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Laura Marguerite Miles
Continuing Bonds: Child-
hood Sibling Loss and
its Perceived Long-term
Outcomes

ABSTRACT

This exploratory qualitative study was undertaken to determine if there are perceived long-term effects on adults who lost a sibling in childhood to death. Secondly, are the long-term effects of this loss expressed in the form of continuing bonds, or making meaning from the loss of a loved one? Continuing bonds can take different forms, from keeping pictures or mementoes of the deceased, to telling stories to the generations that follow.

Seven participants were recruited using snowball sampling. They ranged in age from 41-69, and the death of their sibling occurred 29-63 years ago. Each participant responded to open-ended questions that were asked about the memories they had about their sibling loss. Questions were asked about the long-term effects they believed were a result of their loss, including an impact on their creative, spiritual and professional life. They were also asked if they felt a continuing bond with their deceased sibling, and how that manifested.

All the participants felt that there were long-term effects to sibling loss in childhood. They also reported having some kind of continuing bond with their deceased sibling that they felt to the present day. While the long-term effects were not necessarily in all the areas of creativity, spirituality and profession, most of the participants cited at least one of these domains. They also reported that there were some more negative long-

term outcomes to the loss of their sibling, among them anxiety for their own children, and an inability to mourn losses in a healthy manner.

CONTINUING BONDS: CHILDHOOD SIBLING LOSS AND
ITS PERCEIVED LONG-TERM OUTCOMES

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2010

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CHAPTER I

INTRODUCTION

When I was seven-years old my older brother, Matt got sick. As a seven-year old, I didn't have much of a concept of what that meant other than I had to go to school, and he got to stay home, in his pajamas and watch as much TV as he wanted. Matt was fourteen at the time, to my mind, almost an adult. My relationship with him was ambivalent. He was very protective, but he would at times abuse the power that he had over me. I often felt unsafe with him if my parents were not around. On the other hand, I received a glimpse into the glamour of the teenage years that I would never have seen otherwise at such a young age. I had an in with the adolescents of the neighborhood.

Matt was sick, and then he was better. And when he was better, my parents started buying him things that they never would have done before. Suddenly I was riding around with him on a motorcycle, or sailing on the bay in his new sailboat on a windy Sunday afternoon. What this made me is mad. How come he got a sailboat and a motorcycle and got to stay home, and I got nothing? He didn't deserve it.

After a summer of sailing and motorcycle touring, Matt became sick again. It wasn't until years later that I found out that my brother had had leukemia. He got sick, had a few months of remission, and then died. This was in the late sixties when there was very little treatment available. Bone marrow treatment was still a few years away. Matt died about six months after his initial diagnosis.

My parents decided to do their best to return to normalcy as soon as they could. Their goal was to protect their young daughter to the pain and grief they were feeling, as if nothing had happened or even as if Matt had never existed. As my mother acknowledges now, this was not the best of ideas. I started to have panic attacks, afraid my parents would abandon me. My reasoning was if they could so easily forget Matt, what would prevent them from leaving me behind at the campground or at the shopping mall? Our whole family was reeling from this loss, and we had no idea how to fix things. So we acted like it had never happened.

In the late sixties, there wasn't too much family therapy around. My family wasn't religious, and we didn't have a lot of extended family around. In short, we had very few resources. We soldiered on, but the effects of this loss changed us forever. I believe the change made it more difficult for me to trust others, or learn how to grieve losses in a meaningful way.

In search for a thesis topic, I realized that I had questions about sibling loss from my own personal experience, specifically about the long-term effects of such a loss as children become adults. Sibling loss, I discovered, is not a topic that has been well researched. Only in the last twenty years or so, with the work of Betty Davies (Davies, 1988a, 1988b, 1991, 1999; Packman, Horsley, Davies and Kramer, 2006) at UCSF has it begun to come into its own. Most of the study done has been in researching children or adolescents who have lost a sibling. There have been few long-term studies researching the lasting impact on adults who had this childhood experience.

At the same time, I have always been interested in the power of stories; the power that comes from telling and sharing and creating experience. Once I had landed on my

topic of research, I knew that I wanted to do a qualitative study. I wanted to ask deep, open-ended questions that would allow the participants to tell their story of a long-held memory.

I was also interested in how the telling of a story can be transformative, how there can be a therapeutic effect to having someone hear your story. In some cases, the people that I interviewed had not ever had anyone ask them questions about their experience of losing a sibling. For others, they had not thought about or talked about the experience in many years. No one had ever asked them what it was like to be the sibling of someone who has died. This area of study was not only new in research, but also in the personal lives of those who lived through this experience.

In the course of my research I was honored to hear the individual stories of seven participants as they recounted their unique experiences of losing a sibling. While each was different, they also bore similarities to each other, and to my story as well. Indeed at times it was difficult to not share my story during the course of the interviews. I believe that we all drew comfort from the realization that there were others that had lived through this profound event, and having an opportunity to share the story. We were all in the unique position of being a young sibling in a family going through a traumatic event.

I came to realize how fascinating it was to have adults recount their memories of when they were children. For all the participants in the study, the sibling loss took place many years ago, anywhere from 29 to 63 years ago. Except for the participant who lost his brother 63 years ago, they could all remember very specific details of the death of their sibling. It became obvious that they were still very much affected by their experience so many years later.

Following this introduction that outlines why I chose to study this specific subject, and what has inspired me, will be the literature review that studies the research in the areas of sibling loss and bereavement. It will also define terms that will be used throughout the work, including continuing bonds, or carrying, which is a critical part of this research.

In this exploratory, qualitative study, seven people who lost a sibling to death when they were between the ages of four-and-half, and fifteen years old were interviewed. The methodology chapter explains how data was collected, and how participants were selected. Chapter four presents the findings. In this chapter content analysis was utilized to code the data and put it into ten different categories. Quotes from the participants that illustrate the ten categories are used. In the discussion chapter, the findings are put into the context of previous literature and connections are made. The discussion chapter also reports on the limitations of the research, and areas for further study in social work and recommendations for clinical social work in this area.

It is my hope that this thesis be taken as the beginning of an understanding to the intricacies of childhood sibling loss. From my own experience, I have endured the distress of losing a family member, and not having the tools to understand, grieve, and integrate this experience. As more research is done in this area, and as more stories are told, children who must go through this experience will hopefully have more support, either professionally or through their family and community so that they need not suffer needlessly. As it is said in Buddhist teaching, pain is inevitable, suffering is not.

CHAPTER II

LITERATURE REVIEW

Introduction

There are several different categories of sibling bereavement that are examined in this literature review. The first and most in-depth subject is specifically called ‘sibling bereavement’. This is a fairly new subject in research, however there has been more work done in recent years. In addition to journal articles, several books have been published in the last ten years that are useful in examining the personal experiences of those who lost a sibling when they were children. The literature focuses on the initial impact of losing a sibling and the factors that influence the way a child grieves this specific type of loss. In addition, the literature also focuses on the long-term effects of losing a sibling in childhood and how this loss is felt as the surviving sibling grows into adulthood and throughout the life cycle. For my research, these areas of long-term effects of sibling loss are more relevant, and so I go more in-depth into that area.

A second area that is helpful in defining terms for this research is the study of grief and bereavement, especially in the area of child grief. Although grief has always been with us, it has only recently been studied in a formal way. Complicated grief disorder will be introduced for the first time in the new DSM-V (Zhang, El-Jawahri, and Prigerson, 2006). Defining terminology that is used in this thesis will be an important part in the literature reviewed in the area of grief and bereavement.

In order to give this work a theoretical framework, attachment theory (Charles and Charles, 2006), and narrative theory (Madsen, 2007) is investigated. Attachment theory is investigated as a way to better understand if and how attachment styles can be impacted. Narrative theory is explored to better understand how the stories we tell impact how we see ourselves, our family and our environment. I also touch on post-modernist theory (Kempson, Conley and Murdock, 2008), and how looking through this lens defines grief and loss as a state of being rather than something to be endured. It is not something to work through, but something that changes who we are forever.

Finally, I investigate how the loss of a sibling in childhood can affect the creativity and spirituality of the surviving sibling as they become adults. As a part of this investigation, I explore the stories of famous people from history that lost a sibling and how they and others see this loss as a spark for their creative life.

This chapter begins with a definition of terms. This is followed by an examination of previous long-term studies, factors influencing sibling loss, continuing bonds, theoretical constructs, creativity and spirituality, and finally the conclusion.

Definitions

It is useful to start by defining some terms that are used frequently. Grief and bereavement are often used interchangeably, but they have different meanings. Bereavement is defined as, “the experience of losing to death a person to whom one is attached” (Zhang, El-Jawahri, Prigerson, 2006). Grief is, “the emotional distress associated with that loss” (Zhang, El-Jawahri, Prigerson, 2006). Grief is more associated with the emotional aspect of losing someone that you love, while bereavement refers to all the different aspects associated with the passing of a loved one.

The more recent term, complicated grief disorder, which is discussed in Zhang, El-Jawahri, and Prigerson's 2006 article that updates the research in the bereavement field, anticipates this disorder will be a part of the forthcoming DSM-V. Complicated grief occurs when a bereaved person persistently pines, yearns, and longs for the deceased, and this longing impairs other parts of the person's life. It must last for at least six months. Complicated grief disorder is often co-morbid with PTSD or Major Depression. Those people with complicated grief symptoms have an increased risk for cancer, hypertension, and suicidal ideation (Zhang, El-Jawahri, Prigerson, 2006). A comparison between complicated grief, and the idea of continuing bonds will be explored later in this chapter.

It is helpful also to differentiate between grief and depression. One component of grief is yearning which is not present in depression (Shear, 2009). Shear, in her editorial article, states that even in acute grief, one can feel positive emotions. Sadness is not pervasive during grief, but comes in waves of emotion. When one is grieving there is a preoccupation of memories and thoughts of the deceased, as opposed to depression, which is more of a self-critical rumination (Shear, 2009).

Another term that is important to clarify is sibling. What constitutes a sibling? For the purposes of this study, it is helpful to use criteria by Robinson and Mahon (1997). In their article that analyzes previous studies on sibling bereavement, they use what they call, "critical attributes" in studying this topic. Family attributes include a shared experience or history. They, however, deem it not necessary to share biology. The important component is that they share the experience of growing up in the same family in the same household. Importantly, there is not a choice in the relationship. One does

not pick one's siblings. Because of this, there is no guarantee that your sibling is someone you like, or would like to be around given a choice. This is one of the reasons that the loss of a sibling can be so complicated. There are often ambivalent feelings.

Children and death

Historically, how the death of a child has been viewed has changed. As early as a century ago, a stillbirth was seen as a non-event (Kempson, Conley & Murdock, 2008). Parents were encouraged to not even see their dead child and to move on as quickly as possible. Infant mortality has changed dramatically as well over the years. One hundred and fifty years ago the mortality rate was 278.4 for every 1000 births. Today, that statistic is 9.75 deaths for every 1000 live births. (Kempson, Conley & Murdock, 2008). That is an amazing statistical change in a relatively short amount of time.

We have come to believe in our technologically advanced times that we can have whatever we want, and that includes healthy babies with no chance of their dying. If they are sick, technology will save them. In this climate, children have become increasingly valuable. When they die, many families are not prepared. If they can control their arrival into the world, surely they can prevent their leaving it too early. But for all our advances, 90% of adolescents, for example, experience a loss through death of someone they know. (Batten & Oltjenbruns, 1999). Obviously, we don't have the control over life and death that we sometimes feel we do.

It is helpful to look at studies in the past. The area of bereavement, and especially sibling bereavement, has not been extensively studied although there have been a few studies that may be useful. In her book, *Shadows in the sun: The Experience of sibling bereavement in childhood* by Betty Davies (1999), the history of sibling bereavement

studies is examined. Davies reports that the study of death, dying and bereavement did not really start until the middle of the 20th century. It was not until the late 1960's that doctors started considering the possibility of telling their patients that they were going to die. This belief started with Sigmund Freud, who didn't believe that children were able to process the concept of death until they were adolescent. It wasn't until John Bowlby came along in the 1950's that this belief began to change. Bowlby believed that children could definitely feel loss and separation. Bowlby felt that the problem was that children didn't have the tools to understand their loss (Devita-Raeburn, 2004).

And if health professionals didn't talk to their adult patients about dying, it was strictly taboo to talk to children about dying (Davies, 1999). It was believed that children under the age of ten were unable to grasp the concept of death and were incapable of expressing any emotion about death. It was considered best to leave children completely in the dark, both the children that were dying, as well as any siblings that may be witnessing the death of a brother or sister. Davies (1999) cites studies of the sixties and seventies where researchers began to acknowledge that children know they are ill, and can actually benefit from an open discussion about their situation (Eason, 1970; Spinetta, Rigler, & Karon, 1973, 1974; Raimbault, 1981; Bluebond- Langner, 1977,1978; Spinetta, 1972). These studies of dying children were the beginnings of bereavement studies with children.

Indeed, when Davies sought approval to interview dying children for her dissertation study in 1980, she was initially turned down because it was thought that talking openly about their death would be too detrimental to the children being studied.

Davies had to prove that letting the children talk about death might actually help them (1999).

In Davies' "The study of sibling bereavement: An historical perspective" (2003) she points out that the study of sibling bereavement in the sixties and seventies was about the psychiatric implications for adults who lost a sibling in childhood. The studies looked at adults with fairly severe psychiatric diagnoses, and the role that sibling loss played. Since that time, the studies for the most part have been small, with designs that use non-representative samples, lack of control groups, and unclear definitions. Davies points out that this is often the case with a new field of study (2003).

Exploratory and qualitative studies

Because sibling bereavement is a relatively new field of study much of the research is of an exploratory nature, as in the study conducted by Batten and Oltjenbruns (1999). For this qualitative study, only four adolescent individuals were interviewed about their reactions to losing a sibling. This study will differ in that only adults are interviewed, and many years have elapsed since the death of their sibling. The seven research participants ranged in age from 4½ to 15 years of age when their sibling died.

In Davies' study on the "Long term outcomes of adolescent sibling bereavement" (1991) (n= 12), she explains the use of a qualitative study as the best method when there are many unknowns and there is not yet much empirical data. She admits that her study has the problem of participants being self-selected, and also the issue of using memory recall of participants in the study, this especially being an issue when the memories were from a time when participants were children (1991).

This is definitely a weakness in the literature up to this point; there has simply not been a great deal of data collected on sibling loss other than qualitative studies. As in these previous studies, my participants will also be self-selected. But qualitative studies can also be a great strength. Hearing the personal stories of those who have lost a sibling when they are children is powerful, and speaks to the bonds that we create as children, and that can affect us for the rest of our lives. Devita-Raeburn's book, *The empty room: Understanding sibling loss* (2004), is an eloquent example of the power of an individual's story.

Previous long-term studies

In Davies' book, *Shadows in the sun: The experience of sibling bereavement in childhood* (1999), 33 research studies are cited on sibling bereavement. Of those, three studies examined the long- range effect of losing a sibling in childhood. In Davies' own study using grounded theory analysis (1991) 12 who were between the ages of 11 and 13 at the time of the loss of their sibling were interviewed 11-28 years after their loss. She found that long-term outcomes included, "psychological growth, a sense of feeling different, and social withdrawal". Using grounded theory analysis allowed Davies to let the research lead her, rather than having any preconceived notions.

The limited number of participants and the fact that they were self -selected by means of notices on bulletin boards in the community could be seen as a weakness in the study. However, the fact that the interviews were semi-structured and open-ended gave the participants the opportunity to tell their story in their own words. These same strengths and weaknesses can be said for this research study.

