves.

One participant felt the emotional withdrawal of her entire family, particularly her mother and older brother, after her 24-year-old brother committed suicide when she was 12 years old. She shared that feelings of guilt and regret around the event remain to this day and make his death difficult to talk about. After his death and to this day, they rarely talk about what happened except during extremely emotional moments, around the anniversary of his death, and sometimes under the influence of alcohol. Some parents may not bring up the death or act emotional to be “strong” for the family even though the event is impacting them (Demmer & Rothschild, 2011). Another participant found this to be the case when her brother was being taken off of life support.

Demmer & Rothschild (2011) also noted without the opportunity to have these conversations, bereaved children and adolescents are more likely to engage in risky behavior or experience extreme sadness. This was the case for one participant, who fell into a depression and began using substances, such as weed, molly, and ecstasy. This behavior ultimately led to her losing a scholarship and failing out of college.

Additionally, parental reactions and decisions are made that could ultimately make grieving and mourning more difficult for their surviving children (Funk et al., 2018). One participant noted this behavior was a common trend throughout her brother’s cancer treatment. After her brother was diagnosed, she did not hear from her parents for three days. At this point, she only knew her brother was sick. She then found out through a nurse saying the word “chemotherapy” that he even had cancer. Sometime after, she learned the type of cancer, neuroblastoma, from a newspaper article. This theme carried through until his death 6 years later.

While she now recognizes both of her parents have poor mental health, especially relating to her brother's cancer and death, she notes how difficult it was to have information withheld from her and the trust issues that stem from their actions to this day.

Current literature notes that the way in which a sibling is told about the death of their brother or sister impact their ability to process the death (Funk et al., 2018; Barrera et al., 2013). Again, this was apparent for the participant above, whose parents did not tell her about her brother's cancer or death and instead relied on others to break the news. Considering the trust issues that remain to this day, it could be most beneficial to a sibling's ability to grieve that the parents are honest, upfront, and deliver the news directly to their children.

These findings are interesting, considering each of the participants were in adolescence at the time of their sibling's death. As such, their comprehension of death and its consequences were great and likely known by their parents. The opportunity for fruitful, open, and honest conversations was available but never acted upon. This was common for all participants starting at the time of their sibling's death until the interview. Especially due to age and initial lack of acceptance, it is possible that the parents did not recognize how greatly the death influenced their living children. By the time the bereaved siblings truly confronted their grief in young adulthood, they ultimately did not want to bring up a "sore" subject or found other means of support. The lack of parent to child discussions surrounding sibling death is a combination of both parties not wanting to upset the other. The absence of conversation ultimately impacts and inhibits the grieving process for the entire family.

Three participants noted explicitly that their parents did not seek out support or therapy of their own. As the parents are grieving themselves, it was noted as difficult for support to be given to the bereaved siblings. One found that both of her parents withdrew after her 6-year-old

brother died. She shared the difficulty her parents had coping with his death since most of their time was spent maintaining his epilepsy, which prompted three or more seizures a day. Another shared a similar sentiment about her mother, especially, who took a step back after her twin's death. Now that complex medical care was not needed for her brother, she expressed that her mother acted like her alive children did not need her as much. This impacted her greatly, being the twin of her deceased brother, feeling that her mother was particularly distressed being in her company.

Therefore, the establishment of a support network for the entire bereaved family is crucial (Koblenz, 2016). Similar to the current research, four of the five participants began attending therapy years after their sibling died as opposed to right after. While immediate supports can be beneficial, therapy in adulthood is still favorable (Koblenz, 2016).

The current literature did not greatly discuss establishing and maintaining a legacy for the deceased to support healthy grieving. To partake in task four of Worden's tasks of mourning, participants noted several helpful items (Worden, 2009). The bereaved siblings noted the importance of saying their sibling's name and partaking in activities they enjoyed when they were alive. This helps them maintain the sibling connection and bond that was established in their childhood. Three participants note that feelings of grief become especially prominent during the anniversary of their sibling's death or on their birthday. This is a time where the bereaved siblings especially take part in events that connect them to their sibling. Other milestones such as entering college were discussed as trigger points by participants.

One participant found importance in creating a career out of helping others undergoing cancer treatment and fighting a similar diagnosis. To her, it was important to share his story and help others going through a similar situation. Through this, she established a network of

individuals who care for her, her brother, and using his legacy to help other children undergoing cancer treatment.

While each bereaved sibling differs in how they carry out the legacy of their brother, they all have entered Worden's fourth task of mourning. They share the sentiment that there are days where they feel like they remain in the first task still, accepting that the deceased is really gone. However, through maintaining their legacy and remembering their impact, the bereaved siblings have found a way to cope and heal.

