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Sibling Legacy: Stories about and Bonds Constructed with Siblings Who Were Never Known

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Sibling Legacy:
Stories about and Bonds Constructed with Siblings Who Were Never Known

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ABSTRACT

The death of a child shatters what many theorists think of as firmly held family constructs and there are few available cultural scripts to manage such a loss. The effect of that loss has a long lasting ripple effect on the family. Bereaved individuals, including, if not most especially bereaved parents, often appear to desire to maintain a symbolic connection to their deceased loved one in order to minimize the pain associated with the loss and to affirm that the deceased person’s life (however short) had meaning and purpose. Continuing Bonds Theory best captures this experience. But, what of family members who did not know the person who died, children born subsequent to the death? What is their relationship to the deceased child and what meaning does it hold for them?

Families are the locale not only where much of our most intimate grief work occurs, but also where children first do identity formation and meaning making. This study offers a new way of looking at how families grieve together, exploring family grief expression over the long term from the experience of siblings who did not know the child who died. It is from the perspective of individuals who indirectly experienced the loss. Participants were raised in a family that lost a child, but did not directly experience the loss. I interviewed 49 adults who had lost a sibling. The participants were either not yet born or younger than the age of 3 when their brother or sister died. This qualitative study attempts to better understand how symbolic relationships are constructed, the meanings of those symbolic relationships for the subsequent siblings, and the bearing, if any, there is on the siblings’ identities.

This research study adds to scholarship in the field of Sociology of Death regarding memory work, construction of symbolic relationships, and meaning making in families following
the loss of a child. Memory work is done in social interaction, where actors construct memories that provide support to present identities or choices of action. Each of the participants had some sort of symbolic relationship to their deceased sibling. In this study, I catalog various images of the participants’ deceased brothers or sisters whom they never knew in life, and the varying ways that they have or continue to interact with that symbolic other. Finally, I categorize ways that participants have felt influenced personally by the story of the loss, and the cultural meanings they attribute to the loss.

This study also contributes to the discussion of whether we continue to live in a death denying culture. In spite of shifts in attitudes toward death, such as the palliative care and hospice movement, there is little in our culture that addresses the meaning of dying children. This study describes ways that some families have negotiated strategies to memorialize, honor, and remain symbolically connected to the child who died, each to varying degrees.
ACKNOWLEDGMENTS

The initial idea for this study came from my work with bereaved families, their early struggles after their child or sibling died, and my witness to their amazing endurance and growth. From that work, I began to wonder about the long-term, what happens after the first year or two of adjustment to life without a cherished, innocent child.

I would like to first acknowledge the participants in this study, who shared their stories about growing up in a family who lost a child. Thank you all for your honesty and vulnerability. Your siblings’ legacies carry on.

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CONTENTS

ABSTRACT ........................................................................................................................................ ii

ACKNOWLEDGMENTS ......................................................................................................................... v

FIGURES AND TABLES ....................................................................................................................... ix

CHAPTER ONE ................................................................................................................................... 1

Relationships within Families Following the Loss of a Child: Studying Constructed Symbolic Relationships ............................................................................................................................ 1

INTRODUCTION ................................................................................................................................. 1

THEORETICAL BACKGROUND ......................................................................................................... 5

Symbolic Interactionism ................................................................................................................... 6

Social Constructionism .................................................................................................................... 9

Continuing Bonds ............................................................................................................................ 12

FAMILIES AFTER DEATH OF A CHILD ............................................................................................. 15

Family members co-construct the image of and bond with the deceased ............................................. 17

Family members co-construct the meaning of the death ..................................................................... 20

Family members co-construct newly formed individual and familial identities ................................. 21

Family members negotiate emotional behaviors ............................................................................... 24

SUMMARY AND RESEARCH QUESTIONS ....................................................................................... 25

CHAPTER TWO ................................................................................................................................... 27

Methods ............................................................................................................................................. 27

METHODOLOGY ............................................................................................................................... 27

RECRUITMENT ................................................................................................................................... 27

ETHICAL CONSIDERATIONS ........................................................................................................... 29

PARTICIPANTS ................................................................................................................................... 29

Demographic Representation ........................................................................................................... 32

Who died? .......................................................................................................................................... 33

INTERVIEW ....................................................................................................................................... 34

DATA ANALYSIS ............................................................................................................................... 34

CHAPTER THREE ............................................................................................................................... 37

“Whatever the Memories are”: Narratives and Rituals that Sustained the Sibling Legacy 37
MEMORY WORK.......................................................... 39
RESPONDENT DESCRIPTIONS OF FAMILY COMMUNICATION STYLES ...... 42
NARRATIVES OF SIBLINGS WHO DIED........................................ 46
  Identity .............................................................................. 46
  Morals Shared ..................................................................... 50
  Rituals ................................................................................ 56
  Remembrances .................................................................... 61
SUMMARY AND CONCLUSION.................................................... 64
FOUR..................................................................................... 67
“There but not there”: Symbolic Relationships with Siblings Never Known .... 67
RELATIONSHIPS WITH A DECEASED SIBLING ................................ 70
  Spiritual ............................................................................. 71
  Familial ............................................................................... 76
  Legacy ................................................................................ 80
CONTINUED BONDS VERSUS A CONSTRUCTED BOND WITH SYMBOLIC OTHERS...................................................... 84
SUMMARY AND CONCLUSION.................................................... 86
CHAPTER FIVE ........................................................................ 89
“NO PURPLE HAIR”: Meaning of the Loss for Subsequent/Surviving Siblings .... 89
SIBLING GRIEF ....................................................................... 90
GRIEVING FOR A SIBLING NEVER KNOWN.................................... 91
  No Reaction ........................................................................ 92
  Sadness .............................................................................. 92
  Guilt .................................................................................. 93
  Empathy for Parents or Sibling who Died ................................ 94
  Longing for Sibling ............................................................ 95
MAKING SENSE OF THE LOSS ................................................... 99
  Spiritual ............................................................................. 100
  Science .............................................................................. 102
EFFECT ON RESPONDENT’S IDENTITY ...................................... 104
FIGURES AND TABLES

Table 1 .......................................................... 31
Figure 1 .................................................................. 33
Figure 2 .................................................................. 42
CHAPTER ONE

Relationships within Families Following the Loss of a Child:

Studying Constructed Symbolic Relationships

“It is important to face the question of persons who have no corporeal reality, as for instance the dead, characters of fiction or the drama, ideas of the gods and the like. Are these real people, members of society? I should say that in so far as we imagine them they are.”

(Cooley)

INTRODUCTION

“Yes, my mom you know always made us aware about her and she always talked about her birthday and things and we always went to the cemetery, and we continue to go to the cemetery you know on her birthday and Memorial Day, even though my parents have passed away. She’s still a part of our lives even though she’s not here.” ~ Caroline, a 53 year old woman, whose older sister died at the age of 9 from pneumonia, prior to Caroline being born.

The dead are real people (Cooley 1902). This study examines how deceased persons become real in that others imagine them, interact with them, and that they subsequently influence our identities and behaviors. The way I chose to look at this phenomenon was through the stories told by people who had a sibling die that they never knew. The participants in this study were either not yet born, or were too young to remember, when their brother or sister died. This research can inform how other symbolic relationships form and influence us. More specifically,
this study looks at how symbolic relationships with the dead are formed through memory work with others, categorizes images of that symbolic other and the ways in which participants interacted with their memory of their deceased sibling, and finally, identifies themes of meanings attributed to the loss by the participants.

A symbolic other exists figuratively in our minds. Another symbolic image held by many is an image of God. Grossoehme et al. (2011) and Sharp (2010) have studied how people have interacted with God through written or spoken prayers in order to better cope in times of trouble. It is through our interactions with others, and based on the larger culture’s available symbolic images, that we form images of God (Stone 2004). A never known deceased person similarly lives in our minds only, via the memories shared by others.

Memories are more than a recall of past events. Memory-work is done in social interaction with others. Memories are stories told that inform who we are in relation to others, including the wider culture, and are often told as narratives with lessons in mind (Baddeley and Singer 2010, Fivush et al. 2004, Neimeyer, Klass, and Dennis 2014). Lessons from memories inform future behavior, including accepted emotional responses to loss (Fivush et al. 2004). Participants in this study shared memories of their brothers or sisters whom they never knew in life, as told to them by other family members. The memories chosen highlight the importance of that deceased sibling to the family or to themselves as individuals. This study explores how memory-work in families, their stories and rituals, contribute to constructed bonds between the participants and their deceased siblings, and also informed the participants’ understandings of the loss.
Neimeyer theorizes that meaning making is the central process for grievers in their adaptation to loss (2001). It is through interactions with others, usually and most especially our family, that individuals attempt to make sense of the loss. “Individuals do not grieve in a vacuum. They make sense of their experience by interacting with others” (Nadeau 2001: 96). Nadeau’s study of family construction of meaning after death found that the main strategy used by families in their joint meaning making was storytelling (2001: 101).

Many parents who have lost a child have struggled with the question of how many children they now have. Do they still count the one who was lost? In my experience as a bereavement coordinator for a pediatric hospice, parents generally do continue to consider that child as a member of the family, just no longer physically present. The question is how that fact affects the other members of the family, even future members of the family who never knew the child who died.

The death of a child is undoubtedly the worst loss one might experience, whether that was your own child, grandchild, or sibling. The death of a loved one affects us both systemically via our relations with others and individually via our sense of self. In turn, we respond to death based on the culture in which we live (Neimeyer, Klass, and Dennis 2014). Current grief theorists suggest that after a child dies, family members negotiate and construct the meaning of the death, the memories of the deceased child, the relationships or bonds with that decedent and self-images as they relate to the loss (Buckle and Fleming 2011, Klass 1997, Riches and Dawson 2000).

Current grief theories describe continued bonds with deceased loved ones as both typical, especially for bereaved parents, and as associated with healthy bereavement adaptation (Field
Continuing a connection with someone who has died, based on the lived relationship with that individual, is what theorists mean by continuing bonds. However, I explore bonds that develop between family members who did not have a lived relationship with the decedent. Specifically, I explore the relationship between subsequent siblings (siblings who were born after a child in the family died or who were too young to have any memories of the child who died) and the dead child. Through interactions with others in the family, such as story sharing, memorializing or commemorating activities, constructed relationships developed even where no remembered lived relationship exists.

Social constructionism contends that our realities develop through our interactions with others. A relationship between siblings who in life never knew each other would be an example of a constructed reality. By examining categories of such symbolic images and relationships, we may better understand the means by which individuals construct symbolic relationships and the significance of those relationships for their identity and behavior. Clinically, it would be helpful to better understand the meaning of a loss for subsequent members of a family. After the loss of an offspring, parents can be consumed with grieving, sharing memories, and searching for meaning. It is important to explore the impact of their mourning on other members, even subsequent members, not identified or even thought of as potential griever at the time of the loss. This will allow bereavement professionals to provide knowledgeable guidance at the time of the loss when supporting grieving individuals.