In my study, I focus on adults who lost a sibling in childhood. For that reason, it is important to look at what studies have been done investigating the long-term outcomes of sibling loss. There have been both positive and negative long-term outcomes reported in the literature up to this point, and it is important to note that both are aspects of sibling loss. As noted above, many factors determine what the outcomes on the surviving sibling will be.

In terms of negative outcomes, there have been several more negative type long-term outcomes reported. Among those are unresolved adult depression that continues throughout the remaining sibling's lifetime (Davies, 1991). One may feel that instead of using the grief for creative energy, they feel stagnant in their lives, unable to move on (Robinson & Mahon, 1997). Others refer to being, "frozen in time" (Crehan, 2004).

Perhaps a reason for this feeling of being frozen in time has to do with whether or not the sibling has permission to talk and share their experiences with others. Rosen (1986) reported that 76% of those participants that she interviewed for her study had never talked to anyone about their loss until her interview. She cites contributing factors to non-communication to include; 1. A lack of acknowledgment from others of the loss of a sibling; 2. A continuing loyalty to the parents, and; 3. The desire to remain strong. If siblings don't see themselves as primary griever, they may not allow themselves the time to grieve, and eventually heal from their loss. Time does not heal wounds, if that wound goes unexpressed, it remains and is not forgotten (Rosen, 1986).

Another potential negative outcome of losing a sibling in childhood has to do with relationships. Rosen (1986) found that some participants were less successful in heterosexual relationships once they reached maturity. Charles and Charles (2006) also

report relational difficulties in adulthood. Intimacy can become a difficult issue for the remaining sibling in some cases (Rosen, 1986).

Death anxiety is another reported long-term outcome of sibling loss (Crehan, 2004; Rosen, 1986). There is also a fear of recurrence of the loss (Davies, 1998). Fear and anxiety can become a large part of the remaining sibling's life, especially in cases where the grief has gone unexpressed. If it is unexpressed for years, the anxiety and fear never lessens, and becomes a part of who the remaining sibling is.

Devita-Raeburn (2004) reports long-term effects such as interpersonal problems, difficulties in school, substance abuse, nightmares, depression, and chronic guilt, to name a few. Rosen (1986) also notes that there may be less contact with the family of origin, however this is dependent on how much they are able to express their loss. The more they are able to express the loss, the more contact they continue to have with their family of origin.

Pollock (1978) talks about rage that the remaining sibling can grow to have towards the parents as time goes on if their own grief is not acknowledged. He also discusses how in some cases the remaining sibling has difficulty in finding success in life. They may feel guilty about being successful, about being the sibling that survives. Success is a way of showing that you have moved on in life, and if one is having survival guilt, being successful could be seen as the ultimate betrayal. Staying stuck in time, the time of the sibling's death, could be seen as a form of loyalty to the deceased sibling.

With all of the possible negative long-term outcomes that come from losing a sibling to death, could there be any positive outcomes? Again, this depends on the circumstances such as those that were discussed earlier of situation, individual and

environment. In describing the possible negative long-term outcomes of sibling loss, it appears paramount that the loss be recognized, and most importantly, expressed by the remaining sibling. After that has been done, there is a possibility of having some more positive long-term outcomes of losing a sibling in childhood.

One more positive long-term outcome is a sense of maturity in the surviving sibling (Davies, 1991). A sense of growth, both of the self, and of the family was reported. There were also reports of a higher self-concept (Robinson & Mahon, 1997). Robinson and Mahon also found that remaining siblings had a better appreciation of the sibling relationship, and they also took more responsibility within the family. These all indicate a psychological growth that came from the loss of a sibling in childhood.

Siblings report a curiosity of what their brother or sister would have been like now if they had lived. They also wonder what their life would have been like if they hadn't lost a sibling (Davies, 1998). This makes sense when one remembers that siblings are supposed to be a companion through the majority of our lives. Beyond curiosity, siblings also look at how losing a sibling in childhood has impacted their outlook on who they are, others, and life. There is no doubt, most people who lost a sibling in childhood believe that their outlook on life changes forever from that experience.

Long-term effects of sibling death in adolescence

In this study by Fanos & Nickerson (1991) using quantitative analysis, participants were placed in three groups depending on the age they were when their sibling died: 9-12 years of age, 13-17 years of age, and 18 years of age. Those who were young adolescents (13-17 years of age) had statistically higher levels of anxiety, depression and guilt than the other two groups. In all these examples, the cause of death

was cystic fibrosis. The deaths had occurred 2-21 years prior to the study. In my study the time elapsed since the death of the sibling ranged from 29-63 years. This study was limited to 12 participants whose siblings had all died of cystic fibrosis, which makes it somewhat specific to this disease. In my study, the cause of death is varied, with two dying of disease and five from accidents.

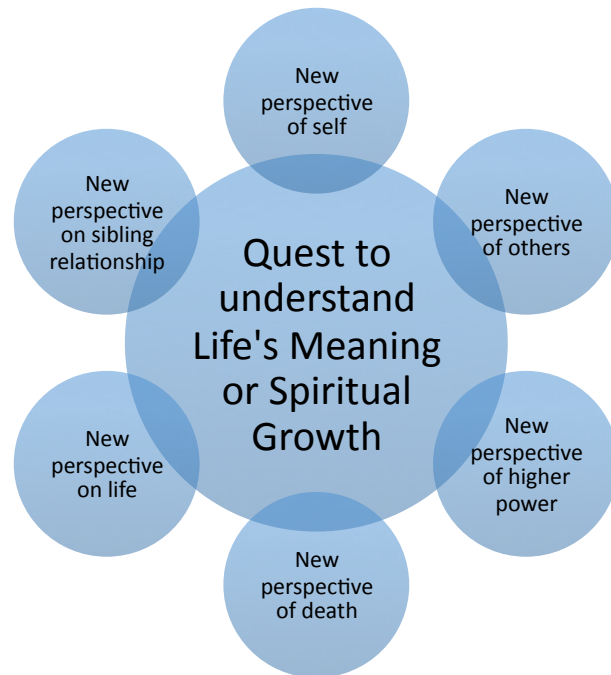
Adolescence and sibling loss

Much of the literature that I have investigated, especially exploring the long-term effects of sibling loss, focused on adolescents in particular. For that reason, some space will be given here to that specific population. In one study, it was found that adolescents who lost a sibling withdrew from friends. Immediate outcomes included shock, numbness, sadness, loneliness, anger, and depression (Davies, 1991).

Long-term outcomes had some positive and negative attributes. A positive attribute was psychological growth. But there was also feeling different and withdrawal (Davies, 1991). Feeling different may be especially difficult for an adolescent.

Adolescents have a feeling of being invulnerable. Death cannot get them. Losing a sibling can drastically change this worldview (Batten & Oltjenbruns, 1999). This loss was a meaning making opportunity for them. They gained new perspectives on themselves, others, the sibling relationship, life, death, and a higher power (Batten & Oltjenbruns, 1999). The figure below shows these results:

Figure 1. Quest to understand life's meaning or spiritual growth.



Batten and Oltjenbruns (1999) also reported the importance of continuing bonds in the adolescents that they interviewed. Even with their sibling gone, the relationship continued to be felt and experienced. There was a legacy that they felt remained.

Adolescent bereavement: Long-term responses to a sibling's death from cancer

In this study by Martinson & Campos, also from 1991, (n= 31) adolescents were again the focus. In this case, cancer was the cause of the sibling's death. The death had occurred 7-9 years ago a much shorter time than in my study. In this qualitative study that included a questionnaire and then an individual interview, the participants felt the experience of losing a sibling had fostered personal and family growth.

Prohibitions against mourning in childhood sibling loss

This is echoed in a qualitative study by Rosen (1986) (n=34) whose findings suggest that expressing the feelings of loss of one's sibling is important if maintaining contact with the family of origin is important. On the other hand, in the Martinson and Campos study (1991) one in six felt the experience continued to have a negative impact on their lives. The factors that contributed to this negative impact included withdrawal from the family, the inability to use the family as a source of support, and difficulty discussing the experience of death. More positive outcomes were experienced when there was more communication in the family, an ability to share the experience of death with others, emotional support from the family, and expressions of pleasure in the presence of the sibling when they were still alive. This was possible in this study because all of the siblings who died in the study were diagnosed with cancer. (Martinson & Campos, 1991).

Interestingly, all of these studies were done in 1991, and all of them focused on those individuals who lost a sibling when they were adolescents. These studies indicate that losing a sibling when you are an adolescent may be more difficult than losing a sibling when you are a younger child. There are examples of adults continuing to process the death of their sibling no matter what age they were when the death occurred as can be seen in the stories in Devita-Raeburn's book, *The empty room: Understanding sibling loss (2004)*. Here, she interviews adults who lost a sibling of various ages in childhood. They continue to integrate this loss well into adulthood. (Not here but in discussion). Perhaps the combination of losing a sibling, and going through the changes that come with adolescence, when peers are so important, can make this loss even more

complicated. There have been no comparison studies looking at adolescents and children and sibling loss.

Sibling relationships

For the purpose of this study, I focus on sibling loss in children from age 4 ½ to 15 years of age. At this time in the relationship, when bonds are being formed, the siblings are living in the same house, sometimes the same room. When a sibling is lost during this stage, the other sibling is not yet an adult, and so is experiencing the loss through the lens of a child or adolescent. Siblings can play many roles in our lives. Siblings can serve as attachment figures, antagonists, playmates, protectors, and socializers (Davies, 1999). Additionally, as siblings, we have no choice in who are siblings are (Robinson & Mahon, 1997).

Much of the literature points out that of all the relationships in our lives, sibling relationships are the ones we expect to last most of our lifetime. We can usually expect to spend 80-100% of our lifetime with our sibling, as opposed to 40-60% of our lifetime with our parents (Davies, 2003). When one loses a sibling in childhood, one is potentially losing a lifetime companion (Davies, 1999). For those of us who lose a sibling in childhood, the wish to stay connected with our deceased sibling may grow with the years rather than decrease (Packman, Horsley, Davies & Kramer, 2006). This can be difficult, as the surviving sibling attempts to redefine their role as perhaps no longer being a brother or sister. One's identity changes with the death of a sibling (Batten & Oltjenbruns, 1999). One may go from being the baby of the family, to an only child.

Developmental stages

A critical factor in examining sibling loss is the developmental stage the surviving sibling is at when they lose their sibling. Andrews and Marotta (2005) in their qualitative study have suggested that children need to grieve as they go through each developmental stage. Packman, Horlsey, Davies and Kramer (2006) echo this statement, stating that a child must re-process the loss of a sibling as they develop. Rosen (1986) has shown in her research that the loss of a sibling can, over time, interfere with the developmental progress of a child. This can eventually lead to problems in an adult survivor of sibling loss if it is not processed.

For children, the idea of death means different things at different developmental stages. For a child 3-5 years old, death can be reversible. It is a temporary state of affairs. When a child is between 5-9 years old, death is seen as something that can happen to someone, but not to them. After the age of 9 or 10, death is better understood as final, and that it happens to everyone (Mandell & Dirks-Smith, 1988). It may be that one cannot fully begin the grieving process until one is fully through adolescence (Crehan, 2004). From this information, it is clear that the developmental stage of the child at the time of the sibling's death plays a critical role.

The developmental stage of the child may result in abnormal grieving that can be exacerbated by absent parents who are experiencing their own grief (Crehan, 2004). If the surviving sibling doesn't receive support from caretakers during this time of grief, it may indeed inhibit their future development, including the ability to form intimate, mature, and trusting relationships. One danger is the over or under reliance on others

(Charles & Charles, 2006). It is clear that developmental issues are very crucial when looking at the impact of sibling loss.

As noted by Shear (2009), is that treatment of complicated grief and depression that may arise in the first months of the loss may prevent a long-term impairment. Some children who did not receive treatment, end up dealing with issues related to their loss well into adulthood.

Factors influencing sibling loss

It is important to examine the specific factors that influence sibling loss in children and adolescents. Rosen in her article that reviews theoretical and treatment issues for social workers, “Child and adolescent bereavement” (1991), cite six major factors that she has discovered from her casework. These are:

1. Relationship to the deceased and the availability of substitute objects.
2. How family members respond to loss.
3. Developmental level of the child.
4. The child’s understanding of death.
5. Ambivalence.
6. How children mourn.

Rosen and other authors mentioned thus far have explored these factors. A few points to be made at this time relate to availability of substitute objects, ambivalence, and how children mourn. Perhaps the deceased sibling saw their sibling in a certain way; as funny, or insightful for example. When they are lost, Rosen has found that it is important that a “substitute object” fill that role in the child or adolescent’s life. That special attribute of the child should not be lost with the deceased sibling.

Ambivalence refers to the love/hate relationship that many of us have with our siblings. If they die, children, in their magical thinking, may feel that they are in some way responsible for the death because of hateful thoughts they may have had towards their sibling when they were alive. This may be especially true if the sibling was sick for a while, and therefore receiving more attention. Freud, in *Mourning and Melancholia* (1917) mentions this ambivalence.

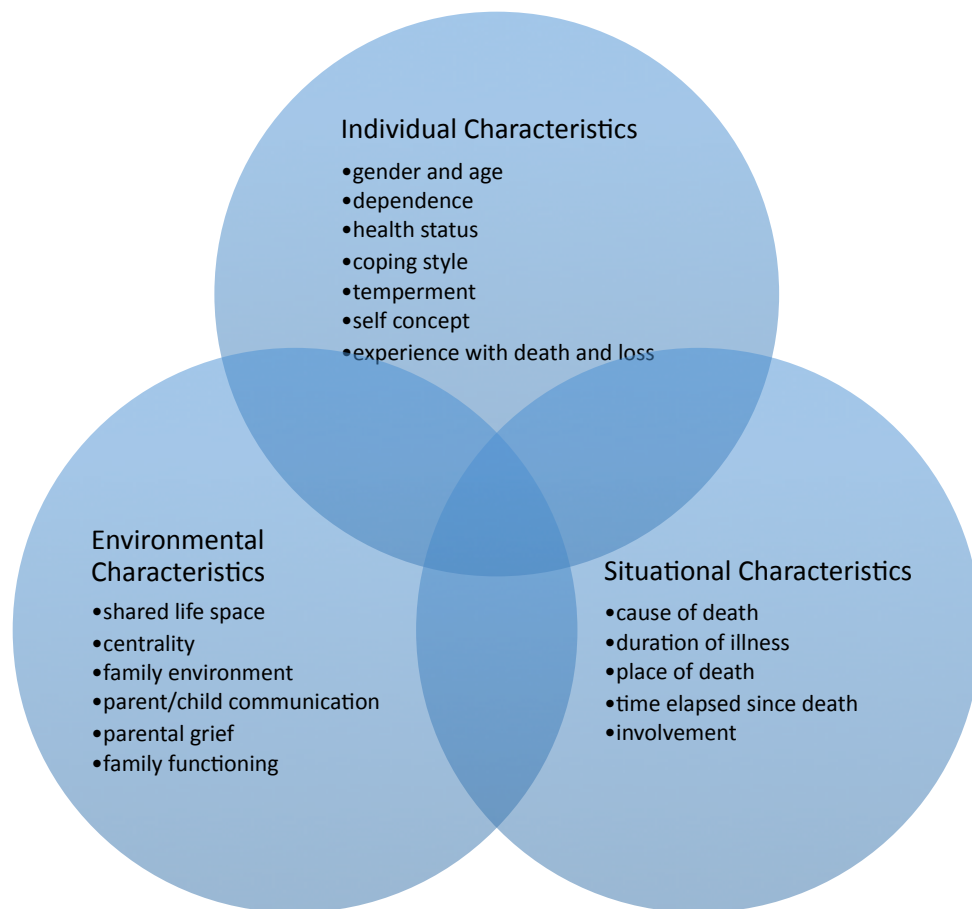
Children mourn differently than adults. When they hear of the death of a loved one, they may ask to watch TV, or play with their friends. This does not mean they are not grieving, but it is a way of touching, and then retreating from the grief (Rosen, 1991). This way of dealing with grief could easily be misunderstood by adults.