Limitations

While this data offers great insight in to lived experiences of bereaved siblings, there are several limitations of the findings. Of participants recruited, all five are female and had a brother pass away. It is possible and likely that the experiences of bereaved males are different than that of bereaved females. This includes the impact of a family's reaction, likelihood of seeking support, and carrying out of the deceased's legacy. Additionally, there may be differences in the grieving process for the gender of the deceased, as well. How a bereaved female copes with the loss of her brother may look entirely different than coping with a deceased sister, or a bereaved brother coping with either loss. This also does not take into account those who identify as non-binary or transgender.

Additionally, as all participants experienced the death of their sibling during adolescence, it is difficult to parse out what factors are a result of development and which are a result of time passed since death. There could certainly be arguments made for the influences of both development and time on grief, separately and as a unit. However, with a similar trajectory for grief experiences in all participants it is hard to differentiate. As such, it would be beneficial for

future studies to recruit participants who experienced the death of a sibling during other developmental stages, such as infancy, toddlerhood, preschool age, and school age.

Another limitation of the study is that all participants are from a New England state. This data is therefore not representative of the United States as a whole considering the supports may be different depending on geographic location. The impact of religion, political affiliation, education, and socioeconomic status could be significant in how likely it is for supports to be available to bereaved siblings. This is a promising avenue to pursue for future researchers studying bereaved siblings.

There is also a great assumption that the participants remembered in depth the emotions and experiences that occurred in their childhood. Especially if the memories were traumatic, there is a chance some of these memories were repressed. As such, the researcher attempted to establish and maintain a trusting relationship with each participant. Still, there is a chance that information was not remembered or chosen to not be shared with the researcher.

Lastly, the age range of the participants when their siblings passed away was age 12 to 18. As such, the findings represent the adolescent age group and how they grieve and cope with loss. The impact of sibling death on development for those who lost a brother or sister during infancy, toddlerhood, or childhood may look different than for adolescents. It would be beneficial to research the lived experience of bereaved siblings who experienced loss before adolescence and compare the findings of this study.

Applications

The findings of this study show the clear want and need for increased support by bereaved siblings. All of the participants, in one way or another, felt that they could have been

better supported in their grieving process either through family conversations, school or neighborhood support groups, or therapy. It is important to set a strong foundation for grief support within these channels to ensure that bereaved siblings are able to healthily mourn into adulthood.

For all five participants, it was noted that their parents withdrew following the death of their siblings, especially the mother figure. It was noted that they understood the difficulty their mothers faced, but that did not change the lack of support they received. As such, supports provided to the family of bereaved siblings is equally as important as receiving their own supports. For a family to be able to care for bereaved siblings, they must be able to care for themselves. The participants shared their parents were resistant to therapy, though they noticed mental health issues within their parents. This dissonance between mental health challenges and lack of therapy may have a link a child's ability to progress in their stages of grief and tasks of mourning.

Noting this, the findings highlight a need for increased counseling and therapeutic support for bereaved siblings and their families. Community programs should be implemented that include counselors, social workers, therapists, and child life specialists to best support children and families after a significant loss. While families cannot be mandated to attend these programs, providing resources and offering the services is a great next step in enhancing grief support.

Summary

The lived experience of the studied bereaved siblings implies that increased support is needed following the death of their sibling. This support should be extended to other family

members, as well, especially parental figures who are grieving themselves. While support was scarce in these scenarios, all of the participants have found a way to cope with the loss and begin establishing a legacy for their deceased sibling. A consensus was established that remembering their siblings by saying their name, partaking in activities they enjoyed, and celebrating their life especially around the anniversary of their death is crucial in finding peace within.

Development likely influences grief in terms of lack of acceptance and isolation and independence, but finding contentment seems to be mostly influenced by time passed since death. Additionally, time after death likely influences lack of acceptance and isolation and independence, as well, in addition to developmental factors. Considering the demographics of the participants studied, it remains difficult to truly parse out differences between development and time.

As such, when providing grief support to siblings following the death of their brother or sister, it is imperative to consider the bereaved sibling's current stage of development, the time since the death, and one's family dynamics. This will contribute to the bereaved sibling's understanding of death and dying, and how their family will respond to the event. The implementation of supports and the coping skills established immediately following the death may change over time. Having consistent and reliable support networks are beneficial for lessening feelings of loneliness and isolation. With care and time, bereaved siblings will likely be able to create a new life with fond memories of their loved one in their mind and heart in adulthood.