I divide this introductory chapter into three sections: theoretical foundations that frame my study, a summary of what research tells us about the family system after the death of a child, and then an introduction to my study of siblings born subsequent to the death of a child. First, I analyze symbolic interactionism, social constructionism, and continuing bond theory as they
relate to child loss within families. I then survey the literature that examines the effect of child loss on the family system, focusing on negotiating the meaning of the loss, and on parental and sibling identities, family boundaries, and the ensuing symbolic relationship with the deceased child. Finally, I introduce my study. I interviewed subsequent members of families bereft of a child in order to better understand how symbolic relationships are constructed, the meanings of those symbolic relationships for the subsequent siblings, and any bearing on the siblings’ identities. Current death scholars argue that contemporary (Anglo) societies offer some cultural scripts to manage our discomfort and denial of death (Seale 1998), such as the hospice or palliative care movement which bring death or dying talk out of the closet (Clark 2013, Leming and Dickinson 2007). However, in spite of some available roles for the dying to remain socially connected (Seale 1998), children who die remain an out of order death (Rando 1986), marginally recognized by even the palliative care movement (Clark 2013: 96), and therefore a dilemma for families who experience such a loss. My study describes the ways in which family members collectively remember a child who has died; and explores the meaning making and effect of that loss on members of the family who did not have a lived relationship with the deceased child.

**THEORETICAL BACKGROUND**

The dead remain influential members of society. Their existence continues to shape us and through us shape society. Both past and present members of society help shape our current social reality. This first section details the theoretical foundation of the paper – symbolic interactionism, social constructionism, and continuing bond theories.
Symbolic Interactionism

Symbolic interactionism, as its name implies, focuses on the meanings attributed to objects as well as the sharing and negotiation of those definitions through social interaction (Blumer 1969; Cooley 1902; Mead 1912). Our understanding of the world in which we live and of how to behave in that world comes from our communication with others. Social interactions not only help us understand our world, but it is through social interactions that we continue to create and shape our world. “The environment consists only of the objects that the given human beings recognize and know… [and] objects (in the sense of their meaning) must be seen as social creations – as being formed in and arising out of the process of definition and interpretation” (Blumer 1969: 312). Interactions between actors facilitate the creation or maintenance of meanings. During these interactions, larger cultural and societal beliefs influence individuals, while at the same time “it is through social interaction in everyday situations that individuals work out the details of social structure” (LaRossa and Reitzes 1993: 144). In other words, there is a reciprocal relationship between society influencing the beliefs and behaviors of individuals; and conversely, individuals through their negotiation of meanings, influencing societal arrangements (Blumer 1969; Mead 1912). In my study, interactions with other family members while growing up informed the participants’ images of the deceased siblings and what those relationships meant to the participants. The images and meanings also were a reflection of symbolic images available in our culture – angels, heaven, genetic ties.

Identity includes “roles within the social system, activity-based identities, social identities based on group membership and salient personal characteristics” (Smith-Lovin 2009: 167). An important theme in symbolic interactionism, especially relevant to my thesis regarding the relationship of deceased loved ones to identity, is the development and importance of the
self. Interactionists contend that we are not born with an innate and consistent self, but rather that self-concepts develop through social interactions (LaRossa and Reitzes 1993: 144). “It is the social process itself that is responsible for the appearance of the self; it is not there as a self apart from this type of experience” (Mead 1934: 294). In symbolic interactionism, the creation and presentation of the self is dependent upon actual others with whom to interact and negotiate the self (Goffman 1959). The question is, if the other is no longer physically present, can that other still influence your identity? What if, in the case of a parent of an only child, part of the parent’s identity is dependent upon the relationship to that child? One way in which parents might negotiate a challenge to their identity and family definition is through the use of their community and family as witnesses as they act out their role in new ways (Grout and Romanoff 2000; Riches and Dawson 1998). The deceased then are kept symbolically alive through stories and rituals and can in turn influence others’ identities.

Toller argues that parents are motivated to maintain the coveted identity of parent to children who have died (2008). This is true even if they have other children, because it is ‘parent-to-that individual and unique child’ which leads to a continued bond with that dead child. Brabant and Forsyth’s research suggests that because of the importance of that identity, many parents continue to include them as part of the family (1994). I predict that for other family members, witnessing and participating in rituals that affirm that parental role enables these other family members to construct their own relationship with the dead child. Such rituals might include remembering the child on his or her birthday, grave tending, or participation in ceremonies in memory of the person who died.

Our ‘imagined’ loved ones who have preceded us in death continue to influence us, our identities and behaviors, by the very fact that we continue to have inner conversations with them.
(Coley 1902). They exist in our minds and continue to have a social presence via our memories and created images of them. “There is no separation between real and imaginary persons; indeed to be imagined is to become real, in a social sense” (Cooley 1902: 284). By keeping their memory alive, we therefore keep alive a certain ‘self,’ the self that exists uniquely in relation to that lost loved one (Toller 2008).

In addition to interacting with living others to construct and maintain images of and relationships with the deceased, individuals may interact with those memories in order to construct and maintain present identity and guide current behavior. In an annual review article, Karen Cerulo (2009: 543) remarks “the literature reviewed here suggests that nonhumans [including the dead] play a more prominent, more active role in social interaction than previously acknowledged”. Similarly, Shane Sharp interviews victims of intimate partner violence and then examines their prayers in order to better understand how “interactions with imagined others help individuals manage emotions” (Sharp 2010: 1). Sharp considers prayer to be an interaction with a nonhuman and nonliving deity, an imagined ‘other.’ Sharp found that the interactions with a deity through prayer helped victims of domestic violence manage their emotions and helped them maintain a positive self-image in much the same way that interactions with a living being does. He proposes further research to help us understand how interactions with imagined others help individuals manage emotions. Another study examined written prayers in a pediatric hospital chapel to better understand styles of coping via the prayer interactions with God (Grossoehme et al. 2011). The point of interactions with symbolic others influencing behavior or emotional well-being is integral to my research question. I explore how a symbolic relationship develops between living persons and deceased persons never known, and further, how that relationship affects the living person’s actions or sense of self.
Social Constructionism

Social constructionism is a sister lens with which to consider death and grief. Peter Berger and Thomas Luckmann (1966) argued that reality is socially constructed, countering the positivistic thinking of their time. “The world of everyday life is not only taken for granted as reality by the ordinary members of society in the subjectively meaningful conduct of their lives. It is a world that originates in their thoughts and actions, and is maintained as real by these” (Berger and Luckmann 1966: 19-20). Individuals create, maintain, and revise the society that they inhabit. How we view the world depends in large part on our relationships, our language, and our larger culture (Gergen 2009). Interactions with others, from childhood on and throughout life, inform how we categorize objects, individuals, or events in our lives. And, the meanings available from our larger culture determine the meanings we ascribe those objects, relationships, or events (Swindler 2001).

Death itself is socially and culturally constructed. Opportunities to continue their ‘self’ beyond mortality, by being a part of something larger and more enduring, motivates individuals to connect to a culture (Becker 1973). In some cases, religious society serves this purpose. “This is to say, it offers the individual the chance to understand his/her life outside the mundane concerns of everyday life, giving the individual the opportunity to define his/her own fate by engaging in moral behavior, sacrifice, bravery and spiritual adventure in the service of a higher purpose” (Seale 1995: 598). Culture provides an opportunity to connect to something larger, therefore an opportunity to imagine that one’s self continues beyond the grave. If children act as one source of immortality for parents (Becker 1973; Seale 1995), keeping the memory of their child ‘alive’ allows bereaved parents opportunities to engage in such immortality projects.
Just as death is socially constructed and culturally bound, so too is the way we grieve. Mourning, or the outward expression of grief, is inherently social. Our culture offers us ways to express our grief and ways to ritualize the significance of the loss.

A social constructionist perspective on grieving denies the essentiality and universality of thoughts, feelings, and words said in or about bereavement. From a social constructionist perspective, whatever anyone, including scholars of bereavement, might call ‘bereavement’ is a social construction. It is inextricably entangled in culture-based social construction processes, social interactions among those writing about grief, the ways their spoken and written language shape and limit what can be said about grief, and their own socially constructed experiences of loss and grief (Rosenblatt 2001: 286).

Grievers can express themselves by being loud and wailing or stoic and rigid. Interactions with the deceased may take the form of dreams, a felt presence, or internal ‘imagined’ conversations. Depending on the culture, such interactions involve all society members or just designated shaman-like persons. One’s culture might either support or discourage continued bonds with the deceased. In the United States, while popular media might suggest a fascination with ghosts, such topics remain relegated to entertainment rather than mainstream everyday dialog. Acceptable interactions with the dead consist of dreams, things done ‘in honor of,’ or behaving a certain way because ‘they would have wanted it that way.’ In spite of these limits, “there is considerable evidence that many people in the United States continue a relationship in various forms with loved ones who have died” (Rosenblatt 2001:290). However, bereaved parents might need to search for culturally acceptable means of maintaining a connection to their dead child. Parents can keep the memory of their child alive through participation in support groups, participation in ceremonies in memory of their child, storytelling or other memorializing rituals. Seale (1998) argues that mourning practices help to deny death and affirm life. “The resurrection of the dead, usually experienced as a theme of organized religion, can in late modernity be understood as a resurrection of hope in survivors about continuing in life” (Seale 1998: 194).
Mourning rituals can both affirm existing identities and help establish new identities. For example, seating arrangements at a funeral indicate the hierarchy of relationship to the decedent. Participation in the funeral itself suggests a level of connection to either the bereaved family or the decedent. Whom a family chooses to notify about a death validates the importance of that person’s relationship to either the bereaved or the decedent. Studies have also shown that allowing siblings to be present or even participate in a child’s funeral helps to recognize that they too are mourners (Silverman 2000: 153). Allowing children to participate in a funeral actually validates the relationship of the siblings although many parents may believe that it would be more protective to shield them from witnessing such a sad event. Mourning rituals also inform about the identity of the deceased. Socially, we understand that the social value of the person who died determines the intensity of the grief expression or experience (Seale 1998: 199). The death of a child, who contributes little to society, beyond the hopes and dreams of future contributions imagined by their parents, presents a dilemma for grievers.

Bereaved parents’ interactions with other family members, community members, or other bereaved parents help to create or maintain treasured parts of their child’s identity. Parents do not remember their deceased child only in isolation. Family members create memories through sharing and negotiating the constructed reality. Remembering and forgetting are social activities, rather than an individual phenomenon of content recall (Middleton and Edwards 1990). “For example, when people reminisce about family photographs, or recount shared experiences of times of happiness and trauma at weddings and funerals, what is recalled and commemorated extends beyond the sum of the participants’ individual perspectives: it becomes the basis of future reminiscence” (Middleton and Edwards 1990: 7). Together, a group indicates what is relevant to the ‘story,’ mutually recounting and reconstructing the memories. Those newly
negotiated memories become the future memories of shared experiences, community events or traumas, as well as individual biographies. Commemoration ceremonies and gatherings where people share stories provide children and adults with frameworks for learning both what to remember and how to remember (Middleton and Edwards 1990: 8). ‘Truth’ is debated, negotiated and reconstructed to become our stories and memories.