Packman, Horlsey, Davies, & Kramer (2006) as well as Davies (1999, 2003) discuss three factors that influence a sibling's reaction to losing a sibling. These include the individual characteristics of the remaining sibling. Individual characteristics include coping styles, health, gender, age and temperament, among others. Individual characteristics can make a large impact on how a sibling deals with death, and individual characteristics can vary from family member to family member.

The second factor is situational characteristics. These characteristics refer to the characteristics that surround the death, such as cause of death, and how much one is involved in the events surrounding the death. Situational characteristics are related directly to the death of the sibling, for example the way in which the sibling died, duration of the illness, if they died from an illness, and how much time has elapsed since the death.

Finally, there are environmental variables, such as shared space with the siblings, family environment and functioning, and parental grief. As is seen in these examples, there are many variables that influence the experience of sibling loss. Oftentimes, confusion is one of the most common characteristics. Add to that the likely absence of parents to help dispel some confusion due to their own grieving process, and it can create a difficult experience that adults often do little to explain or help to support the remaining sibling.

Figure 2. Sibling Response to sibling death based on three areas:



Sibling death and the family

One must look at sibling bereavement within the context of the family (Robinson & Mahon, 1997). Children look to adults for answers and support when a crisis happens in a family, making the family environment critical for them (Davies, 1988). It was found that those families that were more cohesive and active after the loss of a child had less issues and behavioral problems with the remaining children (Davies, 1988). Davies (1988), in her quantitative study that focused on 34 families, using content analysis suggests that one of the best ways to encourage cohesion in a family is to include all members in the grieving process, and not leave children out in an attempt to protect them. Families that utilize social, cultural, recreational and religious opportunities are able to find cohesion within the family after the loss of a child (Davies, 1988).

The loss of a child, and how the parents react to that death will play a major role in how the sibling will respond. When one loses a sibling, one can also lose a parent in some respects. Parents are often in such deep grief, that they are unable to be a support for their remaining children. Children can also be unseen mourners (Packman, Horsley, Davies and Kramer, 2004). All the attention is put on the parents, and the siblings are often forgotten. Or sometimes the siblings feel like they have to deny their grief so they don't become more of a burden to their already over-burdened parents. Indeed, it has been observed that children may hold onto denial longer than adults do, and that problems may not become apparent for quite a while. This may especially be true of adolescents who want to fit in with peers, and so will suppress any feelings of grief that may set them apart (Packman, Horsley, Davies and Kramer, 2004).

Perhaps no one has explored this idea of the invisible mourner more than Elizabeth Devita- Raeburn in her book entitled, *The empty room: Understanding sibling loss* (2004). Devita- Raeburn lost her sibling when she was a teenager. Her brother was an infamous “boy in the plastic bubble”. She interviewed many other adults who lost a sibling in childhood, and recorded their stories in her qualitative study. This idea of being the forgotten mourner comes up again and again in her interviews with individuals.

Survivors talk about the grief as if it’s not their own. It belongs more to their parents than to them. They do not allow themselves to grieve, and hold onto the grief for years, keeping it intact (Devita-Raeburn, 2004). Devita-Raeburn also uses the term “disenfranchised grief” to describe sibling loss. There is a feeling that siblings are not legitimate mourners, like parents are. Their grief is different because they are children, and may not be recognized as such. And so they may become the forgotten mourners.

Pollock (1986) notes that to care for and to be present for remaining children after the loss of one child can be an almost impossible task for some parents. He reports that if the parents are unable to provide the support, the cohesion that Davies discusses, the repercussions can be felt the rest of the sibling’s lifetime. The remaining sibling may not only lose a sibling, but feel as though they have lost their parents to grief as well. The loss a child within a family changes all the members of that family forever. Studies have shown that roughly one in four children are at risk for emotional or behavioral problems from loss of either a parent or a sibling (Worden, Davies and McCown, 1999).

Rosen (1991) reports that children are very loyal to their parents during this loss. They will not move away from a family in pain. They will attempt to make up to the parents the devastating grief they see them going through. They will do this by being the

good child, the one who will never leave. This will often get in the way of the necessary separation that occurs in adolescence. Children will protect their parents whenever possible. They can be prohibited from mourning, their grief overshadowed by that of their parents (Robinson & Mahon, 1997).

The replacement child

How the parents respond to the loss of their child will have an effect on the remaining children. Kempson, Conley & Murdock (2008) and Crehan (2004) both discuss the idea of the “replacement child”. A replacement child is the child that is already alive or born after an earlier child has already died. This child is born to replace the one that is lost to the family, to make up for the loss. This child is burdened with the task of filling the role of two children in the family. This can result in the child feeling like a failure, neither able to measure up to the dead sibling, or find their own individuality.

In the case of the replacement child, splitting may occur, where all the good attributes are put on the dead child, leaving the living child as the bad one, and perhaps a scapegoat (Crehan, 2004). On the other hand, the parents may displace all of their affection on the deceased child onto the remaining sibling, creating a pathological and co-dependent relationship (Crehan, 2004). In either instance, the grief of the parent can have a devastating effect on the remaining children.

Silence

Crehan (2004) also reports that a child can become silent as a form of loyalty to a family that is also silent in regards to their loss. The child learns to collude with the family, and the sibling’s death becomes a taboo subject. In Rosen’s qualitative research

(1986) she discovered that 62% of families she interviewed never discussed their bereavement. Devita-Raeburn (2004) also reports stories of adults, who as children were taught never to bring up the subject of their dead sibling.

Since so many families never discussed the loss of a sibling it becomes the elephant in the room. This leaves siblings to deal with their loss in isolation. The death of the sibling becomes a taboo subject. Crehan (2004) refers to it as a, “conspiracy of silence” (p. 207). She reports that some children will take this silence as an accusation that they are in some way to blame for the death. They can become a scapegoat in the family.

Magical thinking

Children may resort to magical thinking to explain the death of their sibling, creating a more frightening interpretation of the loss (Crehan, 2004). Without an adult to support and ground a child in reality, children can move quickly to fantastical stories to explain the disappearance of a close family member that are more scary than the reality of the situation.

Continuing bonds

The question arises as to how to help the bereaved siblings deal with their loss. Among those left behind, family cohesion is one strategy that is mentioned above. Packman, Horsley, Davies and Kramer (2006) bring up the idea of continuing bonds in their theoretical study. Continuing bonds is a way of keeping a connection with the departed, and making room for them in the lives of those who are still living. Continuing bonds refers to the bond that can continue with the deceased after there is no longer a physical relationship. More recent literature contends that continuing bonds is a way of

coping with the loss of a loved one (Packman, Horsley, Davies and Kramer, 2006).

There continues to be an emotional bond and the deceased is not completely erased from the lives of those left behind.

Continuing bonds may be especially helpful for bereaving siblings. Again, sibling relationships have the potential to last a lifetime, longer than the relationship with a parent or a partner, since siblings can spend most of their lifespan together (Packman, Horsley, Davies and Kramer, 2006). It is important to ask: How does one deal with the grief of that lost relationship? Grief creates a shift in reality for both the sibling and their family. Batten & Oltjenbruns(1999), discovered in their exploratory qualitative study of four adolescents that there can be increased vulnerability, cognitive interference, and a desire for reunion with the deceased. This study is limited as it only interviewed four siblings. Packman, Horlsey, Davies & Kramer (2006) suggest that we shift our view of how to deal with grief and see it more as work. It can be seen more as active coping, and continuing bonds is a part of this work.

If children are not allowed to grieve, they may suffer needlessly. Again, it has been observed that children can stay in denial about their grief longer than adults. Adolescents especially want to appear normal to their peers, and for that reason will deny their grief (Packman, Horsley, Davies & Kramer, 2006). It is also important to note that girls appear to have a harder time losing a sibling than a parent (Charles & Charles 2006), whereas boys are more impacted by a parental loss (Worden, Davies, & McCown, 1999).

Andrews and Marotta (2005) in their preliminary qualitative study uses the term “linking objects” which can be seen as another type of continuing bonds. They found that especially for children an actual physical object can be a way for the grieving sibling

to keep a connection with the deceased. Andrews and Marotta interviewed six children for their study. Again, this limited number of participants can be seen as a weakness in the study. But since it is an exploratory study, smaller numbers can be a good beginning.

These linking objects can be another way of helping children to “work” through their grief. Indeed Rosen (1986) found in her qualitative study that children, even more than their parents, were more likely to engage in activities such as linking objects and continuing bonds. She attributes this to the children’s need for continuity and security. Parents were more likely to exhibit behaviors that broke ties with the deceased rather than maintain them.

Batten and Oltjenbruns (1999) discuss a similar strategy to continuing bonds for dealing with losing a sibling. They name it an ongoing bond or attachment, and also view it as a developing perspective on the grieving process. They see the ongoing bond as a continuing, but changed relationship with the deceased sibling. Although the physical relationship is gone, the deceased sibling’s presence is still felt in what was left behind (Batten & Oltjenbruns, 1999).

It has been observed that the need for the continuing bond with a sibling becomes even stronger as we age. Devita-Raeburn (2004) uses the term “carrying”, to refer to continuing bonds. The surviving sibling will carry the deceased sibling into their lives, without any attempt to replace them. She has recorded these stories of adults who lost a sibling in childhood, and carry the memory of their dead sibling in some way in their present life. One woman started running marathons as a way of “carrying” the memory of her dead brother. She runs to help find a cure for the disease that killed him (Devita-Raeburn, 2004).

Although physically gone, these siblings continue to be a part of the remaining siblings' life. Packman, Horsley, Davies and Kramer (2006) use this term as well to explain the way we can bring forward the deceased and have them be a part of our life without replacing them.

Dreams can also be a way of carrying the deceased sibling into our present lives. Many of those who are working through the loss of a sibling in childhood, will feel their presence in their dreams for years to come (White, 2006).

Hogan and DeSantis (1992) in their qualitative study of 140 adolescents (a large sample but all adolescents) have created continuing bonds categories that they referred to as ongoing attachment categories to help differentiate between the different kinds of continuing bonds. They are:

1. Regretting—desiring to have a better relationship; wishing to continue a shared bond;
2. Endeavoring to understand—searching for reasons for the sibling's death;
3. Catching up—asking what heaven is like; how are things?
4. Reaffirming—loving and missing the sibling;
5. Influencing—seeking guidance from the sibling; and
6. Reuniting—anticipating reunion in heaven.

These categories were created from doing content analysis of one, open-ended question, "If you could ask or tell your dead sibling something, what would it be?" (Hogan & DeSantis, 1992). The idea of continuing bonds is not always a positive one. If the grief is not processed properly, the grief can be passed on to the next generation. This has been referred to as "transgenerational grief". This is grief that is never mourned

when it occurs (Kempson, Conley & Murdock, 2008). The unresolved trauma of grief can be passed along to the next generation as reported in the exploratory study by Charles & Charles (2006).

The use of continuing bonds and its benefits is contingent upon the relationship that the siblings had before one of them died. If there was discord or ambivalence, continuing bonds may not be helpful or be necessary (Packman, Horsley, Davies and Kramer, 2004). As most intimate relationships are, often our relationships with our siblings are complex. Some siblings feel guilty for wishing their sibling dead, or being jealous of the attention that sibling was getting from their parents when they are ill. Guilt can come from the ambivalence within the sibling relationship (Crehan, 2004).

Often, the remaining sibling may feel some disloyalty to the deceased sibling because they are moving on without them. If the surviving sibling can find a way to honor the memory of their sibling while moving on with their life, this can be healing. One example is a sibling who becomes involved in a cause related to their siblings' illness, like walking a marathon to raise funds for cancer research for example (Devita-Raeburn, 2004). Keeping a continuing bond, or carrying is now seen as a healthy way of adjusting to the loss of a sibling (Packman, Horsley, Davies and Kramer, 2006).

Theoretical constructs

John Bowlby, unlike his predecessors like Anna Freud, believed that children definitely had the capacity to mourn. He believed that siblings as young as six months old were able to mourn (1961). The issue is how these children mourn. As has been stated before, children mourn but in a different way than adults. Bowlby also asserted that children need communication from adults about what is going on when, for example,

their sibling dies. The child has little or no control, and is dependent on the adults to help them in the mourning of their loss (Farrant, 1998).

How does the loss of a sibling affect the attachment style of an individual?

Charles and Charles (2006) believe that the grief process can have a great impact on attachment. This study involved data collected from a self-reported questionnaire of 34 psychology undergraduates at the University of Michigan. They had all lost a sibling between the ages of 0-19 years of age. They discovered that the loss of a sibling affects all primary object relations, including those with caregivers. A child's ability to mourn is dependent on the support that comes from these primary caregivers (Charles, and Charles, 2006). They also report that siblings have an ongoing attachment with the deceased sibling as they navigate the grieving process. This ongoing attachment can be an effective way of coping with the loss, and working through it.

Charles and Charles (2006) conclude that if trauma from grief is not worked through it does not disappear, but will stay with a person for a lifetime, and affect their attachments in later life. In our culture, death is often avoided, and rituals that help us cope with loss are no longer used. Avoidance of the topic of the dead sibling (explain better), and lack of communication in the family after this loss can affect attachment style of the remaining sibling for the rest of their life if not addressed.

In terms of attachment styles, Charles and Charles (2006) report that the style of attachment greatly affects the way in which we grieve. They put forth the question: Can attachment style change due to profound grief? At this point, that question has not been answered. Some believe that attachment may not be stable over a lifetime. They do report that attachment is adaptive, as in the case of continuing bonds, with the emotional

and social bond remaining with the deceased throughout the grieving process (and lifetime.) It also probably makes a difference at what age the loss occurs.

A narrative theoretical approach is often useful when working with families dealing with trauma or stress. And in the case of my qualitative study, although I am interviewing siblings who lost another sibling to death, it is really the story of the whole family that is critical, as can be seen in Davies situational, environmental, and individual components to sibling loss (Davies, 1999).

Narrative theory looks at story as experience, in other words how the story we tell shapes how we feel about our experiences. Narrative theory also considers how our experiences are couched in our family and cultural narratives. An individual is not an island, but within the context of their family and culture. And finally, our interactions elicit certain enactments of our stories. The story remains the same. What we chose to focus on and enact depends on our interactions (Madsen, 2007).

As Kempson, Conley & Murdock state in their conceptual article, (2008) looking at sibling loss from a post-modernist perspective, grief is seen as a state of being as opposed to the goal of a resolution. This article also reviews literature on the subject of siblings that are never known because their death occurred before subsequent children were born.