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APPENDICES

Appendix A. Human Subjects IRB Approval

Date: 10-25-2020

IRB #: IRB-FY2021-33

Title: Understanding Grief In Adults Whose Sibling Died During Childhood: A Qualitative Study

Creation Date: 7-21-2020

End Date:

Status: **Approved**

Principal Investigator: Lindsey Murphy

Review Board: MSU

Sponsor:

Study History

Submission Type	Initial	Review Type	Expedited	Decision	Approved
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Key Study Contacts

Member	Cara Smith	Role	Co-Principal Investigator	Contact	clsmith@missouristate.edu
Member	Muhammad Raza	Role	Co-Principal Investigator	Contact	hassanraza@missouristate.edu
Member	Lindsey Murphy	Role	Principal Investigator	Contact	lindseymurphy@missouristate.edu
Member	Amanda McCarthy	Role	Primary Contact	Contact	mccarthy110@live.missouristate.edu

Appendix B. Informed Consent Letter

Researcher(s): [Amanda McCarthy]
Study Title: [Understanding Grief In Adults Whose Sibling Died During Childhood: A Qualitative Study]

1. WHAT IS THIS FORM?

This form is called a Consent Form. It will give you information about the study so you can make an informed decision about participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. We encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

2. WHO IS ELIGIBLE TO PARTICIPATE?

Participants must have experienced the death of a brother or sister during childhood and over the age of 18. Additionally, participants must have access to Internet and the Zoom application for a one hour video call.

3. WHAT IS THE PURPOSE OF THIS STUDY?

The purpose of this research study is to examine the impact having a sibling die during childhood has on an individual's growth, development, coping skills, and emotional well-being. I am conducting this research to increase awareness about how to better aid bereaved siblings following the death of their brother or sister.

4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?

Participants will be interviewed on one occasion. The interview is expected to last approximately one hour. Interviews will be conducted online via Zoom.

5. WHAT WILL I BE ASKED TO DO?

If you agree to take part in this study, you will be asked to answer interview questions about your experiences during the death of your sibling and time after. Specific details regarding your sibling's death and/or condition will be discussed, as well as your personal coping mechanisms and family dynamics. You may skip any question you feel uncomfortable answering.

6. WHAT ARE MY BENEFITS OF BEING IN THIS STUDY?

You may not directly benefit from this research; however, I hope that your participation in the study may assist in your continued grieving and processing of the loss of your sibling.

7. WHAT ARE MY RISKS OF BEING IN THIS STUDY?

Due to the sensitive nature of the research, you may feel discomfort from certain interview questions. If you feel discomfort in answering any questions during an interview, inform the interviewer and the question(s) can be skipped.

8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?

The following procedures will be used to protect the confidentiality of your study records.

Data will be collected through audio-recordings, handwritten notes, and typed files. Handwritten notes will be locked in a filing cabinet, audio-recordings will be transferred to digital copies and password protected, and typed files will be secured by password protection, as well. The researcher will keep all study records, including any codes to your data, in a secure location (a locked filing cabinet). Research records will be labeled with a code. A master key that links names and codes will be maintained in a separate and secure location. The master key and audio will be destroyed three (3) years after the close of the study. All electronic files (such as databases, spreadsheets, typed notes, etc.) containing identifiable information will be password protected. Any computer hosting such files will also have password protection to prevent access by unauthorized users. Only the members of the research staff will have access to the passwords. At the conclusion of this study, the researchers may publish their findings. Information will be presented in summary format and you will not be identified in any publications or presentations.

9. WILL I BE COMPENSATED FOR MY PARTICIPATION?

There is no compensation granted for participation in this research study.

10. WHAT IF I HAVE QUESTIONS?

Take as long as you like before you make a decision. I will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, (*Amanda McCarthy*, 781-249-4386). If you have any questions concerning your rights as a research subject, you may contact the Missouri State University Institutional Review Board.

11. CAN I STOP BEING IN THE STUDY?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

12. WHAT IF I AM INJURED?

Missouri State University does not have a program for compensating subjects for injury or complications related to human subjects research, but the study personnel will assist you in getting treatment.

13. SUBJECT STATEMENT OF VOLUNTARY CONSENT

When signing this form I am agreeing to voluntarily enter this study. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had

the opportunity to ask questions and have received satisfactory answers. I understand that I can withdraw at any time. A copy of this signed Informed Consent Form has been given to me.

Participant Signature:

Print Name:

Date:

By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

Signature of Person
Obtaining Consent

Print Name:

Date:

Advisor Contact Information:

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Appendix C. Interview Questions

Informational

- 1) How old were you when your sibling died? How old was your sibling?
- 2) Who are the members of your immediate family?
- 3) What do you identify as your...Gender? Ethnicity? Religion? Sexuality?

Semi-Structured

- 1) Describe the situation where your sibling died during your childhood.
- 2) How did the death of your sibling impact you emotionally? Physically? Mentally?
Socially?
- 3) How did the death of your sibling impact your family emotionally? Physically?
Mentally? Socially?
- 4) What support systems did you have in place? Which were the most helpful during the
grieving process? The least helpful?
- 5) What advice would you provide to a child who just had a sibling die?
- 6) What coping mechanisms did you use following the death of your sibling?
- 7) Based on Worden's four tasks of mourning, what task were you involved in...At the time
of your sibling's death? A year after their death? Five years after their death (if
applicable)? Currently?