**Continuing Bonds**

Traditional theories about grief (reactions to a loss) and bereavement (the state of being a survivor of a loss) once held that adaptive and healthy models of grief were dependent on severing the bond with the loved one who died (Bradbury 2001: 216). Continuing bonds theory counters traditional grief theorists such as Freud who claimed that healthy adaptation to grief and loss requires the severing of the bond with the person who died (Field 2008). Current grief and bereavement researchers, argue that it is both healthy and normal to maintain an attachment to the one who has died (Becvar 2000: 457). “When that other dies, among other things, the mourner must emotionally disengage himself or herself from one with whom he or she has been intertwined on many levels and in countless ways, and must ultimately transform the relationship to one based on memory” (Rando 1991: 234). Without the physical presence, the relationship becomes solely cognitive, emotional, and spiritual.

Dennis Klass (1993, 1997), a forerunner among theorists in exploring continuing bonds with deceased loved ones, has found in his ethnographic work with bereaved parents that typical adjustment to loss could and often does include a maintained connection to the child who died. The psychic inner representation, the “characterizations and thematic memories of the person, and the emotional states connected with the characterizations and memories,” (Klass 1997: 150) of the child who died are transformed through social interactions. Initially, parents commonly
surround themselves with others who share their loss, either others affected by the death of the child or those who lost a child of their own. Through their interactions with others, parents work out who their child is to them now. Frequently, parents begin to focus on positive traits that their child had and talk about those traits as a way to remember and remain connected to their dead child. Parents also find ways to ‘keep their child alive’ through work or activities inspired by the life or death of their child. “Part of the resolution of grief in [the group] Bereaved Parents\(^1\) is making the pain count for something, or, put another way, of making the parent’s life, especially the experience of the child’s death, count for something” (Klass 1997: 166). Continued interactions with the internalized image of the dead child were evident in Klass’s (1997: 150) study as parents reported “a sense of presence, hallucinations…, belief in the child’s continuing active influence on thoughts or events, or a conscious incorporation of the characteristics or virtues of the dead child into the self”.

William Worden proposes that mourners have four tasks in their grief journey in a typical and “successful” adjustment to loss (2009: 39-53). First they must accept the reality of the loss. Second, they must process the pain of grief. Third, they must adjust to a world without the deceased. And, finally, they must find an enduring connection with the deceased in the midst of embarking on a new life. Symbolically relocating the person who died allows mourners to remain emotionally connected to their loved ones who are no longer physically present while also allowing the mourner to go on capably living in the world.

Symbolic interactionism and social constructionism clearly inform continuing bonds theory in that meaning making motivated by grief recovery relies on interactions with others and

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\(^1\) Bereaved Parents is the name of the support group that Dennis Klass observed in his study of parents who have lost a child.
shared negotiations of memories. Weiss points out that bereaved parents, in particular, participate in activities, such as recognition of special days, birthdays, or anniversaries of the date of death, which allow them to keep their deceased child symbolically alive (Weiss 2001: 49). This continued bond is found to be quite common among the bereaved. Weiss distinguishes a continued bond from a continued relationship with a living figure (2001). “Relationships are formed of all the events occurring between people, whereas bonds are the emotional linkages that underlie those events” (Weiss 2001: 54). Individuals can no longer access the physical presence of their loved one in a continued bond. Bonds typically continue beyond the length of the relationship, especially when the relationship had a high degree of attachment such as the bond between marriage partners, or between a parent and child (Weiss 2001). For the purposes of this paper, I will use the terms relationship and bond interchangeably, but symbolic relationship when the physical presence is no longer there.

Continuing bonds theory was integral to my ultimate research question involving siblings who were born subsequent to the child’s death, or who were too young to have lived memories of the deceased child. Toller (2008) maintains that bereaved parents use others as witnesses in order to validate their identity and role as still a parent, to that unique child that died, as well as any other current or subsequent children. By participating or witnessing rituals or activities that allow the parent to remain bonded to the dead child, I argue that subsequent children would also construct some kind of bond to their deceased sibling based on interactions with their parents and available cultural scripts. Therefore, what does that sibling relationship look like? And what meaning does it hold for the surviving sibling? How is it distinct from a continued bond with a loved one known in life who has passed?
FAMILIES AFTER DEATH OF A CHILD

In this section, I explore the literature concerned with what families and individuals do with memories of their deceased loved ones. Klass (1993) describes relationships that continue beyond the death of a loved one as ‘continuing bonds’ and are expressed through behaviors or activities of the bereaved. Interpersonal relationships help construct these memories (Blumstein 1991; Toller 2008) which can then even act as guides for both present behavior and also identity construction (Riches and Dawson 1996; Toller 2008). Families act as the conduit of cultural meanings as members interact with one another in co-constructing: a) their image of and bond with the deceased; b) the meaning of the particular death; c) their ensuing individual and family identities; and d) their appropriate emotional behaviors and coping strategies.

It is important to consider death in the context of the family as a unit, with established roles and emotional interdependencies. Family members share not only the pain of the loss but also the social experience of the loss, from the rituals surrounding the dying to the disposition of the body (Walsh and McGoldrick 2004). Most significant for my study, the family constructs and shares meanings surrounding the death. The family jointly figures out what was lost to them: “loss of the person, a loss of roles and relationships, the loss of the intact family unit, and the loss of hopes and dreams for all that might have been” (Walsh and McGoldrick 2004: 8). Since the death of a child involves many layers of loss, it is imperative to consider the loss within the family system in addition to relevant cultural contexts.

After a child dies, as the parents attempt to make meaning of the loss, theorists point out certain constructs that may challenge that meaning making, in particular: 1) the notion that the child would outlive the parents (an out of order death); 2) the sacredness or worth of the child;
and 3) the parental identity in the absence of that particular child (Buckle and Fleming 2011, Rando 1986, Riches and Dawson 2000). Research shows that family members do continue to keep memories of their deceased loved ones alive through communication and relationships (Field 2006; Klass 1993; 1997; 2006; Neimeyer et al., 2006); so in a sense ghosts exist even in modern society. Thus, there can be tension between our culture which “moves forward” and focuses only on the living, on the one hand, and individuals and families who have an emotional pull to maintain bonds with their deceased loves ones, on the other hand. Our modern, Western society offers little guidance for continuing a relationship with deceased loved ones. In our present culture, parents have few guidelines to maintain their connection with their child who has died, but still have the underlying motivations as previously discussed.

Siblings who were alive at the time of the child’s death also must deal with the loss. Typically, the sibling relationship is our longest lasting relationship. The death of a brother or sister has consequences for the siblings’ identities, other relationships and their personal development (Davies 1999; Riches and Dawson 2000). There is evidence that siblings also maintain a connection to their brother or sister who died through the ongoing process of remembering. In a study of siblings interviewed seven to nine years after the death of a child from cancer, “most (70 percent) thought of their sibling at least once or twice a month, 20 percent thought of their deceased sibling at least once or twice a week; and 10 percent had thoughts about their brother or sister every day” (Davies 1999: 187-88). Reminders such as passing the cemetery where the deceased is buried, seeing objects that once belonged to the sibling, or experiencing life events where the sibling’s absence is noted, trigger memories (Davies 1999). Davies (2000) found that bereaved siblings are most likely to share memories within their family or with others who have experienced a similar loss.
Family members co-construct the image of and bond with the deceased

Current grief researchers recognize that bereaved individuals normally transform a lost emotional and physical relationship into a symbolic relationship. The continuation of the relationship, while transformed, is common in the grieving process. In one study, Silverman and Nickman (1997) analyzed data from the Child Bereavement Study in which children’s language about their deceased parent seemed to suggest an ongoing relationship. But, further, their analysis revealed an ongoing cognitive process of constructing their image of the deceased person. “The inner representation of who died changes as mourners move through the life cycle and their sense of self and other continues to evolve” (Silverman and Nickman 1997: 74). The children’s’ image of their deceased parent changed as the children themselves changed and grew, but the bond continued. In this instance, relationships changed over time even when one member of the relationship existed only in memory. The Silverman and Nickman study focused on children’s reactions to parental death, but would parents or siblings experience the same process of an evolving symbolic relationship when a child dies?

So, in what ways does the family transform the attachment to the deceased member? How are these memories and relational ties altered and preserved? In some studies, it was family members’ language, dialog, and interactions that helped construct meanings for the individual members (Nadeau 2001; Riess 1981). Reiss’ book The Family’s Construction of Reality (1981: 2), based on his field and laboratory observations of families with a schizophrenic member, first introduced the concept of a family paradigm – “a central organizer of (the family’s) shared constructs, sets, expectations, and fantasies about its social world”. Reiss’ team observed families in laboratory settings, in their own homes, and in their interactions with the larger community. Reiss argues that families behave with each other and the outside world based on an
underlying belief system implicitly shared among its members and constructed, reconstructed, and reinforced through both formal and informal daily rituals. Reiss’s study applied Berger and Luckman’s model of a constructed reality to families.

Each member (of a modern family) accords to the others the power of independent regard. As a consequence, each member’s construction of social and physical reality must be coordinated with the others’. In other words, membership in families of this kind depends on collaborative engagement by all its members in the joint construction of reality (Reiss 1981: 170).

Reiss suggests that family members negotiate and construct a self-concept of the family and a shared understanding of its relation to the outside world. “For a self-concept to be the basis of action it must, at the very least, be subordinate to a concept, felt as reality, of the outside world” (Reiss 1981: 383). Thus, how families view themselves will more likely be felt as ‘real’ if the responses received by persons or groups outside of the family unit seem to agree with that image. Since families consist of a set of relationships and roles, the loss of one of its members would greatly impact the identity of the family as a whole. One part of the grief experience for families, therefore, is a renegotiation of the collective family identity (Riches and Dawson 2000).

Nadeau’s (2001: 336) study of bereaved families found that family members negotiated meanings of the loss through dialog and interactions with each other. Meanings negotiated ranged from meanings of the loss, religious or afterlife beliefs, the nature of the death, to family structure after the death. Nadeau (2001: 336) defines meanings as cognitive experiences created through interactions with other family members. She labels this process of co-construction “family meaning making” (2001: 329). Such ‘storying’ helps families make sense of the death. The process of meaning making among the bereaved deserves more research. Kempson and Murdock (2010) interviewed adults who had lost an infant sibling. Many of the participants never knew the infant who had died except through stories told to them by their parents. Even
though the participants never knew their unborn deceased sibling, they managed over the years to maintain a connection to their sibling, and served as ‘memory keepers’ for the other members of the family, most especially their parents. They made meaning of the loss in various ways such as through their career choice (Kempson and Murdock 2010: 747). For example, one participant in the study lost a sibling who if he had lived would have had multiple handicaps. That participant attributes his later career choice to become an educator with developmentally delayed children to his understanding of who his sibling might have been had he survived. Kempson and Murdock argue that these adult siblings continued a bond with their sibling never known to them.