This is very much in alignment with the idea of continuing bonds. The idea is to make meaning from the loss. The loss is integrated into the survivor's life, is not lost forever, and is forever a part of the surviving sibling's life. Ultimately, this may add a stronger sense of purpose to a person's life, influencing the direction in their life, and giving them a stronger sense of identity. Conversely, there may be a negative impact on

their lives as well, taking the value and purpose from their lives (Kempson, Conley & Murdock, 2008). Packman, Horlsey, Davies, and Kramer (2006) encourage exploration in the future of both the positive and negative expressions in continuing bonds, both meriting a further look

Guilt and coping

In another qualitative study by Rosen (1986), 50% of respondents said they felt some guilt around their sibling's death. Some had survivors' guilt. In some cases, others people imposed the guilt on the child. This may have been because the child was not grieving in a way that adults perceived as proper (Crehan, 2004). As has been noted earlier, children grieve differently than adults, and adults could misunderstand their grieving process. In either case, guilt tends to be a long-term issue for bereaved siblings (Charles & Charles, 2006).

So how does one cope with the loss of a sibling in childhood? Andrews and Marotta (2005) describe relationship and containment as key factors in coping for children. By relationship they mean continuing the relationships that they have after the loss. These include remaining family members, their relationship with a spiritual or religious life, peers, pets, and linking object discussed before. It is also recommended that in whatever way a bereaved sibling finds to cope should be respected by the others around them.

Learning to cope is imperative to the bereaved sibling. If they feel like they have any unfinished business from their loss, they will have a very difficult time adapting and may have problems in creating positive continuing bonds (Packman, Horsley, Davies & Kramer, 2006). Rosen (1986) points out that children more naturally tend to create

continuing bonds or carrying than adults do. Schoolwork and school related activities were cited most often as ways of coping with sibling loss among children. Linking objects were second in importance, followed by religious faith and saying prayers (Rosen, 1986). Linking objects and prayer can both be seen as ways of continuing bonds.

Finally, many of the traditions that we once followed to cope with the loss of loved ones we no longer practice. We have become a culture that is afraid of death, and keep it out of the day-to-day reality of our lives. Without a way to process these losses, especially when they happen in childhood, they can become transgenerational (Charles & Charles, 2006).

Creativity and sibling loss

Creativity is one area I explore in my research. There is some literature about sibling loss and creativity by Pollock in his examination of case studies (1978). In the mourning process, there is a reorganization of intra-psychic structures and a response to a change in reality (Pollock, 1978). In this reorganization, there is the possibility for the spark of creativity. When you free yourself from the past, a possible outcome is creativity. The lost object is replaced with this creativity in certain individuals, some of whom will be mentioned later (Pollock, 1978). Davies (2003) echoes Pollock's views on loss and creativity, positing the idea that loss doesn't necessarily have a pathological outcome.

There is the possibility that sibling loss could eventually lead to healing through the means of creativity (Gill, 2006) Grief can be seen as an energy that could be used in a creative way and through that creativity can come healing.

Some of the best examples of how grieving the loss of a sibling in childhood has led to creativity in adults can be seen in famous artists of history. There are a fair amount of creative people, from artists to writers to musicians, who were profoundly affected by the loss of their sibling in childhood. Jack Kerouac said that the only reason he became a writer was because of his brother, Gerard, who died when Jack was only four years old. And yet, that death, experienced at such a young age, made the largest impact on his life of anything (Pollock, 1978).

Kerouac wrote a book about his brother as an adult called, *Visions of Gerard* (1963), in which he writes, “the whole reason why I ever wrote at all and drew breath to bite in vain with pen of ink...with indefensible Usable pencil [was] because of Gerard, the idealism. Gerard the religious hero—“Write in honor of his death”...”. In Kerouac, one hears the intensity of feeling that the death of a sibling at a young age can elicit.

There are other famous examples of people who lost a sibling as a child, and credit that in part for their creativity. Others include painters Edvard Munch, Pablo Picasso, and Salvador Dali, writers, Emily Bronte and Oscar Wilde, and musician Elvis Presley, who lost his twin at birth (Davies, 1999). All of these creative people talked about how this early loss had a deep impact in them, especially their creativity.

J.M Barrie, the creator of *Peter Pan*, lost his older brother when he was a boy. This brother was the most beloved of his mother, and when he died, in effect, he lost his mother as well. In attempting to entertain his grieving mother, he began writing stories to amuse her, and developed his writing skill. It is interesting that his most famous story is about a boy that never grows up (Pollock, 1978)

Another writer that lost a sibling as a child was Amy Tan. Her story gives a little different perspective, but it is interesting to note because it shows how our sibling help us define who we are. She found out about unknown siblings and it changed her worldview (Kempson, Conley & Murdock, 2008). Although she doesn't discuss it here, one wonders how this loss made her the writer she was to become.

I had once thought I was the only daughter, the middle child, a position I took to have great psychological significance. I then discovered I was actually the youngest of five girls, that one had died at birth. There were three brothers as well, including one I didn't know about; he died at age 2 in 1939. With all taken into account, I was demoted to No. 7 of eight children (Tan, 2001. p.2).

Spirituality

Spirituality as defined by Batten and Oltjenbruns (1999) is the human quest to understand life's meaning. In their exploratory study of adolescents who lost a sibling, they found that some of the participants had increased their belief in a higher power, whereas others expressed anger towards God.

For grieving children, spirituality appears to be an innate capacity. It can be somewhat hampered by the child's limited verbal skills. Preverbal children see death as a disruption in their routine. For preschool children, death may be seen as something that they have created. By age seven, children can have a mature concept of death. Spirituality is was way of making meaning of death. From meaning, we can begin to heal, and our spirituality can be a way of healing (Andrews & Marotta, 2005). For those who experience the death of a sibling as a child, it can be a way into a spiritual life. Having spiritual beliefs can be a way of having continuing bonds with the deceased and offer some comfort. It was found that meaning making can take years, and is ongoing for the bereaved sibling (Packman, Horsley, Davies & Kramer, 2006).

Conclusion

The study of sibling loss is one approach to studying how we process the losses in our lives, specifically those that happen early in life when we may not have all the adult tools that help us better understand this significant event. The more modern idea of ‘continuing bonds’, as opposed to just getting over our losses, and getting on with life as soon as possible, appears to be gaining more credence in the research world as a healthier approach to grief and loss. This post-modernist idea, of always ‘carrying’ our deceased loved ones, and learning healthy ways to incorporate them into our lives is a way to acknowledge the grief without letting it overwhelm us. Perhaps one of the best examples of this is finding spiritual and creative ways to honor those who have physically passed from our lives, but remain a part of who we are always.

Most of the previous studies focused on adolescents. My participants were both children and adolescents when they lost their sibling. Their siblings died in both accidents (n=5) and from illness (N=2).

Most of the studies on sibling loss in childhood are exploratory and have a small number of participants. My study is also small (n=7), but focuses more specifically on the ways that losing a sibling has affected the remaining sibling that is now adult, and especially how they carry the impact of that sibling in their present life, whether through their creativity, or spirituality, or some other way. Most did find that they had a continuing bond with their deceased sibling in some way. For some, it was more profound than others. In any event, this research gives a voice to what other researchers have named, “the forgotten mourners.”

In my study of seven participants who are now adults, they all lost their sibling many years ago, as many as 63 years ago. In the literature that I found, no one else had interviewed people so many years after the loss of their sibling. I study how their loss affected them as they grew older, and how they see that loss in their day-to-day lives as continuing bonds, in the way they relate to others in their life now. I focus on their stories, each an individual experience, but also with commonalities.

CHAPTER III

METHODOLOGY

In this exploratory qualitative study seven interviews were conducted with adults about the experience of losing a sibling when the participants were children. The research question for this project is: How do individuals understand the effect of a sibling's death in childhood on their life as adults, especially in terms of their creative and spiritual lives? In order to allow room for a range of answers to this question, an open-ended interview was conducted. Eight questions were asked that allowed each participant to go into as much detail as they wanted about their experience of losing a sibling when they were young, and how that may have influenced their adult life. Interviews were done on a one-on-one basis. The data collected was subjective and told from the point of view of each participant. They were each allowed to tell their own story in their own words.

The words used in the participants responses, and their recollections and attitudes during the interview regarding the loss of a sibling in childhood were later used for content analysis and coding. The concepts were not determined until they were coded according to their meaning, and this did not occur until the data was collected.

Sample

The sample for this study was seven adults who had lost a sibling in childhood. In order to participate in this study they met the following criteria:

1. They must have lost a sibling that was living with them in childhood to death.
2. They must now be adults, over the age of 21.
3. They all must have lost a sibling when they were children, between the ages of 4- 16 years of age.
4. The death must have occurred at least five years from the time of the interview.

Those excluded from my research are those who are still children, and those who didn't lose a sibling to death, but to some other cause, such as substance abuse, or mental illness. Also excluded are those that lost a sibling to death, but were not living with them at the time. Those who don't speak English are also excluded due to the time constraints of this project and the interviewer who only speaks English.

Elizabeth Chamish, Community Services Director of Piedmont Gardens in Oakland, CA was contacted, and she agreed (Appendix F) to send a recruitment letter (Appendix G) to all of the residents of this retirement community. This is a community of over 190 residents. Ms. Chamish was very enthusiastic about the project, and there was real hope that potential participants would be found and that they would have the time to be interviewed. This turned out not be the case, and the reasons for that could be varied. Some of it may have to do with the generation of the residents there, a generation that may not feel comfortable talking about such a personal story. The reasons can only be guessed at, and would not be within the scope of this research. Without the participation of this large group, there were only those reached through a snowball approach to draw from. Participants were recruited using snowball sampling. All of the participants were recruited in this fashion, through connections with fellow students at

the Smith College School for Social Work, colleagues from the San Francisco Veterans Administration, family and friends.

Being such an emotive subject made it more challenging to find people willing to speak to an interviewer. They could not be contacted directly, but only through those who knew them beforehand. There were no “cold calls”. Although the goal was to find at least twelve subjects to interview, ultimately, only seven participated. The table below gives some of the demographic characteristics of the sample:

Table 1. Demographic characteristics of participants.

Name	Current age	Gender	Religion growing up	Current religion/spirituality	Ethnicity	Profession
Ben	69	Male	Jewish	Jewish	Caucasian	Attorney
Mollie	41	Female	none	none	Caucasian	Social Worker
Angie	46	Female	Catholic	Catholic	Caucasian	Admin.
Kevin	55	Male	none	none	Caucasian	Law
Anna	44	Female	none	Buddhist	Caucasian	Museum registrar
Susan	62	Female	Catholic	Non-dem	Caucasian	retired
Carol	53	Female	Episcopalian	none	Caucasian	Executive in IT

The sample included five women and two men, all Caucasian. Four grew up with a religion of some kind, while three did not. Five of the deceased siblings died in an accident, while two died from illness. Information on the death of the sibling is shown in the table below.

Table 2. Characteristics related to deceased sibling.

Name	Age when sibling died	Age of deceased sibling	Cause of death	Years since death
Ben	6	14	Hodgkin's Disease	63
Mollie	11	13 & 16	Plane crash	30
Angie	12	15	Plane crash	32
Kevin	7	2	Congenital heart disease	48
Anna	15	18	Hit by car	29
Susan	9	7	Hit by car	53
Carol	4.5	11.5	accident	49

Data Collection

Narrative data from open-ended questions (Appendix C) from individual interviews in person and via telephone were obtained from a sample of seven volunteers who met the selection criteria. Procedures to protect the rights and privacy of participants were presented to the Human Subjects Review Board at Smith College School for Social Work before data collection began. Approval of the project (Appendix A) assured the study was in concordance with the NASW *Code of Ethics* and the Federal regulations for the Protection of Human Research Subjects. Interview questions (see Appendix C), as well as an informed consent form (see Appendix D) detailing the risks and benefits of the study, were sent to each participant prior to the interview. The participant and the researcher each kept a signed copy of the informed consent document for their records. The initial contact, as well as the beginning of the interview afforded

the participant the opportunity to inquire about the researcher, the study, their expectations as to how the data might be used, and answer additional questions. At the conclusion of the interview, the participant was asked if they could be contacted again should further questions regarding the data emerge.

The interview, ranging in length from 25 to 40 minutes, took place between March 13th and May 4th, 2010. Two interviews were conducted in person using a digital voice recorder. For the remaining four interviews by telephone the same recording device was used with a telephone microphone. The digital files were downloaded to a Mac Book, and converted to a WMA file. The WMA file was sent to the transcriber Ra Cristiciello, who signed a confidentiality agreement (see Appendix E). She transcribed the interviews, and returned them back to the researcher as a Word Document.

Interviews were transcribed in their entirety in order to extrapolate the maximum amount of detail given. At the end of the study, all data was removed from the computer, transferred to a flash drive, and stored in a locked area with confidential participant data.

An interview process was chosen to collect data for this study to obtain subjective experiences from participants that could better be understood through narrative. By obtaining the participant's point of view, the reader would be able to have a glimpse into the participant's feelings, motivations, memories, and experiences.

The questions asked during the interview were self-developed, open-ended questions in order to elicit information from the sample. The questions were formulated based on previous research and also on questions developed by Rosen (1986) in her study. These questions were reviewed by the HSR committee as well as by the writer's thesis advisor before they were finalized.

An example of questions asked includes describing the relationship with your sibling before they died, describing the experience of the death and it's aftermath, and what impact this death has had on the participant's life up to the present day. Specific questions related to the participants opinion on how this death impacted their creative, spiritual and career life were asked.

Demographic information was gathered first, (illustrated in Table 1). Then questions were asked about the participant's remembrances about losing their sibling in childhood, noticing both their reactions, and their recollections about the way others around them reacted. They were also requested to recall the events that took place after the death of their sibling. The second set of questions asked the participants to relate their loss to their present life, and how they perceive the impact of loss on them as adults. The questions ask them to focus specifically on their creative and spiritual lives, and how losing a sibling may have affected them in this regard.

There was some risk of discomfort associated with participation in this study. Participation might have brought up painful memories as they reflected upon those experiences that may have elicited difficult feelings. A list of low-cost counseling resources were available to individuals in case they felt the need to speak with someone about any feelings that came up as a result of participation (Appendix H).

The benefits in participating in this study may have helped participants explore their personal experience of losing a sibling in greater depth and perhaps provide new meaning, as well as provide invaluable information to others who may be in the same position. There is also value in simply having an opportunity to talk about it. Participants were not compensated for their participation in this study.

Confidentiality was maintained throughout this study. No participants' names appeared on any papers or recordings, as numerical codes were assigned to their information. This researcher and her thesis advisor reviewed and analyzed the data together. Any writings or publications on this topic will be presented in the aggregate. Any quotes used for illustrative purposes do not include identifying information or will be disguised to protect their identities. The information gathered (audio recordings, transcriptions, notes, and signed informed consent forms) will be locked for a period of three years, as required by Federal guidelines. After that three-year period, all data will be destroyed when no longer needed, or kept safely stored.

Participation in this study was voluntary. Participants could have withdrawn from the study at any time during or after the interviews until the date of May 22, 2010 and they could have refused to answer any question during the interview. They could have withdrawn from the study, or chosen not to answer certain questions, without penalty, and services pertaining to referrals would not be affected, nor would information regarding their participation be disclosed. Participants were asked to contact this researcher at the number or email stated in the informed consent if they chose to withdraw from the study, or if they had any questions regarding this process.

Data analysis

Data collected from the demographic information were analyzed and are presented in Table 1 of the *Findings* chapter or a table of demographics can go in the methods. Narratives were compared throughout the process of the study and data coded using content analysis. In this sense, there was open coding and provisional codes were

assigned to all indicators. In using this inductive method, the qualitative responses were grouped by similarities and differences.