I offer an alternative theory that the bond was not just continued, but constructed in the first place based on family memory-work and meaning making based on available cultural scripts. Klass (1993) also finds that meanings are created among family members and other extended communities of loss (support groups, for example). In Klass’ study, members of the family and their extended group jointly remember, construct, and maintain the memory of the deceased loved one, who they were and what they were like. Klass (1993: 346) argues that, just as with other aspects of bereavement, “inner representations of the dead are not simply individual phenomena, but they are maintained and reinforced within families and other social systems.” Because of the shared loss within a family, even though the specific relationship will vary among the different members, sharing memories allows for a maintained image of the loved one as well as a continued identity for the bereaved in regards to that lost living relationship. I extend Klass’ findings to members of the family who did not know the child who died, who have a relationship not maintained, but constructed based on interactions with others. For example, by communicating with others about their deceased child that is one way a parent might continue to hold that parental role. Also rituals of remembrance, such as grave attendance, memorial
ceremonies, events in memory of the deceased, when witnessed, might also allow the bereaved parent to reinforce their identity and relationship to the deceased. “Bereaved parents’ inclusion of family and friends in these rituals suggests that identities are not completely terminated by the absence of the person who died but that other relational parties may play a role in the construction and reconstruction of identity in situations of loss” (Toller 2008: 317). Including members of the family who never knew the deceased in rituals of remembrance constructs identities for the others in relation to the person who died.

Theorists have also found that families share and reconstruct memories through objects. Riches and Dawson (1998) found that photographs and other special keepsakes such as school work or awards, served as “objects of discourse” for bereaved family members in constructing memories with others. In their study, Riches and Dawson believed that the photographs served as proof that the child lived, affirming the parental role that once existed. Especially in the early days after their loved one’s death, pictures in some ways also confirmed the fact of the death for the bereaved by reaffirming the life that had been lived. Parents in the study chose the pictures and other relics intentionally based on the times or meanings they wished to highlight. The stories shared around those objects helped the bereaved both celebrate their child’s life as well as to allow the bereaved parent to construct a new identity as parent of a deceased child.

**Family members co-construct the meaning of the death**

After a death, families negotiate and construct meanings of the death and the decedent. How and why did the death occur? Did the person who died or others around them have any culpability in the death? What does immortality look like? Was there a purpose for the loss? What can be learned from the death? Family members consider the meaning of the death itself,
its impact on their respective identities, emotions, the new family boundaries, and the social network to which it now belongs.

How do families co-construct meanings after the death of one of its members? Meanings depend upon the shared constructed reality within a culture or family system. Symbolic interactionism and social constructionism are useful frameworks with which to consider the ways in which family members create death reality. Following a death, the collective family narratives help to begin assembling and forming all of the newly shared meanings. Rosen (1999) argues that family members must share the reality of the loss, share the experience of the pain of grief, reorganize the family system, and reinvest and redirect its goals and relationships. “The family’s shared acknowledgement of death is reflected in their communicating about the subject in clear, non-euphemistic terms” (Rosen 1996: 229). Families begin to reconstruct meanings, roles, and relationships after a loss of one of its members through the tool of communication, their language. Riches and Dawson’s (1996) study of parents whose child died found that surviving parents contributed to the constructed relationship between the children and the deceased child in several ways. In the Riches and Dawson study, parents talked about the deceased child with their child(ren), included the child(ren) in memorializing activities, and gave the child(ren) linking objects – special mementos from the deceased.

**Family members co-construct newly formed individual and familial identities**

Wheeler’s (2001) qualitative study of bereaved parents considered the meanings given for the child’s death and life. She found two themes in the parents’ search for meaning – the search for cognitive mastery (of the loss) and the search for renewed purpose (for their own life). A death, particularly the death of a child in our modern Western society, threatens previously held assumptions about the world and the way it works. Such a loss shatters beliefs about security, the
ability to protect one’s children, and the natural order of our own death preceding our children’s. Wheeler (2001: 63) concludes that “acceptance of the death of a child involved finding a way to make meaning of it… [and] for some parents keeping the memory of the child alive was a way of making meaning of the death.” In our culture, a person’s life becomes meaningful through accomplishments or influence on others (Becker 1973). In my professional experience, for example, many bereaved parents credit their child for helping them appreciate life’s ‘smaller’ things or giving them more tolerance of ‘petty’ things.

Theorists have found that maintaining a connection to the deceased child could actually benefit the parents in adjustment to bereavement. Ronen et al., (2009) asked a group of bereaved parents to complete both a complicated grief inventory and a continuing bonds questionnaire to assess the impact of a child’s death on the parents. The authors found that the parents who maintained a bond with their deceased child, through internalizing positive qualities of their child (such as feeling that the child was courageous, in the case of a child who battled an illness) or finding positive meaning in the loss (marriage or other relationships were strengthened), adapted better to life after loss, as measured by the Inventory of Complicated Grief, a validated self-report questionnaire that measures symptoms of grief and adaptation to loss.

Recall that in symbolic interactionism, the creation and presentation of the self is dependent upon others to present and negotiate the self. Rituals allow the sharing of memories, as well as the reaffirmation of identities and roles, in a public way (Riches and Dawson 1996; Toller 2008). “Bereaved parents enacted rituals such as grave tending and celebrating the child’s birthday in order to negotiate the tension of being parent without a child to parent” (Toller 2008: 312). They have lost both a relationship and a role. In Kempson and Murdock’s (2010) study of persons who had lost a sibling whom they had never known, almost half of the participants recalled rituals,
such as grave visits or birthday remembrances, while they were growing up which involved the commemoration of their deceased sibling. So, while the parent maintains their relationship to the deceased child and maintains their parent-to-that-child role, they concurrently contribute to a constructed relationship between siblings who had never known each other.

So, is the deceased child still a member of the family? What are the family boundaries after a death occurs? Who is in and who is out of the family determines the family ‘boundaries.’ Pauline Boss has written much about the stress that families face when their boundaries are ambiguous related to uncertain or unclear loss. Boss (2004) describes two types of ambiguous loss: a physical absence with psychological presence (such as a missing person where death is uncertain), or a psychological absence with physical presence (such as a member with dementia). Due to the desire of parents to maintain the role and identity of being a parent after the loss of a child, they fall in the first category of ambiguous loss, one where the child is physically absent, but psychologically, spiritually or at least symbolically, present. Brabant and Forsyth (1994) drew on Goffman to explain the dilemma that many parents find themselves in after the death of their child when confronted with the question of how many children they had, or in other words how to state their family boundaries:

Half of the parents in (their qualitative survey) study had two family definitions. One may be thought of as the backstage family. This family included the deceased child, and for the parents this was the real family. There was also, however, a family that did not include the deceased child, and this was the family that some parents presented to others. This may be thought of as the front-stage family. At times, such as when an acquaintanceship develops into a friendship, the presentation of the family changes.

Thus bereaved families often modify their presentation of self in their adaptation to life without their loved one, depending on the purpose of the encounter and the level of intimacy shared.
Family members negotiate emotional behaviors

If emotional control beyond intimate settings is the culturally sanctioned response to grief, bereaved individuals may feel isolated and seek outlets so that they can express their grief, among more accepting groups or similarly bereaved family members. “A vocabulary of intimacy allowing the safe expression of grief is, on the whole, rarely found in modern social discourse. This is not surprising: emotional control is essential for social order” (Riches and Dawson 1996: 145). Interactions with observers help grievers identify and express the sanctioned emotion. After a loss, individuals receive constant feedback from everyone they encounter – other family members, school, church or neighborhood community members, support groups, and so on - about the appropriate meaning of the death and how they as grievers subsequently react to it. Linda Francis (1997) demonstrated the construction and management of emotion, and subsequent identity formation in two loss support groups. Through dialog and interactions, individuals ultimately find meaning in the death and in the way in which they choose to incorporate it into their new identity. They also negotiate with whom they share their more intimate emotional expressions and with whom the ‘time is up’ in terms of the length of the mourning. Thus, bereaved parents often do their memory making and meaning finding within the context of their family or new social groups defined by the shared loss of a child. As other family members, particularly surviving or subsequent siblings, witness and participate in the rituals which support such emotion letting or memory making, they concurrently construct their own relationship with the decedent and learn coping strategies.
SUMMARY AND RESEARCH QUESTIONS

“It is not just that ‘he who controls the past controls the future’ but

‘he who controls the past controls who we are’” (Middleton and Edwards 1990: 10).

The death of any family member results in grief and adjustment by its members. The death of a child, an affront to our modern expectations about life order, is a traumatic experience for a family. Modern society is not equipped to deal with the death of a child. The loss to the family includes not only separation from a beloved member, but loss of a hoped-for future. Bereaved parents are confronted with others who become uncomfortable with their expressions of grief after only a short period of time. Many report messages of ‘get on with your life’ after only a few short months. Yet, in our society, parental identity is highly valued, thus there is incentive to maintain that role even for children no longer living. Research has shown that connections do continue after death; scholars use the concept of ‘continuing bonds’ to describe this phenomenon. After a child dies, family members choose which memories and what kind of memories to continue through interaction and dialog. This allows identities of importance, such as parent or sibling to that specific child, to continue. It also allows parents to continue the self of the child by symbolically keeping him or her alive. Photographs and other keepsakes serve as props to reinforce those memories. Witnesses at ritual events also validate the memories and the relationships. I suggest that as a result of parental practices that support their continued bond with the deceased child, that even family members who did not know the decedent while alive, ‘indirect grievers,’ construct their own bonds. The aforementioned researchers have established
the concept of continuing bonds as typical for many bereaved individuals. I argue that the expression of continued bonds by the bereaved (most notably the parents) concurrently and often unknowingly results in constructed symbolic relationships for members of the family who never knew the child who died. In other words, does a continuing bond between some lead to a constructed symbolic bond between others?

This study offers a new way of looking at how families grieve together. It is from an indirect griever’s perspective. Participants in this study were inside the family who lost a child, but were outside the direct experience of the loss as they were either not yet born, or too young to remember, when their brother or sister died. This study contributes to our understanding of family meaning making after loss over a long term, how symbolic relationships are constructed, and how indirect griever’s are similar to and different from direct griever’s.

The aims of my study were to first describe the ways in which family members collectively remember a child who has died and second to explore the impact of the loss on members of the family who did not have a lived relationship with the deceased child. Following in this dissertation is a chapter on my research design. In chapter two, I describe my qualitative study, where I interviewed 49 participants about a sibling who died, prior to the participant’s birth or before they were old enough to remember. In chapter three, I describe how families communicated about a topic as sensitive as the death of a child and the themes of the narratives and rituals used to construct those memories. In chapter four I explain symbolic relationships and the images of and bonds the participants describe of their imaginary siblings never known. In chapter five I categorize the meaning of the loss and its effect on surviving siblings’ identities.
CHAPTER TWO

Methods

METHODOLOGY

The research problem at hand is to better understand symbolic relationships formed via the experience of having a brother or sister, whom you never knew, die. In order to elicit the ways in which, over a long term family cycle, bereaved families have collectively remembered a child who has died, as well as to understand the meanings of that loss for subsequent family members, I have chosen to interview adults who had a sibling die before the respondent was born or old enough to remember that deceased child. I used open ended interview questions to best obtain their thoughts and significant experiences, as told to me in their own language.

RECRUITMENT

In order to be eligible for the study, participants were required to be eighteen years old or older and to have had a brother or sister die. The participants had to be younger than the age of three or not yet born when their brother or sister died. I chose the age of three or younger so that the participants would have primarily relied on the stories told to them by others rather than have any memories of their own about their deceased brother or sister. I chose to interview adults so that there will have been significant enough time since the loss to see what families have in fact done with the memories of the decedent over a long period of time, beyond the initial mourning period. In this way I could better understand how long term established behaviors associated with a continued bond with the deceased child influences subsequent family members. I am more
interested in what families do with the memories over a long period of time than in their initial
grief reactions.

I recruited participants in several ways. People who have lost a sibling prior to their own
birth are not an easily identified demographic group. This is not a loss that draws people together
to any particular, easily accessible setting. Therefore, I first contacted colleagues in our local
community who run support groups for bereaved parents and/or siblings (namely Fernside, The
Compassionate Friends, Companions on a Journey, and Reach Out to Grieving Parents), and
asked them as gatekeepers to recommend and approach eligible participants. This initial word of
mouth method did result in five persons who met my criteria and agreed to an interview.

I wanted to have as much racial diversity as possible, and certainly enough to feel that
different communities were represented, in order to ensure that the voices represented in my
study were as inclusive as possible. In an effort to increase participation from African
Americans, I posted fliers at a two local Churches with predominantly African American
attendees. Unfortunately, I did not obtain any additional respondents from these sources.

In hopes of reaching participants who had experienced varied family reactions to the
death of a child, I also sent out a mass e-mail to employees of one of the largest organizations in
the Cincinnati area (employees of Cincinnati Children’s Hospital Medical Center). This was a
way to reach a large number (18,000+) of people with a wide range of ages and backgrounds,
any of whom could have lost a sibling prior to the age of 3 years. The remainder of my
participants found out about the study from this e-mail.

See recruitment flier in Appendix A.
ETHICAL CONSIDERATIONS

The Institutional Review Board of Cincinnati Children’s Hospital Medical Center (CCHMC) approved this study on 01/17/2013, Study ID 2012-3683. All participants provided informed consent. During the consent process, the interviewer stressed confidentiality and the limits of confidentiality, specifically that I would change names would in any written or verbal use of direct quotes or descriptions of their stories. I also informed participants of the voluntary nature of their participation in the study and that they could refuse to answer any questions, end the interview at any point, or withdraw from the study.

See Consent Form in Appendix B.

The interviews of course asked questions about a child who died, one related to the participant. Even though the event occurred many years ago, I would expect there to be potential feelings of sadness. I did not anticipate any reactions that would be overwhelming to the participant, but am a trained grief counselor and had access to additional community resources if any participant requested additional support. No participant asked for nor appeared to need additional support.

I did change all names of participants or their family members in subsequent text, including examples and quotes.

PARTICIPANTS

I interviewed a total of 49 people who met criteria. All of the participants had a sibling die either before the participant was born or when they were aged three or younger. Thirty five of the participants were not yet born when their brother or sister died. All but one of the remaining
participants were young enough that they had no recall of their sibling who died. One participant was age three when her sibling died and could recall that “a baby did not come home from the hospital,” but did not ever get to meet the sibling who died. The majority of the participants (36) were not yet born when their brother or sister died.

See Table 1 for participant characteristics. Participants’ ages ranged from twenty to seventy one. Forty identified as Caucasian, five identified as African American, one identified as half Caucasian and half African American, one identified as American Indian and one identified as Chinese American. All but three of the participants were female. Since I was asking about family patterns that occurred in the participants’ families of origin, I was interested in the socioeconomic status of the household in which they grew up. I asked participants to think about the time when they were sixteen years old and to compare their family to other American families at the time. I then asked if they thought their own family’s income was “far below average, below average, average, above average, or far above average.” No families were far above average, twelve families were above average, twenty families were average, twelve families were below average and five families were far below average, according to the respondent’s point of view of the household in which they grew up.
# Respondent Characteristics

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Table 1
Demographic Representation

My goal in outreach and in collecting demographic information from the respondents was to ensure that all voices were heard and that not one small group was overly represented. Gender is the most confounding demographic factor in this study and must be taken into consideration before generalizing my results.

While my effort to outreach to African Americans did not seem to be overly fruitful, the resulting respondent ratio of 10.2 percent African Americans is not terribly far from the national average of 12.3 percent African Americans (United States Census 2010). What is perplexing though is the overwhelming response from women versus men. It could be that women are more socialized to be the carriers of relationship based information in families.

Provocatively, there are gender differences in early parent-child reminiscing. Whereas there are few stylistic differences between mothers and fathers in the way in which they discuss past events with their preschool children, both mothers and fathers talk in greater detail and encourage and affirm their daughters’ participation in shared reminiscing to a greater extent than their sons’. In turn, girls tell more elaborated and detailed narratives of their own past than do boys (Reese and Fivush, and Reese, Haden, and Fivush, as cited in Fivush et al. 2004).

It could also be that in our culture, women are, in general, socialized to have empathy for others, express their emotions, and share confidences (Doka and Martin 2010: 139). Such tendencies might make women more open to a study enquiring about a sibling who died, but that is only speculation on my part.

Socioeconomically, the families of origin represented in this study have a sufficient enough range to surmise that I represented voices from different educational or economic backgrounds in this small study of 49 participants. There was also a variety of causes of death for
the sibling who died. Large families, as well as families where the respondent was an only child were also fairly distributed.

Who died?

The participants shared as much as they knew about their brother or sister who died, at which age their sibling died and cause of death. The ages ranged from gestational weeks, stillborn, to 29 years. Most of the children who died were infants, under the age of one. This makes sense, for in order for their parents to still be interested or able to conceive again, they would likely have lost a younger child. See Figure 1 for a break out of the ages of the children who died. The causes of death included pregnancy complications, congenital anomalies, SIDS, heart disease, respiratory illness, genetic condition/illness, accidents (drowning, hanging, falls), war/homicide, cancer, and unknown.

![Age of Child Who Died](image)

**Figure 1**
INTERVIEW

This was a semi-structured interview by phone or in person determined by the convenience and preference of the participants. The interviews generally lasted from thirty to forty-five minutes. The shortest interview was over in about fifteen minutes and the longest interview was just over an hour. I prompted participants to talk about their experience of having lost a sibling that they themselves never had the privilege of knowing, either because the participant was not yet born, or they were too young when their brother or sister died. Due to the sensitive nature of the interviews, namely asking about a sibling who died that they never knew and how their family responded to that loss, the tone of the interviews were generally subdued and several participants became tearful as they recalled their stories. I asked participants questions in the following areas: the circumstances of their sibling’s death; any information they knew about their brother or sister; ways in which (if at all) their family commemorated the child who died; the participant’s relationship to their deceased sibling; and the effect of the loss on the participant.

See Interview Guide in Appendix C.

DATA ANALYSIS

Grounded theory is the process of systematically analyzing data such that themes and theories emerge. It is inductive rather than deductive, the opposite of testing a priori theories with new population samples and data (Glaser and Strauss 1967). Qualitative studies emphasize the range and diversity of meanings of human experiences, rather than seeking frequencies of a particular behavior.
Frequency is only one dimension for analysis. While the researcher delights in numerous examples of a theme or topic, the goal in ethnographic analysis is not representativeness. Rather, the ethnographer seeks to identify patterns and variations in relationships and in the ways that members understand and respond to conditions and contingencies in the social setting. That there is “only one case” often does not matter (Emerson, Fretz, and Shaw 1995: 162).

I taped each interview and took notes. A professional transcriptionist, bound by a confidentiality agreement, typed all of the taped interviews. Transcribed interviews were analyzed utilizing QSR’s NVivo 9, a software program that helps organize codes and sort emerging key themes. Demographic data, namely age, gender, race/ethnicity, socioeconomic status of participant’s family of origin, age of the child who died, age of respondent at the time of the sibling’s death, and cause of death, was catalogued in an Excel Spreadsheet.

I read and re-read each interview, coding for ideas and themes that emerged from the data. Initially in open coding, the number of themes is unlimited, allowing the researcher to explore many avenues for interpretation (Emerson, Fretz, and Shaw 1995). I then collapsed themes when they seemed similar and categorized by either an overarching theme or in answer to a particular question (Corbin and Strauss 2008). Qualitative research seeks to reflect the experience of its subjects, therefore frequency of a theme or idea is not as relevant as it would be in quantitative analysis (Emerson Fretz, and Shaw 1995). I included some ideas in the following results even if they were “just one case” in order to demonstrate variations in experiences of growing up in a family that lost a child that the respondent never knew. Also, themes emerged that reflected a range of experiences, and participants at times would describe something (i.e., an image of their brother or sister who died) where they fell into more than one category. The categories therefore represent the richness of participants’ experiences rather than limit them to one box or another.
The following chapters describe memory work, “how” symbolic relationships form; the variety of symbolic relationships; and the meanings the participants attributed to the loss they did not go through first-hand.
CHAPTER THREE

“Whatever the Memories are”: Narratives and Rituals that Sustained the Sibling Legacy

Suzanne is a 57 year old professional woman who had a sister die before Suzanne was born. In fact, her mother was pregnant with Suzanne when the other sibling died. She grew up with 7 living siblings. It wasn’t until Suzanne was around the age of 8 or 10 that she learned that she would have had another sister. In going through a box of old pictures with her sisters, they came across a picture of a newborn. “Which one of us is this?” they asked. “Oh, that is Julia. She died as a baby,” was her parents’ response. Yet, her parents provided no further information. Naturally, the children were curious and asked questions. “Wow, there would have been another one of us... That would have made an even 4 girls and 4 boys...” But, when asked, their mother just sort of ignored the questions and their father would state, “That was in the past.” They learned not to ask.

Over the years, Suzanne especially was curious and would inquire of aunts who would have been around at the time. In doing the math, she learned that her mother was probably pregnant with her (Suzanne) when she found 6 month old Julia having difficulty breathing. From extended family members, she did learn that Julia died in the hospital (but after what period of time she couldn’t learn) and that there was a funeral service held, but was not able to learn the cause of death. She knows her sister was buried, but as far as she can remember, her parents never went to the grave. Her extended family members shared that her father wept uncontrollably at the service and that her mother was tearful, but stoic; not nearly as upset as they expected her to be. Suzanne described her mother as a cool, distant personality – a
description that did not match her older siblings’ experience of their mother. When Suzanne
herself was expecting a child, the cause of her sister’s death became a concern for her.
Continuing to get no answers from her parents, she looked up the death certificate to see if it was
anything that she should be concerned about genetically. The diagnosis listed was not one that
would warrant any genetic concerns, rather a random respiratory illness gone wrong. But the
secret, along with her relationship with her mother continued to haunt Suzanne. When Suzanne
was 50 years old, she decided to again bring up the subject with her mother directly. She asked
her, “Mom, you were pregnant with me when Julia died, correct?” Her mother confirmed this.
Suzanne asked how that was for her and her mother replied simply, “I asked God why I couldn’t
just keep the baby I had.” Suzanne felt this confirmed a feeling that she had always had about
never having truly been wanted or loved.