Themes and similar responses were noted throughout the process as the data was being gathered. This was done by cutting and pasting all responses to questions together, reading through the responses, and highlighting themes, keywords, and unusual responses in different colors. These responses were also coded in a Microsoft Excel spreadsheet, inputting the data according to the keywords and themes that became apparent, with each question having a dedicated spreadsheet. Participant numbers, and a grid indicating their responses provided a quick view of the data collected.

Limitations and biases

Methodological biases were observed and noted throughout the process. This sample of self-selected volunteers from snowball sampling was not a random sample. The sample size (7) was a small representation of persons who lost a sibling in childhood and only offered a glimpse into the views of a select few. A representative sample was not obtained in regards to ethnicity, with all seven participants identifying as Caucasian. 5 of the 7 participants were female. These limiting factors prevented generalizability among the greater population of those experiencing the loss of a sibling in childhood

The interviews were conducted in person and by phone. This could have been a sampling limitation since all participants were required to have access to a phone. Additionally, the researcher may have influenced participants on the phone based on voice, intonation, inflection, and manner. . Simply being interviewed may have also been a limiting factor because people may respond in a differently because they know they are

being recorded for an academic research project. They may wish to appear in a certain way for the researcher, and not answer as honestly as they could.

As noted above, researcher bias, assumptions, and perceptions may have been an influential factor. Although the researcher had the HSR committee and her thesis advisor review the interview questions during development, the questionnaire was nevertheless self-developed and therefore subject to scrutiny. An effort to obtain information from participants without influencing them was to frame questions as being open-ended.

This researcher has lost a sibling in childhood, hence the interest in this particular subject. For me, I lost a sibling when I was seven years old to leukemia. My family had a great deal of difficulty in processing their grief, and this made me curious as to the other ways families may have dealt with this traumatic experience. Because of this personal experience, I have a particular focus. I'm interested in how families are impacted by loss, especially when they have no idea of how to process their grief or find supports. I'm also more focused on the long-term impact of losing a sibling in childhood, and how people see that shaping who they become, particularly in the creative and spiritual realm.

Chapter IV

FINDINGS

This exploratory qualitative study looked at the memories of losing a sibling in childhood, as well as the perceived long-term outcomes of such a loss. The principle research question was: How does one experience the death of a sibling in childhood, and what if any, are the perceived long-term outcomes of this loss? The findings will present the results of seven individual interviews conducted with adults who lost a sibling in childhood; what their memories are of their sibling, their family, and the event of their sibling's death, as well as how they feel this has impacted them over the course of their lives.

Findings also explore how the surviving sibling keeps their deceased sibling as a part of them, as a continuing bond as discussed in the literature review. These findings were derived from seven open-ended questions formulated to let each participant tell their story of the loss of their sibling in their own words. Participants were encouraged to explore their own experience of their sibling's death, as well as their current feelings around this loss. The findings were then coded into ten different categories using content analysis techniques. These categories constitute the headings for this findings chapter.

The first section will explore the nature of the relationship between siblings followed by the grieving process, changes in the family and parents, ways of coping, the role of guilt, feelings around life and death, differences between religious and secular

families, effects on the remaining sibling's creativity, spirituality, or religion, and career, long-term effects, and continuing bonds.

For the purpose of maintaining confidentiality, all of the names of the participants, as well as any names mentioned by them in the course of the interview have been changed to protect their privacy. There were seven participants in all. Following is a brief description of each.

Anna: Current age is 44. Anna was fifteen when her eighteen-year old brother died when he got hit by a car driven by a fellow high school classmate.

Susan: Current age is 62. Susan was a nine-year old when her seven-year old brother was also killed by getting hit by a car that was driven by a teacher at their school.

Mollie: Current age is 41. Mollie was an eleven-year old when her two brothers and her father were killed in a plane crash that the father was piloting. Her brothers were thirteen and sixteen at the time.

Ben: Current age is 69. Ben was a six-year old when his fourteen-year old brother died from Hodgkin's disease.

Kevin: Current age is 55. Kevin was a seven-year old when his two-year old brother died from a heart problem he had had from birth.

Angie: Current age is 46. Angie was a twelve-year old when her sister was killed in a plane accident that their father was piloting. In this instance, the father survived, but was severely injured.

Carol: Current age is 53. Carol was four and a half years old when her eleven and a half year old brother was killed when he was strangled by a rope swing.

The nature of the relationship between siblings

Each participant had a unique relationship with their sibling before they died. They range from quite close ($n = 4$) and having very vivid memories of their death, to having very few memories of the deceased sibling at all ($n=1$). Some of the participants were older than their deceased sibling and some were younger. They ranged in age from 4 ½ to 15 years old at the time of their sibling's death.

For Anna who was a teenager when her older brother died, she noticed the relationship changing as the siblings grew older:

I would say that it was a growing closer relationship. I would say like two years, we started to get closer and we actually went to school together. We started to enjoy each other's company and not fight as much. I think he was growing up and so was I. So it was a relationship that was pretty close.

Susan who was younger, also had a good relationship with her younger brother, although she reported a conflict that happened right before his death that she still remembers:

Well, I thought I had a good relationship with him. But a weird incident happened a couple of days before he died. And it sticks out in my memory. I had a doll that was called my tummy doll. And he did something to the doll. He hid the doll, he threw it behind the davenport and poked its eyes out or did some bad thing to my doll. And I was really upset with him a couple of days before he died. And so in my fit of anger, I said I wished you were gonna die. I wished you were dead.

Angie also had a good relationship with her older sister. She looked up to her:

She was my best friend. We had just moved to a new town, and pretty much only had each other. Never made very many friends there. She was just really cool. Somebody to look up to and try to be like.

Carol had an older brother that she also really looked up to and wanted to be more like him:

And he and I were incredibly close. I was like his little buddy. He was my protector. He was the classic big brother. He taught me all sorts of things. And we were so close – I mean, people still tell me about it – we were so close though that there's- on his headstone, it's engraved or whatever, is an image of a boy with his hand on a little girl's head. And that is me and him, on his headstone.

Kevin, whose little brother was only two years old when he died of a heart defect, still had very strong memories of this very young sibling who had such a profound effect on him in the short time that he was there:

And he was pampered and loved by everyone because we all knew how precarious his health was. And I changed him and fed him and played with him and he was just a wonderful, wonderful little boy.

Mollie, who lost two older brothers in a plane crash, mentions that she was especially close to one of the brothers with whom she had a lot in common. “We just were very much in synch in a lot of ways.” Her sister, she says, was closer to the younger brother that died.

Ben, who was nine at the time of his older brother's death from Hodgkin's Disease is the only one that has very little memories of his brother before he died:

Because the only thing I really remember about my brother is – and it's really not even about him – he was in a hospital I think in Manhattan. And I remember going to visit him and seeing the old double-decker buses in Manhattan. Which I hadn't seen. We lived in Brooklyn. And I don't even remember actually seeing him in the hospital. And my remembrance of him at home is practically nil. The only thing I remember – it's not of that time – is, there was a picture of him that we had in the living room where I grew up showing him when he was a year younger at his Bar Mitzvah age, which is 13. And he died the following year. So there's a picture of him in his- you wear a tallis when you – a prayer shawl – when you're Bar Mitzvahed. And I remember the picture. But outside of that, remembrances of him directly- I just don't have it.

Ben, at sixty-nine, was the oldest of the participants. He has the least memories of any of the participants in this study and it may be because of his age. He reported

many more memories of his deceased sister who died much more recently and with whom he has had a long relationship.

The grieving process/disenfranchised grief

Each participant except for one, or 86%, had a specific story about how they and their family experienced the grieving process. Although they were children, they could remember very intense emotions that they and their family were feeling. Angie said:

It was devastating. And I actually dreamt that something was gonna happen to her. It's almost like I wasn't shocked. But my mother's scream was horrible. And I just knew. I didn't even have to ask what was wrong. I just knew right away. And it just was devastating to everybody.

For Carol, the memory of the moment when she found out is still vivid. She can recall sensations; touch and smell:

And then the impact when he died was pretty profound. So one of the neighbors came over and knocked on the door and told my Mom. And I remember very distinctly. It was in an area behind our house- going towards that area there was a crowd of people, you know, kind of around. They wouldn't let me get very close. But my very distinct image is of clutching a tree. And I can still smell and see the bark. It was very thin barked tree. Anger, it was a very terrible time. It was like a black period in our life. It's almost like the lost year.

As seen in this quote, there is this feeling that time slows down, and that very specific things are remembered, even after many years, like the feel of the bark against your hand. Mollie also remembers specific details in the moment she found out about her two brother's deaths:

I remember the day like yesterday. And I remember sitting on the couch and my mother said: "I have something to tell you girls." And she basically said your father and your brothers have died in a plane crash. And my sister burst into tears. And I said, "Can I go out and play?" So we had very different reactions. I ended up just going outside and started singing very loudly, "My brothers are dead, my Dad is dead". I remember the day, I remember specifically the day. And Joan and Ted coming to the door. And going to Lorna's. And my weird reaction.

Other participants remarked that they felt like they couldn't believe that it had happened. Susan:

Well my reaction was I think disbelief. Disbelief that it really happened. And we were all asking our parents about it and how'd it happen and why did it happen and what happened. And I think we just couldn't believe he wasn't there. And then after a month, it sunk in that he really was gone. And he really wasn't coming back.

In the above instances, the death occurred quite suddenly as a result of an accident. After the initial shock of the death, participants reported different ways in which the grief was experienced by both them and their family. Many spoke of a coming together of their family and community in the sharing of food. Mollie: "Then there were many days of people coming and going and food and all of that". Carol: "You know, it was the classic- the house was dark, the curtains were drawn, people would come and bring casseroles, you know, and there was that just kind of quiet period." Anna: "There was a huge—family and friends around. I mean, actually, right when he died it was amazing because every time the doorbell rang it was somebody from out of state. Like we were completely surrounded by friends and family."

Four participants, or 57%, mentioned there being a funeral. In an example of disenfranchised grief, as described in the literature review, the children were not allowed to attend. In another, there were allowed to attend, but the mother didn't allow the casket at the funeral, or for her children to attend the Catholic rosary. Participants stated that this part of the grieving process was not as clear. Mollie: "That was a bit of a blur."

For Anna, the shock of her older sibling's sudden death after being hit by a car caused her family to completely shut down.

As the grieving process goes, it was really shut down. I mean my parents- there were no photos of him around the house. And so the grieving process was just kind of clamped down. We didn't talk about my brother, we didn't have pictures of him. We didn't go to his grave that much or anything. It was really hard. I think that was maybe not the healthiest way to deal with it but that was the only way that my parents could deal with it in a way. Was just to sort of not look at it.

Kevin talks about the grief that he felt, but did not see in the rest of the family: "I cried a lot. It was very painful. I don't remember that much grief (in his family) about it. But I sure felt it and my brother did, too." Each participant in this study, except for Ben, has very specific memories of their sibling's death and the grieving that followed. Ben had no memories, other than, "a picture of him that we had in the living room where I grew up," had no specific memories of his own grieving, although he does have memories of his parent's grief years later.

What I do remember – and my mother lived until she was 86. On Friday night, when the Sabbath comes, she would light traditional candles when the Sabbath comes. And you say a prayer over the candles. And I remember at- it was an extremely sad time. I mean, I would see tears roll up in her eyes. You know, she would just- I know what she was thinking. At least I thought I knew what she was thinking. And really when the Sabbath comes, it sort of should be a joyous time. Not a very sad time. But it was always a very sad time for her. And, you know, and I saw this deep loss in her reaction. So that's what I remember. And that lasted until pretty much she died.

Changes in the family/ changes in parents after the sibling death

The effect of losing a child in a family changed all of the siblings and their families. They report changes in all of the family and more specifically in their parents, and in the relationship with their parents. Some report the death of their sibling as the family before the trauma, and a different family after the trauma. For Anna, the change in the family was overwhelming:

When it happened, it just shattered our family. My Mom and Dad were just devastated. It just left a big gaping hole in our family that I think never ever quite

healed. And I was a kid, too. I was 15 and I just didn't know. I think the hardest part was watching my parents and just how devastated they were. Like, I think I was scared of them. It kind of scared me. And all of a sudden, I was like an only child because my brother was dead and my sister was in college in another state. And that was a really unusual place to be. It was just like suddenly the total dynamics had changed. And then my parents were completely absent because they were so traumatized. It was almost like I lost my parents when I was 15 because they were so traumatized. That was partially how that changed my relationship with my Mother, who was really the one that kind of ruled the family. She no longer was somebody who I- she didn't have any more command over me in a way or something. She sort of lost her role as someone to watch over me. She was sort of broken inside. She was just totally traumatized. And I'm just like- that's ok, that's grieving, just be there for her, support her, just give her as much support as you can. Don't worry about all those feeling- especially right now, because it's the shock of it.

For Susan, she noticed that her mother, "became more protective." Ben also remembers his mother becoming more overprotective.

But after that for, you know, until I – I don't know – until I moved out of the house I guess and got married, she was very overprotective. Very aware of where I was or where I wasn't. I think that was also perhaps an offshoot of her losing her first- born. She wanted to make sure that she didn't lose anybody else.

For Mollie, she noticed her mother being more protective, but in more subtle ways.

She later said that for years, when me and my sister would play, she would stand at the window and watch. Because she was so scared we were gonna get hit by a car. So- but she never told us that. So she was not a helicopter Mom. She certainly didn't- but she was terrified of losing us.

Kevin felt like his parents didn't want him to see their sadness.

I remember my Mom being very melancholy about it, but I don't remember her sobbing or breaking down. I think they put on a brave face for my brother and I. - I think that we were- my recollection is that they didn't- they were trying to shield us from it. I saw my parents suppressing their grief. Yeah, we both (he and his brother) cried about Eddie dying. Mostly- because of all the repression of emotion, we didn't know how to act.

Carol speaks about the way the family felt like two different families, a before and after family:

It was like a black period in our life. It's almost like the lost year. You look at pictures- there's a big gap. All the sudden there's no pictures. And it, you know, forever changed us. It's like so true with most people that I know who have lost, as a child, is that there's, the family life before and life after. There's that major demarcation in life.

Carol also talks about how the family members separated, each into their own grief:

But what happened was everybody retreated into their own worlds. So there was no kind of coming together. It was really more everybody went into their own worlds. And we didn't grieve as a family. You know, he (her father) is very pained by it. You know, he has shared with me that, you know, he wanted to die. When my brother died, he didn't want to go on. He didn't. But he had that sense of responsibility to the rest of us. To forge ahead. There's a way you kind of become, the parent of your parents. And there were things my parents weren't doing and being there for me in a way they should have and used to be. But because they withdrew into their own worlds, I had to kind of make my own way. So I think having to make my own way really shaped me growing forward.

For Angie, whose sister died in a plane crash that her father was flying, the change in the family lasted for many years for both her parents in their own way:

But my mother, - climbed into a hole and didn't come out really, well, until a couple years ago actually. And my Dad I think was in denial for a lot, a lot of years. I know my Dad hadn't ever been up to the cemetery. And I'm not quite sure he ever went up until my grandma died two years ago. But you know, he suffered for so long. We all had our own ways, you know. My brother didn't remember but he had to grow up with an automatic grieving family. And I had my own issues cuz my mother was so psychotic over it that she would say some of the craziest things like: Why would they want her and not you? She would lock herself in her room. She would just stay in there for days. She didn't really have much to do with us. They don't call her Crazy Betty for nothing.

Ways of coping

Each participant found different ways to cope with the loss of their sibling. Four of the seven participants or 57 % stated that the death of their sibling was not discussed much by the family. Ben reported that, “ I don’t remember it being talked about.” Carol said that, “ We always had that unspoken rule of—you don’t talk about him after he died. You never talk about it. ” Anna’s family had the most extreme example of avoiding the topic of her brother’s death.