Now, Suzanne assures me, the interviewer, that her mother was a good and caring
mother and raised her children as well as one would expect. This was simply one element of their
relationship, albeit one that was deeply meaningful for Suzanne, who states she often felt guilt
for something she obviously had no control over. Suzanne continues to quietly remember Julia
on her birthdate and the day that she died. She has also shared Julia’s story with her own two
children. The cause of Julia’s death became significant again as Suzanne’s children questioned
whether they should be concerned about genetic conditions in their own childbearing years.
When asked if she felt she had a relationship with Julia, Suzanne says, “No. She’s someone
who’s there, but not there.”

Suzanne demonstrates one way in which families communicate about a child who died.
In essence, from Suzanne’s perspective, her parents had intended for Julia’s life and the story of
her loss to be a family secret. Only Suzanne’s mother could explain the purpose of her silence
related to Julia’s death, but for Suzanne that silence led to feelings of inadequacy for being the “replacement” child for the one desired but lost. It also led to feelings of guilt since she imagined that due to being pregnant with Suzanne, Suzanne’s mother might not have had the time or focus to notice the severity of the illness in Julia, thereby allowing the infection to become too severe, “Did I make my mom so sick during pregnancy that she couldn’t look after this baby?” (Suzanne). Suzanne doesn’t recall any particular ritual or tradition in her family of origin that helped maintain Julia’s memory. Suzanne herself maintained her sister’s legacy by sharing Julia’s story with her own children. A piece of the story that was highlighted as important by Suzanne is the cause of Julia’s death NOT being related to any genetic concern. It was enough of a concern for her that she took the initiative to look up her sister’s death certificate. Suzanne often silently remembers Julia on special dates, notably her birthday and the anniversary of her death. The silence that Suzanne’s parents kept surrounding Julia’s death did not mean that there was not a story. Julia’s legacy affected Suzanne and her understanding of her relationship with her mother. Suzanne, as an insider to the family, but outsider to the direct experience of the loss, is an indirect griever. She and others like her can shed light on family mourning behaviors over a long term, and the impact of those behaviors on subsequent family members.

MEMORY WORK

Memory-work is done in social interaction. Rather than memories referring to a factual recall of the past, people choose which points to remember or highlight based on the lesson to be shared. Memories are recalled by some, shared with others, and then negotiated as to which parts to embellish, in order for there to be a moral to the story told (Middleton and Edwards 1990;
Those memories then become foundations of the familial being, a part of our past that informs who we are as individuals and in relation to our family and greater culture. Sharing memories about a deceased loved one is part of the grief process, where individuals socially explore meanings. “Although grief and mourning may be universal and biological, both the story of the death itself and our changed relationship to the deceased are personally narrated, socially shared, and expressed in compliance with or contradiction to widely varying communal rules” (Neimeyer, Klass, and Dennis 2014: 487). When family members share memories, choose which memories to highlight, or even which memories to keep secret, those are ways in which they make meaning both of the loss itself and their own identities in relation to the loss (Baddeley and Singer 2010). Parent-child reminiscing can serve the purpose of creating or recreating a sense of self for the child both as an individual and in relation to the family, and to help develop emotional well-being (coping), especially when telling stories about negative events (Fivush et al. 2004). Stories about our past have lessons and stories help us explain who we are (Baddeley and Singer 2009; Middleton and Edwards 1990; Miztal 2003; Neimeyer, Klass, and Dennis 2014).

This chapter explores which memories of the deceased child and of the loss itself are carried forward in the eyes of siblings born subsequently or who were too young to remember. Memories help us understand our past, establishing or reinforcing both individual identities and family identities (Fivush 2008). Families use memories as resources for making sense of the present (Middleton and Brown 2005: 39). Family boundaries, such as determining who is or is not in the family, are informed by remembering (Middleton and Brown 2005: 39). Family reminiscing is a social process where parents and children together create stories that carry individual meaning (Fivush 2008: 52). In a study of adoptive parents, researchers found that
adoptive parents used photographs and narratives to construct a meaningful and coherent past for their adopted children (Brookfield, Brown, and Reavey 2008). Brookfield et al.’s study demonstrates a similar situation where a child’s past and relationship to a biological parent unknown to them is dependent upon the stories provided by others. In the adoptive parent study, identities of importance such as family membership and an individual life narrative, as well as reaction to past loss, are informed by memories that are socially constructed with a purpose for present circumstances, rather than factual recall of the past (Brookfield et al. 2008: 476). Joint remembering is a method by which family members emphasize issues of identity, both personal and familial, and issues of emotional reactions to past events (Middleton and Brown 2005: 90).

Recall that the aims of my study were to first describe the ways in which family members collectively remember a child who has died and second to explore the impact of the loss on members of the family who did not have a lived relationship with the deceased child. When a child dies, families choose which memories and what kind of memories to continue through their interaction and dialog. The communication styles in relation to the loss story, including the means by which participants learned that they had a sibling pass away, and the narratives and rituals that maintained those family memories, varied from family to family in my study. Many, unlike Suzanne, always knew, or at least could not recall ever not knowing about their sibling who died. In this chapter, I first summarize the different ways that the respondents felt their families communicated about the topic of their deceased sibling and compare that to other studies about communication of sensitive or taboo topics. Then I will describe the themes of the memory narratives of the deceased siblings recalled by the respondents. Finally, I will describe other ways that the families memorialized children who died over the years by their families and the different levels of engagement with those rituals by the participants in the study.
RESPONDENT DESCRIPTIONS OF FAMILY COMMUNICATION STYLES

How did the families represented in my study talk about the child who died? How was something as significant as the loss of a child communicated in families over the course of time? While participants either always knew about their sibling or found out by happenstance, the communication styles were not as simple as being ‘open’ or ‘closed.’ Among the participants who always knew, there still were those who felt that the subject was taboo or that there were details, including their parents’ feelings, which were never freely discussed. In combing through the transcripts, I determined four categories of how respondents described communication styles in their families around the death of the unknown child: open, protected, closed, or transitioned. Nineteen families were described as open; twenty-two were protected; five families were closed; and three families transitioned from closed to more open or protected communication. See Figure 2 for a breakdown of participants’ experience of their family’s communication style.

Figure 2
Communication styles about a deceased child, even over a long course of time, seem to be similar to communication styles about other ‘taboo’ topics such as dying or terminal status. Like types of awareness between hospital staff, family members, and terminally ill patients as labeled by Glaser and Strauss (1965), these participants described communication styles around the topic of their deceased sibling which I categorized into four types: Open, Protected, Closed, or Transitioned. When Glaser and Strauss studied interactions between hospital staff, family members and patients expected to die, they categorized four types of communication which they labeled “awareness types.” In ‘Open Awareness,’ all parties openly acknowledged the impending death. When all parties knew about the patient’s prognosis, but ignored it in their communication or pretended that the patient was going to live, Glaser and Strauss called that ‘Mutual Pretense.’ Where there was complete secrecy among the ‘knowers,’ Glaser and Strauss called that ‘Closed Awareness.’ They had a fourth category in which the patient’s suspicions of his/her terminality lead him to challenge caregivers, which they termed ‘Suspected Awareness.’ Once that challenge occurred, the awareness type changed from Closed to either Open or Mutual Pretense. My categories of communication about a deceased child paralleled Glaser and Strauss’ categories of communication about impending death.

The ongoing sharing of memories about the children who died, as described by the participants in this study, fell into four general categories of communication styles. Open communication experienced by participants in this study occurred when participants found their parents to always be approachable. Their families chose to keep the memory alive. Parents stated that it was important to them that people not forget their child. Stories were told on long car rides, or while sharing family history. Quite simply, interactions between all relevant parties acknowledged the loss in their communication and behavior. These participants felt comfortable
raising the subject with their parents, other siblings, and often with extended family members. In families which participants described as open communicators, family members freely shared information about the sibling who died through stories or through rituals of remembrance. Conversations about what life might be like if their brother or sister had lived were not uncommon.

In what I refer to as a protected style of communication, the participants knew about their deceased sibling, but did not always feel comfortable talking about it with one or both of their parents. One parent might talk more about the loss than the other. This was usually, but not always, the mother. Or, they might not have ever heard their parents talk about their emotions related to the loss. Extended family members or older siblings who were alive and old enough to remember when their sibling died often filled in blanks. Protected communication occurred when all parties knew about the existence of their brother or sister who died, but through their interactions pretended otherwise, or limited communication on the subject. Participants in my study picked up on cues from their parents or older siblings that the subject of their deceased sibling was taboo.

Complete secrecy characterized closed communication. Closed communication regarding the deceased sibling did not mean that there was not a story. “Silence about the departed, and perhaps about the circumstances of the loss itself, may serve many purposes or functions in the dynamics of family members who are each seeking to re-align both their personal narratives and their understanding of the larger family story” (Baddeley and Singer 2010: 201). A few of the participants interviewed felt that their families were very closed about the discussion or even the revelation of their sibling who had died. In these families, the loss was a family secret. Now, once the family secret was breached, inquiries by the participant was met either by a transition to
a more open type of communication or efforts to maintain the secret. My study was retrospective so I did not have direct accounts of interactions, but rather participants’ recounted experience of their family’s communication upon reflection and after a long period of time. For families whose communication styles participants felt became more open over the years, either from a Protected or Closed style, I labeled that style of communication as Transitioned. Styles of communication influence the story told, which memories become highlighted, and what meanings or lessons are taken from the stories.

I am not making the argument that how families communicated determines whether a bond was established between the respondent and their deceased sibling whom they never knew. I summarize them more to demonstrate the range of communication styles represented in this study. Talking about a child dying, even if it was a long time ago, appears to be a topic similar to other ‘taboo’ topics, such as terminal status was in Glaser and Strauss’s study (1965). What families share in the retelling of those memories does however matter. The more parents talked with their children about the sibling who died, and their interpretation of events, the more control and input the parent had in co-constructing the memory for the subsequent sibling. If the parents talked about their feelings for instance, they modeled for their children one type of coping strategy. “Families that are able to talk about emotionally complex and difficult events in more open, integrated and coherent ways may help provide children with the resources to cope with and resolve aversive experiences” (Fivush et al. 2004: 55-56). In the sharing of the memories, families explored together the meaning of the loss, the moral of the story.
NARRATIVES OF SIBLINGS WHO DIED

There were two overarching themes in the stories that the participants shared about their brother or sister who died and whom they never knew in life. The stories recounted by the participants either talked about identity of their family or themselves - who they were, or shared a moral. Fivush et al. (2004) point out that “one of the central functions of reminiscing about shared experiences is to create and maintain social and emotional bonds” (57). Interestingly, even when the experience was not shared (the respondents were not alive when their sibling died), as discussed in the sections below, the sharing of the memory helped connect the respondents to the child who died, to the family story, thus reinforcing their identity as members of this unique family.

Identity

Many of the narratives that the respondents shared during the interviews described how their family was distinct from other families. It helped the respondent explain how they fit into their family of origin, even how they came to be.

Family Constellation. Some of the stories addressed the shape and size of the respondents’ family. Certainly, some understood the loss of the child as having directly affected their family formation. For example, some attributed their parents’ break up to the death of the child whereas others pointed to a large gap between siblings or the absence of siblings altogether as results of the death.

Well probably the other thing is I never wanted to be an only child. That was a big issue in my life... I always... I never asked. You know kids say well you know “I want a brother or sister”...I never asked because it was pretty clear to me ... that it wasn’t going
to happen. ~Audrey, whose older sister Maria died from unknown causes shortly after or at birth. It was many years before Audrey was born.

For Teresa, someone who did not realize that she did not know about her deceased older sibling first mentioned her sibling’s existence. Silence, whether perceived positively or negatively by the respondent, reinforced and communicated a certain story for the family and the respondent. By disclosing to Teresa that she had an older sibling, her grandmother challenged Teresa’s identity as both first born and an only child. Teresa’s parents divorced. The loss of their first child was part of Teresa’s family story that led to a painful separation and a long estrangement from her mother.

There’s a comment that had actually come out of my grandmother’s mouth at the time and she had said “you know well Briana”, something to the effect, “Briana was born first.” I had made a comment about being an only child and she said “Well Briana came first.” And I looked at her like, “Briana?” and she said, “well you had a sister who died before you were born.” I kind of looked at her and it kind of took me a minute to get the information,... ~Teresa, whose older sister Briana died a few hours after birth. Teresa was 7 or 8 years old at the time that she learned she was not her parents’ first born child. Teresa’s parents separated when Teresa was a year old.

Jason’s parents also divorced and he imagined his family might have been different had his sister lived.

I would like to think that life would be different and that my parents would have maybe still been together. ~Jason, age 31, whose sister Shelly died in a drowning accident at age 3.
There may have been a large gap between the living siblings, explained by the death of the sibling.

Um, yeah, because my oldest, my older brother, there’s five and a half years difference in us. This brother (who died) would have been in between us. He was closer to my age and you know I would wonder “What would it be like if I had one that was only two years older?” You know probably when I was little the five and a half years wasn’t as big, but as we got older and I’m ten and he’s sixteen, well a 12 year old brother would have been a little different than the 16 year old brother. ~Grace, age 50, whose brother Hank died when he was one day old from Hyaline Membrane Disease.

Respondents frequently mentioned identity of family constellation as a result of the sibling’s death. This certainly contributed to the respondents’ understanding of that piece of their family story, the piece that explained the particular arrangement of their family.

**Family Constitution.** Some of the stories about their deceased siblings also explained the make-up of the family, what identified its members. Some were aware of their sibling because of comparisons made. Allison’s parents described the baby they lost as having features similar to their mother’s. The few memories shared about Abigail reinforced Allison’s identity of sharing a closer resemblance to her dad’s side of the family. Allison describes her parents as “not very open” kind of people, but when she thought about Abigail, she thought about how sad it was that, if Abigail had lived, she would have looked like their mother, thus in Allison’s mind, part of the loss was for her mother who did not have a living child that resembled her.
I mean I always knew about her when we were pretty young. Because I kind of looked like my dad’s side of the family and so we always knew that Abigail looked more like my mom’s side of the family. ~Allison, whose sister Abigail died from ‘complications during pregnancy’ shortly after her birth. Abigail died several years before Allison was born.

Jason’s family also shared stories connecting him and his brother to their sister who died, affirming their similar sibling identities or traits.

All of my family was very open, you know my aunts and grandparents, and then at just random times, something would come up and they would be “Oh you know what? Shelly used to do something like that.” ~Jason, whose sister Shelly died in a drowning accident at age 3, prior to Jason or his brother being born.

Jason also attributes the beginning of his own story to his sister’s death and his parents’ grief. In his own words, he was “conceived apparently within the grief.”

Brenda understood her family’s chosen religious affiliation to be the direct result of her brother’s untimely death. Here is a very clear example of how the sharing of memories reinforces a family’s identity in terms of their faith identification. This participant (born several years after her 5 year old brother died) was baptized herself before leaving the hospital and, while she didn’t share a concern for her brother’s “soul,” her own children were baptized while very young. This was one lesson lived out from the story of her brother’s untimely death.

So I think on her part it was a lot of guilt that she, you know that they had never had him baptized. It was not, it wasn’t their conscious choice not to baptize him... they just had never had him baptized. ~Brenda, aged 50, whose brother Richard died from an accidental fall at age 5, years before Brenda was born. Her parents were Catholic, but
the priest indicated that it was a ‘problem’ that Richard had not been baptized which was so painful for her parents that they held his funeral at the Presbyterian Church instead and raised their subsequent children in the Presbyterian Church.

If the child died of a genetic illness, the participant may have always known that they too were tested or they understood their risk of inheritance. The sharing of their sibling’s memory reinforced their concerns about the possibility of being medically vulnerable to certain conditions.

Cause all of us kids were tested as well, once we were one, just to make sure whether we were carriers or um you know had it. ~Paige, who had two siblings die from Cystic Fibrosis prior to Paige being born. Her sister Vicki lived until age 5. Jack died at two months.

The memories shared reinforced familial and individual identities. Again, the event of loss only became a shared memory after the parents included the subsequent siblings in the telling of it. The memories of the siblings connected the respondents to their families through understandings of their unique family structure, or their shared identities within the family composition.

Morals Shared

Many of the stories taught lessons, like Brenda above who had her own children baptized very young as a result of the story of her brother who had not been baptized prior to dying. Families would use the stories to highlight the importance of faith or health care. And they modeled ways that their family grieves or talks about the dead. “We rely on memory for the provision of symbolic representations and frames which can influence and organize both our actions and our conceptions of ourselves” (Mitzal 2003: 13). The sharing of memories as a
family helps evaluate the past in relation to the present and future, informing our affect and behaviors (Middleton and Edwards 1990: 39). The themes of the lessons shared centered primarily on faith, and family practices in relation to grief or how (or even whether) to talk about death.

**Faith.** The following respondents felt that faith, or a greater understanding of the universe, was a lesson learned from their siblings’ deaths. In sharing the memory of the sibling who died, parents instilled either a religious faith or a belief in a spirit. They also taught that death is a part of life.

*My parents were very religious, very Greek Orthodox, and death is not something to be feared. It is simply God’s will and yes, while it makes you sad, you know, my mother accepted it.* ~Madelina’s brother was born still from unknown causes before Madelina was born.

*I do believe he (Donald) has helped me in my spiritual path. Being closer to you know realize that life goes on, that we are only on Earth for a short period of time, but our energy and spirit lives on.* ~Cathy, age 60, whose brother Donald died at the age of 2 from a head injury. Cathy was not born when her brother Donald died.

*Um, well I appreciate my mother telling me about her experience. And giving me her point of view that sometimes the spirit and the body just don’t agree and it happens.* ~Jackie, age 35, whose brother Fred died from a heart defect a few hours after he was born. Jackie was not yet born when Fred died.
**Remember.** Kiley and Brenda’s parents taught them that it was important to remember family members who died, instilling a duty to honor and not to forget.

*My mom always said she wanted to keep it like up for the ‘open thing’. She said she never wanted it to be like a thing for me and my sister. Like (if) we weren’t told until we were like 12, like “oh I didn’t know we had a sibling.”... I think like my mom has always been very open about it. She would always say, especially with Dexter, is her biggest thing is she didn’t want him to be forgot(te)n ever. ~**Kiley, who had three siblings die before she and her living sister were born. She had an older brother who lived to almost 8 months, but then died due to complications from prematurity and she had a brother and sister who were twins, who died very shortly after their birth also from prematurity.***

*I think I was taught about remembering your family members who have passed away and what and how they’re remembered. ~**Brenda, age 50, whose brother Richard died when he was 5 years old from an accidental fall.***

*I also loved that my mother who lived to be 90 made us promise that my sister Christina would be included in her obituary upon her death. ~**Margaret, age 60, whose twin sister Christina died 2 days after they were born.***

**How to grieve.** Some families stressed openness in discussion of the dead and their emotions, while others reinforced death as a taboo topic. Eileen took the virtue of strength in the face of adversity as a lesson from her sister’s death.
Yeah. I always think now, not when I was younger, but now, if I am half the woman my mom is I will be a good person. I mean I will get through everything... She always was a strong woman and so for me... you know it was just like she just picked up and went on no matter what happened she just kept going. ... ~ Eileen, age 28, whose sister Regina died from unknown causes when she was 2 days old. Regina died about eight years before Eileen was born. Eileen learned about Regina at the time that her father died, when Eileen was seven years old.

And, Karen learned that expression of emotion is a good coping strategy when faced with loss.

To know also they can talk about it with them, these things happen, these emotions are there, this is what will happen. It’s okay to have these emotions. It’s okay to ask questions. ~Karen, age 29, whose sister Ruth died a few hours after she was born. Karen was 2 ½ years old when her sister passed.

Several respondents’ families modeled silence or withdrawal around the loss of their sibling who died. Salena’s family did not talk about people who died, or their feelings. It was viewed as questioning God.

My dad never talked about him. But as you know, our family, we don’t talk about the dead. We don’t talk about the people. We just kind of let people lay to rest...I think I would be the same because that is how my whole family is. Like I don’t want to be like that. I don’t want to forget my kids and it’s going to be hard for me.~ Salena, age 31, whose brother Albert died from heart problems when he was 8 years old. Salena was born many years after Albert died. Sadly, Salena herself lost two young babies.
Paige was one of the respondents whose parents had different styles of communication about the sibling(s) who died. In Paige’s case, she appreciated the openness she experienced from her mother, who shared memories of her siblings as well as her own feelings as a grieving mother. Her father, however, modeled that death is a taboo topic.

_The only thing I know of them is when mama would talk about them… I went to my dad’s all the time, but we never discussed the dead._ ~Paige, who had two siblings die from _Cystic Fibrosis prior to Paige being born. Her sister Vicki lived until age 5. Jack died at two months._

The lessons the families shared from the memories included messages about beliefs in regard to life and death, and family practices in relation to emotion and talking about death. As opposed to the parent-child reminiscing in the Middleton-Edward study, where the memories involved events in which the children participated, these participants’ memories were from a family history during which they were not yet born. The memories shared by the parents brought the participants into the family story and through the sharing helped make sense of present family practices.

**RITUALS AND REMEMBRANCES**

Rituals and commemorations reinforce relationships and help construct shared memories, “the acquisition of shared forms of seeing and experiencing” (Miztal 2003: 127). Knottnerus argues in _Ritual as a Missing Link_ (2012) that rituals “are a crucial aspect of people’s cultural life, interpersonal relations, and the group dynamics operating in the many social environments most individuals move through in their daily lives” (4). Therefore, the study of rituals can provide clues to the cultural meanings attributed to the memories (Knottnerus 2012). Social memories are located in commemorated events (Miztal 2003: 13), therefore many of the rituals
described below reinforce the meanings already described and contribute to the family memory of the child who died.

Families remembered and honored the siblings who had died in various ways. Pictures, if they existed, were a common way of sharing memories. As Ted, below, states, pictures helped make the sibling real.