And then what we did was we ended up moving away, like within six months of that. And it was almost like they acted like it never happened. And I think that was probably not the best way of dealing with it. I didn’t really rock the boat. And I knew how to sort of fake it.

The other three families had other ways of coping rather than trying to forget about it as soon as possible. Kevin’s family had another child just months after his brother died. “Well all of us, when my sisters – Stephanie was born in January of 1963 – all of us appreciated her a lot more because you know, she was life. And it helped us with the loss of Eddie.”

In the case of Mollie and Angie, their families took advantage of outside help. Mollie’s family went to grief therapy.

And then we all had grief therapy- family therapy. My mother’s a social worker, too. Which I don’t really remember, actually- the grief therapy. But apparently we went for like six months, every week as a family and talked about it. We always sort of talked about them.

Angie, who came from a Catholic family went to counseling that was offered by her church. “They had this death and dying, grieving course that’s through your religion. And we were going there.”

As time passed, each participant continued to find ways of coping with the loss of their sibling. For Mollie and Anna, they became rebellious. Mollie said:

I moved out of the house at 17 when I was a senior in high school. I moved out and rented a room somewhere. So I was, you know, trying to break away and be independent and do my own thing. So I wouldn't say she- indulgence isn't the right word. It just changed the whole- it changed who I was. And it changed how she had to treat me. I think if my brothers had lived, I wouldn't have moved out of the house at 17. And I wouldn't have been doing all drugs and dating coke dealers.

Anna's life after her brother's death echoes the wildness that Mollie refers to:

I just needed somebody to watch over me and so I looked to these older guys in the neighborhood. I was just looking for somebody to take care of me. I just look back on myself now with sympathy. Like, oh just a teenager just trying to get by. I started hanging out with some troubled folks and ended up started hanging out with drug dealers and stuff. The next like three years were really just bad behavior. But my parents never said anything. And they just looked away. I think they were just glad that I was alive.

Carol, whose family didn't talk about the loss of her sibling found a different way of coping in her later years.

I couldn't talk about it until I was in my late 30s, after having gone through like significant psychotherapy. Where, as a part of that therapy, as an adult I finally grieved my brother's death. So that now I can talk about it.

For Kevin, there are still unanswered questions that he continues to struggle with:

I don't feel it every day. I don't- I'm just, in fact thinking back is reopening these old emotions. And I don't find them pleasant. So I don't like to think about, you know, like a lot of people, don't like to think about things that bother me. I don't have a solution to it. That I wanna find a solution to it and there is no solution to the death of my brother. It's always painful, it's always wasted. A wasted life. Well, his death offended my sense of justice in the world. So that was just my first, most bitter taste of it at that age. Since then, of course, there's been a lot more examples. But that was the first one. And I just couldn't trust somebody that would kill a baby like that. And that's how I looked at it at the time.

The role of guilt

Susan and Anna discussed the role that guilt played in the death of their siblings. Because Susan had wished her brother dead over the incident of her doll, she had some feelings as a child that she was in some way responsible for her brother's death.

I had thought in some way I felt guilty that I had caused the death because I had said that. And I knew that that wasn't a good thing to say that. But of course then when I got older I realized that it was not anything that I said. It was an accident.

In the case of Anna, she feels some guilt about her rebellious years after her brother died, and the anxiety that caused her parents. But felt that her that it was her older sister who felt the most guilt for years after her brother died because she wasn't around. She was in college when he was hit and killed by a car:

And my sister was in college – her first year of college – and so she felt really traumatized by it because she didn't, she wasn't there when it happened. And so I think she sorta felt guilty about that all her life. I realize that it was really hard on her because she wasn't there and she has always carried this kind of guilt around for not being there and not being more attentive to my parents and their needs. She just feels guilty. And I've always tried to tell here there's no reason to feel guilty. But that's just how she's carried it. And I think that's something she's carried all her life and it's affected her psyche. Where I don't feel guilty about it. I used to feel guilty about being such a crappy teenager and doing all those drugs and hanging out with those derelicts.

Feelings around life and death

Sometimes losing a sibling at a young age brought up thoughts and feelings about life and death earlier than would have otherwise occurred. Four of the seven participants, or 57%, brought up this topic of how this experience affected their ideas around life and death and this sometimes overlapped with feelings about religion and spirituality. For Susan, her experience taught her to appreciate life at a younger age.

In the scope of things, death is part of life. And it's part of a natural occurrence in life. I just think it's part of life. It just happens. It's out of our control. And when

God takes us when it's our time, that's it. Well I think it makes you more aware of life and death and the meaning of it. And to value it more than you would otherwise.

Anna also learned a healthy respect for life and death, and it made her appreciate being here in the present moment.

Better be ready for it. And I know that first hand. And a lot of Buddhism is about not seeking nirvana so much. It's about- where are you here today? Are you present? Because you're not always gonna be here.

Mollie, as she became a teenager had little fear for death. As a part of her rebellious years, she reports not caring much if she lived or died.

I was very wild when I was 16, 17. I basically had a death wish. I was like- you know what, they're already dead. So if I join em, big deal. So I lived very dangerously. I did things- I did drugs, I drove too fast.

Kevin was not able to understand how such an innocent child could die. As an adult, 48 years later, he still cannot understand how such a thing could happen.

That was my first loss. But I mean, of course not the last. We're all going to see people we love die. But it makes no more sense now than it did then. Death just seems like a bad flaw in any kind of a plan for conscious beings. There's just no rightness to his death. There's nothing good about it. There's, you know- I can see a lot of positive things in otherwise negative events. You know, you can look for a silver lining. But there's just no silver lining about that. We were all saddened because of that. If there's a common thread, it's just that new life will help you forget the older death.

Differences between religious and secular families

Four of the participants, or 57% were raised in a religious household. Three, or 43% of the participants were raised in a family with no religious tradition. For those raised religiously, the death of their sibling was couched in the traditions of the church as seen in Susan's response:

And I think that because we went to Church every Sunday and in our Church we had people getting married and people dying and all kinds of things that happened

within the community, of a religious community- I think that I thought of it as part of the nature of things.

For Mollie who was raised outside of religion there was not that framework: “you know, we’re not religious. So we didn’t have a whole lot of- they’re looking from heaven, that kind of thing.”

In Anna’s case, both her parents were raised in a religious tradition, but they chose not to raise their own children that way. Because of that, they made certain that religion would not be a part of they or their children lives as they dealt with the death of a family member:

And spiritual and religious practices- my parents were brought up- my Dad was brought up southern Baptist and my Mom was brought up Roman Catholic. And they both were very strict when they were brought up. So when they raised us, they pretty much told their families that they were atheist. We never stepped one foot inside a Church, we never talked about religion, we never discussed it. It wasn’t even ever an opportunity to sort of think about.

Effects on the spiritual/ religious/creative/career lives of remaining sibling

While some of the participants interviewed felt pretty strongly that the loss of their sibling did have an effect on the spiritual/religious, career or creative life, others felt that it really had no measurable impact on those parts of their lives. In reflecting back, participants also felt uncertain as to what kind of impact the loss had on different aspects of their lives as adults. For some, these questions gave them the first opportunity to look at their loss in these terms. Susan and Ben, or 29% of the participants did not feel that their sibling’s death had any impact on these parts of their lives. Susan states, “I don’t think I had a different career because of that, or I had a different religion or- I don’t see

what- I don't think it made me different." Ben similarly states, " I don't think it affected my religious practice. Career choice- I don't think that either. No."

Spiritual/religious

Anna talks about the influence her brother's death had on her spirituality:

So here I am in my 40s and I've actually kind of come around to really appreciating and being interested in Buddhism more just as a way of life and a way of thinking and an approach to compassion and being more kind of grounded.

Carol and her brother's influence on her spirituality:

I'm not religious or whatever, I absolutely believe in a higher power. And I do believe there's this kind of connection of the dead in some soothing, comforting way. You know, they're present. They're looking out for you. As I said, draw strength from it. Call upon it.

Kevin mentions having a hard time with religion and spirituality after his brother's death:

That's always been one of my big barriers to religious faith. Because I could not trust in a God that would do that. At the very least, God doesn't take part- I read a number of books about this. I've been very interested in it my whole life because I'm trying to, you know- you try to make sense of things that hurt you. Because, you know, it's just like- at 55, it's like you're on the front of the Titanic. You can just see the gleam of the iceberg ahead, you know. And it would be nice to have the faith that everything is gonna be alright. Or to experience something and be reunited with all these people that have gone before. That would be nice. It's wishful thinking, and we all do wishful thinking all the time. There's no- when really hard times come, there's no comfort. And you find yourself praying anyway. When you think you're gonna die or someone you love is in trouble. You know, it's not- there's no comfort. We are not big enough to hold this load, each of us.

Creativity

Anna also sees a connection with her creativity.

I'm sort of a practicing artist. I don't sell my work or anything like that, but I do a lot of creative different things. And maybe that's something that I picked up from him. But as far as creativity goes, maybe just being influenced by his creative soul that he had and just something that I've always had as well.

Carol mentions creativity as well: “But the first thought that came to mind was that in my writing. I’ve written about him in very creative ways.”

Career

For Mollie, she does report that her career choice is different than it might have been, but as far as spirituality or creativity, she sees no impact. “Did their death influence my career choice? I think so. I think I would’ve been an attorney otherwise. (She’s a social worker). I’m probably very un-spiritual actually. Creativity- I’m not very creative either.”

Kevin also reports that the death of his little brother impacted his career choice:

My first career was in medicine. Because that was the big white whale. That was, you know, medicine should have saved him. And there’s nothing more important than your life and your health. And law was a helping profession. And I’m in family law where I try to take care of kids. Definitely medicine was. And then law was a second place really to the practice of being a doctor.

Perceived long-term outcomes of sibling loss

Participants in this study reported many different long-term outcomes to losing a sibling as a child. Some participants reported some similar outcomes and some were unique to their experience. All participants reported some long-term outcome, whether it was a more positive or negative consequence of their loss. Anna and Susan both mentioned how the loss made them appreciate the time they have with loved ones who are still here. Anna said, “I’d like to think that it gives me a more of an appreciation for people.” Susan reported about her loss, “So these experiences- to realize how precious life is and every moment is important with that person.”

Mollie and Carol stated that going through this experience taught them to not take the little things too seriously and focus on what matters. Mollie:

But I feel like I have a real pretty good sense of what's important. You know, big picture, what's important. I sort of cut to the chase. I don't think there is a lot of time to waste. I don't sweat the small stuff.

Carol refers to the experience as making her feels things deeply, and to have more empathy:

And it's allowed me to kind of tap into a deeper feeling about stuff that then I can- I think it's allowed me to be more empathic in general. Reverence for the dead. Respect for death. And a little bit of in your face like- I'm not afraid of this. I think I'm much more empathic.

Mollie and Anna say that the experience has made them more decisive in their adult years. Anna says, "It's made me a really kind of decisive person." And Mollie states, "So I think I- I would say I came out stronger because of it. I think I'm a- I just don't have a lot of time for B.S."

Anna also feels that the loss has set her apart and made her feel different from others.

I guess it's just I feel like I have this experience that some people in the world have had and some people haven't. And it's almost- there's no way you can get that experience unless you've gone through it. It's like losing a limb or something like that. You can't ever know what it's like to not have an arm unless you've lost an arm.

Anna, Kevin, and Angie, 43% of the participants, feel like they expect bad things to happen more than they may have felt if they had not lost a sibling. Anna reports, ". I think it's just impacted the way that I think about the world. And knowing that things are impermanent. And that hard, painful things happen. And they happen all the time."

Kevin echoes her words:

I'm more nervous about kids. I'm more nervous because I know how easily things can go wrong. And I just worry. It's too easy to see the negative possibilities. I think it's made me more pessimistic than I might have been. And more able to see the glass as half empty than half full.

For Angie who lost her sister in a plane crash, she is still unable to trust air travel, especially for her own kids, however she also rarely goes on a plane: "It was all about caution and control and I won't take my kids on airplanes unless I absolutely have to. You know, so planes are probably the biggest thing. I absolutely cannot stand them."

Kevin learned to suppress his emotions watching his parents experience their child's death and reports that he still has problems around this issue:

I think it taught me to suppress emotions because I saw my parents suppressing their grief. And that was not a lesson that helped me in my life. It's something I had to unlearn over the course of many years.

Ben feels that the way his mother overprotected him after his brother's death has had a long-term effect on him. "...So that's what I remember. And that lasted until pretty much she died. And I've had, you know, my various hang-ups about that over the years."

Mollie feels that anger is one of the legacies she still carries from her loss. "And I'm still angry. Today, I'm very angry that my children do not have their uncles. That really bothers me." Ben, although not stating anger reports envy in the fact that he no longer has siblings in his life, when he sees others who still have this relationship:

And I'm sort of envious, you know. And I've said that- how lucky she is. (His wife for still having siblings in her life) And when I hear stories about siblings not getting together or alienating each other, I sort of think to myself and I say to my wife, you know- What a shame, that should never happen really. And you're lucky to have a sister and a brother to relate to. And I feel that I don't.

Carol feels like she has taken on the role of protector more, and this is a long-term outcome, although she is working to not always play that role today:

I really don't like to be dependent on other people. I like to be the one who takes care of them. I don't want them to be the one that takes care of me. So I tend to be more in the protector role now than letting myself be in the protectee role. And I've worked at it so it's more balanced. But all that kind of I think plays back to that death.

Carol also feels that one of the biggest changes in her was how quickly she became an adult, and became that protective person that has lasted so many years.

And that was something that I know happened as a result of my brother dying. That I would kind of always look at what's going on. And having somewhat of a guard up. You know, I was four and a half but I became an adult right then. In that moment. You know, like that before and after. I was- there's a way I grew up.

Continuing bonds

The idea of continuing bonds, or carrying, a way to keep the deceased person in your life in some way, either by reminiscing, keeping photos or mementos, or doing things that remind us of our sibling in our present life was asked of each participant, if they had some way of carrying their deceased sibling with them in their adult lives. Continuing bonds are a way of not forgetting, but no longer being in the deep mourning of grief (Packman, Horsley, Davies and Kramer, 2006). Some had several ways of carrying their sibling with them, while others had only one. Anna and Susan discussed how they still think about their sibling, many years after their death. Anna: "I sort of think about him probably every week. It used to probably be every day. But now he still is in my thoughts." Susan also thinks about him, although not as often as Anna, but as she spoke with this researcher, she became tearful as she recalled her brother:

Well, I think of him. I don't think of him every day. But I think of him when we get together for family functions or family reunion. Or- we have a family picture.

That's sad- now I haven't thought of that for a long time. That's really sad. And we miss him. I miss him. Yeah. So, I do miss him.

Pictures of the deceased sibling was the most common way of continuing the bond. 5 of the 7 participants, or 71% reported that they continued to keep pictures of their deceased sibling in their homes. For example, Ben states:

I have a picture of him- in family pictures that we have on our hallway wall. We have a whole load of family pictures of my wife's side and my side and our kids. And, you know, I see that picture. It's on my way to my bedroom. And I see it almost every night. And that's pretty much how I think about it.

Similar to pictures, two participants, or 29% mentioned keeping mementos of their deceased sibling in their homes. These are things that once belonged to their sibling and remind them of who they were. Angie reports: "Well my oldest daughter, because she's named after her, my mother has been giving her things- little things throughout the years that were my sister's. Mary Poppins doll and rocking chair and all those kind of things." Carol states:

I have things of his. Like I have his Cub Scout stuff. And I have like- I took one of his Cub Scout things that says Truckee on it. And I have it on one of my jean jackets as a little emblem. So there are little things that I have that are little reminders. You know, kind of impromptu shrines kind of crop up.

Anna uses stories to keep and carry her brother in her present life. She tells these stories to people who didn't know her brother, to keep his memory going: "He's a part of my life and even though my husband never met him, he brings him up sometimes. Just from the stories that I've told. And so he's still kind of alive in some ways."

Mollie feels like the people who knew her brothers are special people in her life that helps her to keep her memories alive:

There's not many people left in this world that knew them. So I really value those people that knew the boys. Because a lot of those people- I met after they died. So

there's a core group of people that knew them. And those relationships are extra special to me.

Kevin works on an ancestry tree as a way of remembering his brother: "Well, the ancestry tree that I've been working on for several years that Lisa and I- well, Lisa started and I picked up, that's a way to keep him and other members of my family alive."

Three of the participants or 43%, all of whom had children of their own, talk about continuing bonds in terms of the next generation. For Mollie, she sees her brothers in her own sons:

In my boys, I see my brothers. Especially my four year old. He's got the same freckles that the 13 year old has. My seven year old is never going to play a team sport, just like Jaime. Just like me. So I see my brothers in my children. And I talk to my children- oh, your Uncle Jerry had freckles just like you had. Or- you know, your Uncle John, you know, he was a really good soccer player, too. That kind of thing.

Angie also sees her sister in her own children. Her daughter's middle name also comes from her sister. Angie also mentions telling stories about her sister, and having pictures up as a way of having continuing bonds:

And my oldest daughter has her middle name. And actually looks a lot like her. And apparently I looked a lot like her. One of my kids will do something that reminds me of her. Or one of my daughters has her crazy hair. Probably the most important one was naming my daughter after her. And I tell my kids stories about her. I keep pictures of her up. We call her Auntie Jennifer. They call her Auntie Jennifer as if they knew her.

Both Angie and Carol mention their deceased sibling has being a kind of guardian angel for them in their adult lives. Carol states: "I always have felt like he's, you know, that angel on my shoulder. Especially when I'm having trying times or whatever." And Angie says, "She's never been gone, I don't think. She's all of our guardian angel. I can see her with us all the time."

In the next chapter, the discussion chapter, I will look at each category in the findings chapter, and find correlations from the literature review. I will discuss the implications of my findings. The implications will also be applied to the field of social work, including areas for future research. I will also discuss the limitations of this study, and end with my conclusions.

CHAPTER V

DISCUSSION

The objective of this exploratory qualitative study was learn about the unique stories of adults who lost a sibling in childhood, and how they see that experience playing out in their lives today. Special emphasis was placed on their spiritual, creative and professional lives. Each participant was given the opportunity to tell the story of losing their sibling in their own words. For some this was the first time they had this opportunity. This chapter discusses the findings that came from these dialogues. The categories revealed in the findings chapter will be discussed more in depth in implications. Limitations and future directions for social work is followed by the conclusion.

Implications

Relationships between siblings

All but one of the participants reported that they were close to their sibling before they died. Ben, the one who doesn't remember much about his sibling was the oldest of the seven participants and the most time had elapsed since his brother died, 63 years. This long period between the loss and the interview may have influenced his recollections or lack thereof. It may be that because these participants were self-selected, only those that felt closeness with their deceased sibling were interested after many years in talking about this singular experience.

The literature has shown that the relationship to the deceased is one of the six major contributing factors influencing the impact of the loss of a sibling (Rosen, 1991). It appears that for those who say they were close their sibling when they died, the impact of that loss is felt years after. As Packman, Horsley, Horsley and Kramer (2006) have reported, siblings are one of the few relationships where there is an expectation that the relationship will last nearly a lifetime. The fact that the siblings have lost this relationship, especially at such a young age is profound for some people.

Demographics and situational and environmental factors

Davies (1999) discussed the responses to a sibling's death discussed earlier, and many of them played out with the participants of this study. It was apparent that the individual characteristics, including gender, age, and temperament made a difference in how the sibling experienced their loss. Those siblings whose temperaments were close to their deceased siblings, felt that loss keenly. Situational and environmental characteristics also appeared to make a difference in how the surviving sibling responded to the death. Unintentionally in this study, 5 of the 7 participant's siblings died suddenly in an accident. This situational characteristic may have made a difference in the sibling's response. It must have been overwhelming to have a sibling be with you in one instant, and then suddenly be gone for a lifetime, especially when you are experiencing that as a child.

Grieving

For Anna, Kevin, and Carol, they all vividly remember their families shutting down after their sibling's death, unable to deal with this trauma that shook their family. In all of these cases, the shut down lasted for years. Devita-Raeburn (2004) refers to this

as intact grief. Carol specifically stated that it was not until she went into therapy that she was able to grieve for her brother and like those who, “ in real time appropriately grieve our losses.” As evidence of this she was able to do this years later when her mother died. When her mother died, she mourned the loss as it happened, rather than ignoring it.

Devita-Raeburn encourages us to reclaim our story, and talk about our loss.

When one does this, they can truly grieve and acknowledge what was lost to them. In the process of interviewing participants for this research, some noted that they had never really had this opportunity before to tell their story. The process of this interview was, for some, a way of reclaiming their story.

Packman, Horsley, Davies and Kramer (2004) report grief is being seen in a new way, as work. For some of the participants, the death of their sibling was seen as a way to work out and attempt to understand what it is they experienced at a young age, especially those who didn't get much direction from the adults in their lives. Packman, Horsley, Davies and Kramer (2004) also report that children will suffer needlessly if they aren't allowed to experience their grief. This was apparent in some of the interviews in this study. Some are still suffering from their grief, all of these years later. Kevin and Mollie are still angry. Kevin is angry with God, while Mollie directs her anger more at fate. Susan becomes tearful speaking about her brother. The unspoken grief remains.

Changes in the family/changes in parents

All of the participants remarked on how much the family changed as a result of the death of their sibling. Perhaps the biggest change for the siblings as children were the changes they observed in their parents. One example of this is the “overprotected child” referred to by Crehan (2004). Several of the participants referred to their parents

becoming more overprotective of the remaining children after their loss. Ben, Susan and Mollie mention feeling overprotected by their parents, and how that make a difference in how they were raised. Mollie mentions feeling rebellious, and Susan reported that her younger sister who was more protected than she, became very wild. Ben stated that he had his “hang-ups” from his mother’s over protectiveness.

Crehan (2004) also mentions the absence of the parents after losing a child. Participants discussed how the loss of their sibling meant a loss of their parents as well. Anna particularly feels like she went from a middle child to an only child who had also lost her parents because they were so traumatized. It’s as if the family is sailing on a boat, and with the loss of one of it’s members, the boat loses it’s ability to remain on an even keel, and the remaining family members are left scrambling to find their equilibrium. Carol mentions this kind of “before and after” scenario to her family in relation to the trauma they suffered. The family needs to redefine itself after the loss.

Robinson and Mahon (1997) report that sibling bereavement must be seen in the context of the family. All of the participants discussed how the family changed with this trauma, and how these changes impacted them for all their lives, and indeed shaped the way they relate to others now in their own families. Their past experience also influences how they respond to trauma. Kevin mentions this in how he still has difficulty knowing how to respond to traumatic events, and this he learned from his parents. Kevin also discusses how he has trouble in expressing his emotions, which he believes he learned from his parents in watching their response to his brother’s death.

Coping

Some of the participants were better able to cope with their loss than others, as were some families better able to cope. Two participants had outside help, and the loss was discussed. Other families closed down, unable to talk about their loss or even look at it, pretending that it didn't happen, as was the case with Anna. It appears that most of the participants interviewed did not have very good coping skills at the time of their loss, nor did their family.

Some of the coping techniques mentioned in the literature (Andrews and Marotta, 2005; Packman, Horsley, Davies and Kramer, 2006) include creating containment, and respecting the individual styles of coping for the mourner. Unfortunately for the participants in this study many of the ways that have been developed for children to help process their grief were simply not around at the time of their loss. The participants in this study lost their sibling between 29 to 63 years ago. There simply was not much research being done in the field of grief work. Indeed, grief and bereavement as a disorder are only now being introduced into the DSM V (Zhang, El-Jaawahri and Prigerson, 2006). Families coped in the best way they know how, and for those that were not as well resourced, the suffering was greater because of their inability to cope. It appears that in terms of coping, in some ways it was a matter of luck in terms of being born into a family within a strong community, church, or extended family. For those who were born into a family that was more isolated, like Anna's family, there were not as many coping tools available. These families appeared to have a harder time coping with their loss.

Guilt

Rosen's 1986 study found that 50% of the research participants felt some guilt about their sibling's loss. While some of the participants mentioned guilt during their interview, it was not a predominant theme. Some mentioned other people having more guilt about the death of their sibling, such as other siblings or parents. Anna mentions her sister having a lot of guilt because she wasn't there when her brother was killed, and that this guilt lasted for years. "That's just how she carried it. And I think that's something that she carried all her life and it's affected her psyche. Where I don't feel guilty about it." However, Anna goes on to say that she does feel guilty about her rebellious teenage years that followed. "I used to feel guilty about being such a crappy teenager and doing all those drugs and hanging out with those derelicts."

Charles and Charles (2006) state that guilt over the lost object can lead to avoidance of intimacy because one fears being responsible for the death of another love object in the future. People feel guilt be for the death of their loved one, and don't ever want to be put in this situation again. And so they avoid ever being in danger of an intimate relationship again. In this research, there were no examples of this, and all of the participants were in long-term relationships and had intimacy in their lives.

Life and death

Experiencing death at such a young age made all the participants noticeably more aware of life and death than their peers. They gained knowledge that other children their age did not have, and they felt this difference. When the participants talk about the 'before and after' aspect of the loss, part of it seems to be this awareness of death, and that things don't last forever. For some, like Mollie, this meant not taking things for

granted, and “not sweating the small stuff.” In a way, it seems that the loss of their sibling made them grow up and gain a healthy respect for life and death that may not have happened otherwise. Whether they view this as a positive or negative is debatable. Some appreciate having a better sense of reality, while others feel burdened with this knowledge. As Kevin says, “Death just seems like a bad flaw in any kind of a plan for conscious beings.”

Davies (1999) states that children who grow up in the western world have less direct experiences of death than in many other cultures. Those who lose a sibling in childhood are usually unique among their peers, and siblings of deceased brothers or sisters remark on this difference. They have a direct experience of death that most of their peers have not had yet. Davies (1999) also reports that one of the long-term outcomes of losing a sibling in childhood is an appreciation for life, and those who they care about. This was certainly the case for some of the participants in this research.

Differences between religious and secular families

Two of the participants discussed using their religion as children to help them get over the loss of their sibling; Susan and Angie. They were both raised in Catholic households. Rosen (1986) reports that, “There was a tendency for siblings from Catholic families to communicate more frequently about the loss than children from Protestant or Jewish families.” In this study, although small the same tendency appears to be true. Future research could use a larger sample and explore this potential relationship more closely.

Kevin and Mollie reported that they both felt angry about the loss of their sibling, and Kevin in particular stated being angry at God. The literature also cites examples of

siblings who became angry at God for the loss of their sibling (Batten and Oltjenbruns, 1999). Kevin and Mollie were both raised in secular families. It would be interesting to explore if those who were angrier felt this way because they did not have the structure of religion or spirituality as children to help process these strong emotions.

Spirituality/religion/creativity/career

Batten and Oltjenbruns (1999) define spirituality as, “the human quest to understand life’s meaning.” Forty-three percent of the participants talked about the death of their sibling affecting their spiritual lives. For Anna and Carol, it appears that this impact has been a more positive one. The experience compelled them to more fully pursue that quest to understand life’s meaning. But for Kevin, the experience made him angry at a God that would allow such a thing to happen. The anger continues to this day. As Packman, Horsely, Davies and Kramer report, the search for meaning to a sibling’s death can take years, and is constantly ongoing (2006). Kevin is still searching for that meaning.

In terms of creativity, Pollock states that, “the positive outcome of the mourning or liberation process is creativity” (1978). Carol has used this experience to develop her writing. The experience is like a catalyst to her creativity. Anna also talks about how she has inherited some of her creativity from her creative brother, almost as if she is carrying the torch of creativity for him. He appears to have had an influence on her own creative process. Perhaps for her the positive outcome of the loss of her sibling was her own creativity. Both Carol and Anna suggest this possibility.

Several participants felt that their career choice was impacted by the experience of losing a sibling in childhood. Mollie and Kevin specifically mentioned this. In these

cases the career of choice had to do with helping others, such as social work and medicine. For some, the experience of this loss may make one feel like helping others who find themselves in similar situations.

Perceived long-term outcomes

All the participants reported a long-term outcome to their sibling loss in childhood. Some are more positive such a greater appreciation for life and those they care about, not taking things too seriously, and having more empathy. Other, less positive long-term outcomes include being anxious about loved ones, anger at God, and suppressing deep feelings, something that was learned from parents, as in the case of Kevin. Anna mentioned feeling different from her peers, something also referred to in Davies study (1999).

This qualitative study was unique to most previous studies in that the years that had elapsed since the loss was quite long therefore looking at perceived long-term effects was feasible. The shortest time since the loss was 29 years, and the most was 63 years. In Davies study (1991) the most years that had elapsed since the sibling's death was 28 years. Ben, whose brother died 63 years ago, remembered the least of all the participants, having difficulty remembering his brother before he got sick, even though he was 9 years old at the time of the death. Carol, who was the youngest when her brother died, at only 4 and ½ years old, still has quite vivid memories of her brother. Again, the individual, environmental and situational factors play a role in the sibling's response (Davies, 1999).

Davies mentions several long-term outcomes of sibling loss. Among those are feelings of maturity at an earlier age, and feeling different (Davies, 1991). Anna mentions feeling different from those around her after losing her brother. She felt she

knew something that they did not know. Davies also discusses adult depression (Davies, 1991). While none of the participants discusses depression directly, they do discuss difficulty with emotions, feeling angry, as in the case of Kevin and Mollie, or being unable to discuss their emotions and feelings of grief as in the case of Carol and Kevin.

Rosen (1986) mentions that during her interviews, some of the participants stated that they had never talked about their experience before talking with Rosen. Several participants mentioned before the interview that they had never had much opportunity to talk about their experience, and often felt awkward if it came up in conversation. 86 % of the participants stated that they appreciated the opportunity to talk about this part of their life experience. It felt as if they were all a part of a unique group of adults who had experienced something quite profound at a very young age.

Crehan (2004) and Charles and Charles (2006), both mentioned the possibility of relationship problems as a result of losing a sibling in childhood. None of the participants mentioned this issue. 86% of the participants are in long-term relationships, with one being a widow from a long marriage. In this study, this appeared to not be the case. 57% of the participants have children of their own, and although some participants mentioned some fear around the safety of their children, it didn't appear to affect their having children of their own.

Continuing bonds

Continuing bonds as defined by Packman, Horsley, Davies and Kramer (2006) states that, "despite the permanence of physical separation, the bereaved remains involved and connected to the deceased and can be emotionally sustained through continuing bonds." This is seen as a shift in ways of bereaving. All of the participants

had some way of carrying their sibling into their present life such as keeping pictures, mementos, or telling stories about their deceased sibling. The most common way of creating continuing bonds was with pictures or mementos of their deceased sibling.

Angie mentioned dreams that she had had of her sister as a way of continuing the bond.

This is mentioned by White (2006) as a way of carrying a sibling into the present.

Kempson, Conley and Murdock (2008) define continuing bonds in post-modernist terms. Rather than resolving the loss and moving on, it is a state of being, always a part of who you are. It becomes integrated into the person you are as an adult. Carol describes integrating her loss, and learning how to grieve, “in real time” although it was a process of many years. She states that when her mother died a few years ago, she was able to feel the grief as it was happening, and then integrating it into her present life. She learned this after her experience with her brother’ death many years ago. She discovered that it was better to grieve in real time, rather than deny the reality of her feelings.

For Kevin, the trauma of losing his brother still appears to not be resolved. He is still angry about his loss, and cannot understand it. Charles and Charles (2006) state that if the grief is not resolved it can be passed along to the next generation. For this study, those participants with children mentioned them in relation to continuing bonds. They talked about their sibling with their children, or that their children reminded them of their deceased sibling in some way, either physically, or in the way they talked, or their abilities in sports. It didn’t appear that the grief was being passed down to the next generation, at least in the discussions for this interview. Perhaps more directed questions about this specific area would bring forth more definitive conclusions in this area. Mollie

reported her anger that her children would never know their two uncles, although she didn't specifically state discussing this with her children.

Kempson, Conley and Murdock (2008) also discuss this, referring to it as transgenerational grief. But they also state that these ghosts can have a positive or negative impact on the surviving sibling. For most of the participants in this study, the impact appears to be positive. The question of whether the self-selection method used in recruiting participants for this study influenced this positive outlook is a question that could merit further study.

Limitations and directions for clinical social work research

During the process of this research, broader questions addressing issues for clinical social work became apparent. Although the topic of sibling loss in childhood was the subject for this qualitative thesis, it became evident to this researcher that the topic of trauma in childhood and how one deals with this trauma, and how the family deals with trauma is important to study for those social workers working with distressed families.

Although it was not a part of this study, it became apparent to this researcher that narrative theory would be an excellent approach if working with these kinds of families. After hearing the stories of these adults, it was clear that certain stories were being told about the trauma that were often not healthy for the family or the individual. Those who were able to reframe their story and talk of their sibling relationship in healthy ways, not just focus on the loss, were able to integrate their experience more fully and carry their sibling with them through their adult life in an uplifting way rather than remaining angry for much of their lives.

In narrative therapy, it is believed that 1) Stories shape experience, 2) individual stories are embedded in and shaped by family and culture, and 3) interactions create enactment of particular stories (Madsen, 2007). Long after the sibling is gone, the stories remain. How is it decided which stories will be told, what will be left out, what will be given more emphasis? Yes, these losses are heartbreaking, but they need not weigh us down for the rest of our lives. Narrative theory is a way to change our relationship to our stories. They are still our stories, but they empower us, rather than keeping us from our best selves.

The participants in this study experienced the trauma of losing a sibling in an earlier era when there was not much support or even understanding of how to support families when they were hit with such a profound loss. Families were pretty much expected to fend for themselves. This era was also a time when the extended families of the previous generation were the exception rather than the rule, as was the case for most of the participants. Extended family members or support from their church or community were no longer assured. Because of this, the individual characteristics of the participants, the resilience of the family, as well as situational characteristics often determined the outcome of losing a sibling in the long term (Davies, 1999). There are so many variables that determine the outcome of a trauma within a family, so much so that it is difficult to make generalizations from this small exploratory, qualitative study.

In terms of this study, it was evident that as traditional supports for families continue to wane, the role of the social worker for families can be instrumental in helping children and their families cope with trauma. It would be useful in future studies to compare differences in responses based on age, gender, religious background, and

community involvement. As this was an exploratory study and the sample size was small, it was impossible to make definitive statements, although the opportunity to tell the stories, sometimes for the first time, was perceived as useful. There has not been much study in exploring the long-term affects of sibling loss or other traumas over many years. Hopefully in the future this area can be explored further with a larger sample.

The findings show that many of the participants feel the experience of their loss many years after it occurred, and it changed who they would become as adults in some ways. Of course it is impossible to say in exactly in what ways because many other events happened in each person's life that changed who would become as well. Some of the participants remarked on this as well, stating that they weren't sure if it was the loss of their sibling or some other factor that made them explore their creativity for example. If we are the sum of our experiences, it would seem that those that are most profound would have the largest effect on who we are.

Further study that would be useful for social workers would be to interview a larger sample size of adults who lost a sibling in childhood using narrative theory as lens to explore their stories. Through this research it became apparent that stories can become static in a family system as they get told over and over again. One character gets cast as the depressed mother who never recovers, another the angry son who will never understand. If it is true that stories shape experience (Madsen, 2007), how would things change if the stories were changed?

Conclusion

This research project was started as a specific idea, prompted by the researcher's own personal experience of having lost a sibling in childhood to death. As the work

progressed it became more and more apparent that the real interest lay in how or how not adults integrate trauma from childhood into their adult lives. While this study focused on childhood sibling loss, the stories could also be significant for anyone who experienced some sort of childhood distress. In the future, it would be informative to use narrative theory to explore the impact of childhood trauma on individuals and families. And beyond the individual, it is as essential to look at whole families and how they process a trauma within their system. This thesis project has developed into a jumping off point to further study the long-term impact of loss, and how best to integrate these experiences in a post-modern sense, and not leave them behind us, but have them become a part of who we are, and not to ignore or deny, but to integrate them into our own narrative.

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Appendix A

Human Subjects Review Approval Letter



Smith College
Northampton, Massachusetts 01063
T (413) 585-7950
F (413) 585-7994

February 17, 2010

Laura Miles

Dear Laura,

Your amended materials have been reviewed and they are fine. It is really helpful that the people at Piedmont Gardens are being so helpful. You have added some good questions that are well focused on your main question. However, we didn't mean you necessarily had to delete the ones about the impact of the death on the family. That may also contribute to your understanding of the impact of the loss on them as adults. You certainly can put some or all of those questions back in.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your project. I do urge you to find the Michael White material on loss.

Sincerely,

A handwritten signature in cursive script that reads "Ann Hartman | Ph.D.".

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Pearl Soloff, Research Advisor

Appendix B

Demographic Questions

Age:

Gender:

Ethnicity:

Work or Profession:

By whom were you raised?

Who did you live with growing up? (ie. Mom, Dad, brothers and sisters.)

What is your living arrangement now?

Spiritual or religious orientation growing up:

Spiritual or religious orientation presently:?

Your age when sibling died:

Age of sibling when they died:

Appendix C

Interview Questions

1. Describe your relationship with your sibling before they died.
2. Describe your experience of the death of your sibling, focusing on your personal experience of this event.
3. In what ways did you and your family experience the grieving process?
4. How did this loss change your relationships with other family members?
5. In what ways do you still feel a connection to your lost sibling? How does this play out in every day life?
6. Are there specific ways that you use to remember and keep your deceased sibling in your life now? Describe.
7. In what ways has losing a sibling to death during your childhood impacted your career choice? Creativity? Spiritual or religious practices?
8. How has this loss changed the way you relate to others in your life now?

Appendix D

Informed Consent Letter

Dear Research Participant,

My name is Laura Miles, and I am a graduate student at Smith College School for Social Work. I am conducting a research project designed to explore the experiences of adults who lost a sibling to death in childhood, and if and how that experience may have impacted them throughout their lives. This exploratory study will investigate the continuing bonds felt by the remaining sibling, and what role, if any, the deceased sibling plays in the remaining sibling's life, especially pertaining to their creative and spiritual lives. You have been asked to participate in this study because you have lost a sibling in childhood, when both of you were still living at home with your family. This study will be presented as a thesis, for the Master's of Social Work degree at Smith College School for Social Work, and may be used in possible future presentation or publication on the topic.

As a participant, it is understood that you have lost a sibling when both of you were between the ages of 6-18 years, and you were both living in the same home. You must currently be over 21 years of age. When we go over the consent, I will answer any questions you may have and then if you choose to participate, you will sign the form and then fill out a brief demographic survey which will ask your age, gender, ethnicity, profession, spirituality or religion, and some questions about your family of origin. Next, I will ask you to sit for an audio taped interview with me that will last approximately 45-60 minutes. The interview itself will consist of semi-structured questions focusing on your experience, and memories of losing a sibling, and the impact of that loss on you life today. I will travel to a mutually agreed-upon location that is private and convenient for you. If I use a transcriber, he/she will sign a confidentiality agreement.

Participation in this study may trigger strong feelings related to your loss, even though it happened years ago. It may be helpful for you to discuss any issues that arise as a result of this interview with a professional mental health clinician. If you feel a need for support, a list of referrals is included.

While there will be no financial benefit for taking part in the study, participation will allow you to share your knowledge and experience about losing a sibling in childhood. Your contributions will provide important information that may be helpful in furthering the knowledge of loss in general, and sibling loss in particular. From a personal perspective, participating in this study is an opportunity to explore the ways in which your deceased sibling helped to make you the person you have

become. The potential personal insight is a significant benefit to participating in this study.

Your confidentiality will be protected in a number of ways. The data from the interview will be separated from names and phone numbers as part of the confidentiality plan. You will not be asked to identify your name while the tape is running, and you are asked not to include any identifying information in any examples of case material you may use. My research advisor will not have any access to the data until all identifying information has been removed. I will keep the consent form including any contact information such as phone numbers, names, and email addresses, the demographic questionnaires, tapes, transcripts, and other data in a locked and secure environment for three years following the completion of the research, consistent with Federal regulations. After that time, all material will be kept secured or destroyed. All data will be destroyed when it is no longer needed.

Participation in the study is entirely voluntary. As a voluntary participant, you have the right to withdraw from the study at any time – before, during, or after the interview – without penalty. You may withdraw from the study up to two weeks after the date of your interview. If you withdraw, all of the material related to you will be destroyed. If you need to contact me to withdraw, or have any questions or concerns, I can be reached at the phone number or email listed below. If you need to reach the Human Subjects Review Committee, they can be contacted at Smith College for Social Work, Lilly Hall, Northampton, MA 01063.

YOUR SIGNATURE BELOW INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION; THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Signature of Participant

Date

Signature of Researcher

Date

Thank you for participating in this study. If you have any questions or would like to withdraw from the study, please contact:

Laura Miles
(xxx) xxx-xxxx
xxx@smith.edu

Please keep a copy of this consent form for your records.

You may also address any concerns to the Chair of the Human Subjects Review Committee of the Smith College School for Social Work at (413) 585-7974.

Appendix E

Professional Transcriber's Assurance of Research Confidentiality

STATEMENT OF POLICY:

This thesis project is firmly committed to the principle that research confidentiality must be protected. This principal holds whether or not any specific guarantee of confidentiality was given by respondents at the time of the interview. When guarantees have been given, they may impose additional requirements which are to be adhered to strictly.

PROCEDURES FOR MAINTAINING CONFIDENTIALITY:

1. All volunteer and professional transcribers for this project shall sign this assurance of confidentiality.
2. A volunteer, or professional transcriber, should be aware that the identity of participants in research studies is confidential information, as are identifying information about participants and individual responses to questions. Depending on the study, the organizations participating in the study, the geographical location of the study, the method of participant recruitment, the subject matter of the study, and the hypotheses being tested may also be confidential information. Specific research findings and conclusions are also usually confidential until they have been published or presented in public.
It is incumbent on volunteers and professional transcribers to treat information from and about research as privileged information, to be aware of what is confidential in regard to specific studies on which they work or about which they have knowledge, and to preserve the confidentiality of this information. Types of situations where confidentiality can often be compromised include conversations with friends and relatives, conversations with professional colleagues outside the project team, conversations with reporters and the media, and in the use of consultants for computer programs and data analysis.
3. Unless specifically instructed otherwise, a volunteer or professional transcriber upon encountering a respondent or information pertaining to a respondent that s/he knows personally, shall not disclose any knowledge of the respondent or any information pertaining to the respondent's testimony or his participation in this thesis project. In other words, volunteer and professional transcribers should not reveal any information or knowledge about or pertaining to a respondent's participation in this project.
4. Data containing personal identifiers shall be kept in a locked container or a locked room when not being used each working day in routine activities. Reasonable caution shall be exercised in limiting access to data to only those persons who are working on this thesis project and who have been instructed in the applicable confidentiality requirements for the project.

5. The researcher for this project, Laura Miles, shall be responsible for ensuring that all volunteer and professional transcribers involved in handling data are instructed in these procedures, have signed this pledge, and comply with these procedures throughout the duration of the project. At the end of the project, Laura Miles, shall arrange for proper storage or disposition of data, in accordance with federal guidelines and Human Subjects Review Committee policies at the Smith College School for Social Work.

7. Laura Miles must ensure that procedures are established in this study to inform each respondent of the authority for the study, the purpose and use of the study, the voluntary nature of the study (where applicable), and the effects on the respondents, if any, of not responding.

PLEDGE

I hereby certify that I have carefully read and will cooperate fully with the above procedures. I will maintain the confidentiality of confidential information from all studies with which I have involvement. I will not discuss, disclose, disseminate, or provide access to such information, except directly to the researcher, Laura Miles, for this project. I understand that violation of this pledge is sufficient grounds for disciplinary action, including termination of professional or volunteer services with the project, and may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

Signature: _____ Date: _____

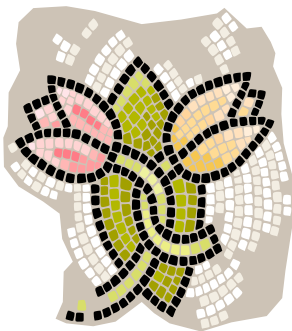
Laura Miles: _____ Date: _____

Appendix F

Letter from Piedmont Gardens

Appendix G

Recruitment letter for Piedmont Gardens Residents



Did you lose a sibling when you were a child?

Dear Piedmont Gardens Resident:

Hello! My name is Laura Miles and I'm the daughter of resident xx. I am a Master's of Social Work Student from Smith College, and am doing a research project on the topic of sibling loss in childhood. I am looking for people to interview on this topic. If you lost a sibling when you were between the ages of six and eighteen, and you would like to talk about your experience, and how it affected your adult life, please contact me! I have times available on Wednesdays or weekends to interview people here at Piedmont Gardens.

If you, or someone you know, might be interested, please contact Laura Miles at:

xxxxxx@smith.edu



Thank You!

Appendix G

Low-Cost Referral Sources

Integral Counseling Center

2140 Pierce Street, San Francisco, CA 94115 415.776.3109

info@integralcounseling.org

San Francisco Psychotherapy Research Group

9 Funston Avenue, The Presidio

San Francisco, CA 94129

(415) 677-7946, ext 1

www.sfprg.org

Oakland Center for Holistic Counseling

2501 Harrison Street

Oakland, CA 94612

510.444.3344

www.jfku.edu/counseling_centers

Jewish Children and Family Services

Serving San Francisco, Marin, Sonoma, and the Peninsula

San Francisco Office: Miriam Schultz Grunfeld Professional Building, 2150 Post St. (between Scott and Pierce), 415-449-1200

Palo Alto Office: Koret Family Resource Center, 200 Channing Avenue, 650-688-3030

San Mateo Office: Eleanor Haas Koshland Center, 2001 Winward Way, Suite 200, 650-931-1800

San Rafael Office: Dr. George Sugarman Swift Building, 600 5th Ave., 415-491-7960

Santa Rosa Office: 1360 North Dutton Ave., Suite C, 707-571-8131

www.jfcs.org/services/individuals-couples