*Of course when you’ve got all kinds of pictures and this-that-and-the-other thing, it just keeps everything alive in your mind.* – *Ted, aged 57, whose older brother died around the age of 5 from an accidental hanging. Ted was only 9 months old at the time of his brother’s death.*

Some families did not have pictures, especially if the child was quite young or never came home from the hospital. One participant knew there were pictures, but they had been lost in a house fire. Some of the participants recalled seeing pictures or a video of the funeral. Families framed and displayed pictures, or tucked them safely in photo albums, or photo or memory boxes. Certainly, families that had a more open communication style had these items out on display or easily accessible in a memory box or special location. Families with a closed or protected communication style generally had these items tucked away, if they had them at all.

Gravesite visiting was another common way for participants to share in the memory of their sibling who died. Often on special dates, the child’s birthday or Memorial Day, the family would go to decorate or just visit the grave. Others began including visiting their sibling’s grave after other members of the family died and were buried nearby. Some have moved away from the town where their sibling is buried so no longer visit or only visit when they are back in their hometown. While not all families used grave visiting as a ritual, if parents modeled that for them as children, it was often a tradition they carried on. One participant, Teresa, whose sister’s life
was a well-kept family secret, as an adult sought out her sister’s gravesite as a “mission of closure” for the sister she never knew.

Rituals

Rituals are the repetitive behaviors to which we attach symbolic meaning (Smit 2011). Rituals affirm membership in the family and provide a general sense of family identity, connect the past to the present, and help keep family memories alive (Smit 2011: 361). Respondents had different levels of engagement with the rituals that existed to remember their brother or sister who died. The rituals varied in formality of ritual, life cycle participation (childhood only or ones they continue today), and whether it was a public or private event.

*Formal rituals versus rituals of everyday living.* Participants were included in formal rituals that remembered or honored their sibling, such as graveside visiting or remembrance masses, as well as everyday rituals. Dinner time conversation might be one time that families remembered their missing member, or in response to “poltergeist activities.”

The following respondent, Caroline, grew up in a large family. Her sister Gwendolyn died at the age of nine, several years before Caroline was born. Caroline knew that her oldest living sister looked almost identical to Gwendolyn from pictures shown as well as family stories told. Caroline relays her mother’s concern that Gwendolyn’s death was particularly hard on her oldest sister and says she often talks about Gwendolyn with that sister. Gwendolyn was also born on the same day as one of Caroline’s nieces, so on that niece’s birthday, several family members would remark that Gwendolyn would also be turning the same age. Caroline was included in formal rituals of remembrance and in fact, carries them on today. Her mother stressed the importance of keeping her sister’s memory alive, which Caroline continues to honor even now that her parents have passed.
Yes, my mom you know always made us aware about her and she always talked about her birthdays and things and we always went to the cemetery, and we continue to go to the cemetery you know on her birthday and Memorial Day, even though my parents have passed away. She’s still a part of our lives even though she’s not here. Still honor that.

~Caroline, whose sister Gwendolyn died at age 9 from pneumonia. Gwendolyn died before Caroline was born.

Kathryn and Violet, in the following quotes, describe informal, every day and lighthearted ways that their siblings were remembered. Though a lighthearted ritual, this family shared their belief in an afterlife, angels.

No, I mean we would sit at the dinner table. We’re a Catholic family and just say, you know, she is an angel. And if the front door happened to open, like the wind hit it, we would be like Jasmine is joining us for dinner… Yeah, yeah, it was always a good thing when we talked about her. There were always smiles, there were never tears talking about her. “Kathryn, age 29, whose sister Jasmine died at age 1 day, unexpectedly but from presumed prematurity. Kathryn was born approximately 4 ½ years after Jasmine died.

In my growing up years, she would get mentioned, and every now and then, one of us would wonder, “I wonder what it would be like if she were here? What would she look like? What would she be doing? You know, would she be smart? Would she help me with my homework?” ~Violet, whose sister Denise died at 2 days old from a heart defect. Violet was born 3 years after Denise died.
Parents initiated both formal and informal rituals for their children, which then became shared experiences. The respondents above clearly respond to their parents’ invitation to ritualize their siblings’ memories by contributing their own ideas to the experience.

*Childhood rituals versus rituals carried into adulthood.* There were times when the respondents discontinued a tradition they had as a child. Often, respondents mentioned that they no longer lived in the city where their brother or sister was buried, so could no longer visit the gravesite. Other times, they were simply rituals initiated by their parents, which the family eventually stopped doing as time moved them further away from the loss. Some of the participants continued rituals started by their parents or started new ones with their own children in order to honor and remember their sibling.

In the following excerpt, Kathryn explains that it was the ritual that she shared with her mother that made her comfortable in talking about her sister who died. They would bring a wreath to her gravesite on special occasions.

> *I think I was comfortable (talking about her sister) because it was, we had our ritual, you know, so it never... I never felt uncomfortable about it.*  
> ~Kathryn, age 29, whose sister Jasmine died at age 1 day, unexpectedly but from presumed prematurity. Kathryn was born approximately 4 ½ years after Jasmine died.

Even without a special occasion, they would sometimes go to the grave to visit, which is a tradition that Kathryn carries on to this day with her own children. Kathryn’s use of the term ‘baby garden’ is a cultural clue to the special significance attributed to the loss of a child.

> *My kids will always go and they know that in the baby garden you look at the statue and she stares right at Jasmine and that is how I find her and it’s kind of like a game*
for them. They will look and they will try to find her. ~Kathryn. A “baby garden” is an area in the cemetery where the infants are buried.

Every single year on our birthday, you know at Church, you can just bet on it my mom is going to stand up and give her testimony and how everything that happened and like she tells the whole story every year. And like, so yeah, it’s always been a big part of our life and everything. ~Macy, whose twin died, shortly after birth. Macy spent years observing her mother “testify” about her loss to her fellow church members in honor of Macy’s and her twin Cole’s birthday.

Macy goes on to bring Cole’s memory along on other occasions where the two should have been together in life.  

We had a memory candle for him at my wedding. And, when I graduated from high school, it was like the thing to get your hat spray painted. And, so I just had like his name just spray painted in the corner of my graduation cap. ~Macy

For Kathryn and Macy, the rituals started by their parents held deep enough meaning for them to continue them in their adult life. Their connection with their sibling had become real enough for them to continue to honor their memory in their own way.

**Public versus private rituals.** In addition to ceremonies at church or rites of passage, such as graduations or weddings, respondents talked about more individual and private ways that they memorialized their sibling who passed.
Kim’s sister died the day after Thanksgiving. Kim, though her parents did not talk a lot about Jenny when Kim was young, did understand from her parents’ stories the reason that their family had a “non-traditional” Thanksgiving meal (something besides turkey and mashed potatoes) and heard enough to understand the pain for her parents at such a young age to lose a child. As a mother now herself, she especially relates to the parental grief and has her own private ritual of prayer whenever Jenny crosses her mind.

*I actually say a prayer every time I think about it for any parent who’s lost a child.*

~Kim, whose sister Jenny died at age 4 unexpectedly during surgery due to an unexplained illness about 1 ½ years before Kim was born.

Sophia always knew about her brother Sam, who died before she was born. When her parents were still married, they would visit the gravesite together often. After her parents “split,” Sophia would go alone whenever she was in the town where he was buried. She understood from her family stories that her mother wanted a divorce after Sam died, but then after conceiving Sophia, her parents postponed the divorce a few years. Sophia had her own private ritual of making trinkets for Sam on Sam’s birthday when she was young.

*I remember when I was little I started like after my parents split. I had this little box of trinkets and I would make something for my brother for his birthday. I did that until I was like in high school… But I don’t know. I think the reason I used to make those trinkets and stuff is that my parents did something unusual where they split up my living brother and myself when they divorced. So I essentially grew up as an only child even though I had a sibling and should have had two siblings. So…I just, I wanted to pretend that I had brothers.* ~Sophia, whose brother Sam died at age 2 from heart complications and Down Syndrome.
Even if some families did not talk much about the child who died or weren’t included in public or formal rituals, some participants were able to link their parent’s behaviors or emotional responses at certain times of the year with their brother or sister who died. They covertly observed their parent’s more private rituals of remembrance.

*I know my mother had several like nervous breakdowns. And I just remember it seemed like whenever one of those happened, the subject of her (Katy’s sister who died) would come up. You know my mother was really sad about it.* ~*Katy, whose older sister Maureen died many years before Katy was born. Maureen was stillborn, unknown cause of death.*

*Well I started putting the pieces together that when it was around his birthday it was pretty common that was why mom was crying in the living room.* ~*Cathy, aged 60, whose brother Donald died before Cathy was born. Donald died at the age of two from a fall and head injury while hospitalized for a chronic illness.*

The respondents engaged at all different levels of ritualizing their siblings who died, formally, informally, publically and privately. They initially participated as witnesses to rituals that their parents generated, then, for some, those rituals became traditions that the participants themselves either carried on or made their own. They talked about the duty to honor or to keep their sibling’s memory alive as reasons for carrying on their sibling’s memory.

**Remembrances**

The bereaved often use props, such as photographs or other items that belonged to the deceased, to highlight stories told as they make sense of their loss (Riches and Dawson 1998). In this study, participants also talked about personal memory items, many now in their possession.
Family members kept hand or feet molds, footprints, christening gowns, blankets, and so on, in memory boxes or protected in a china cabinet. Similar to photographs, linking objects (objects that either belonged to the child who died or remind the family of that child) serve to uphold their memory, or are chosen to highlight certain traits of that child (Riches and Dawson 2000: 109).

Growing up my dad actually had at his house their birth certificates with hand prints of them and had little caps... like their little caps and they just said A and B on them. ~Edie, age 20, whose parents had twins who were stillborn before Edie was born. Edie used to like getting out “Baby A and B’s” things and looking at them when she was little.

Others had linking objects, from their brother or sister, given to them, such as dolls, toys, or a coin collection.

Of course they gave me his little coin collection and they weren’t anything valuable, but stuff he had found through the years. ~Deborah, age 56, whose brother Carl died at age 14 from bone cancer. Deborah was only a year old when he passed.

Some things remained with the family household, but acknowledged as belonging to the child who died as an honorary memory item.

There were a few toys he had as a child that my brother and I even ended up playing with. But we were always told those were George’s toys. And then there was an orange owl nightlight that was his and, um, he lived and died in a house that’s different from the one that my brother and I grew up in, and so they
brought that (nightlight) from that house to this house, and it’s still in my parents’
kitchen to this day. And so like that’s kind of George’s nightlight. ~Anna, age 32,
whose brother George died from Spina Bifida at around 4 ½ years old. Anna
and her older brother were both born after George died. Anna came along at
least 6 years after George’s passing.

Families often kept documents, birth and death certificates or memorial cards, with other
valuable papers.

Still in going through my mom’s stuff you know there might have been prayer
cards. You know us Catholics always needed our prayer cards. I still… I know I
can put my hand on one of Drew’s prayer cards if I had to. ~Samantha, whose
brother Drew died from possible SIDS or a heart condition at just a few weeks
of age. Samantha was about a year and a half old when her brother died.

Prayer cards are playing card sized cards given out at funerals and have
pictures of saints on them.

Gravesite visiting, sharing pictures or mementoes that link to the child who died, and
story-telling were all ways in which families honored and kept alive the memories of the children
who died. Rituals and mementoes symbolically tell a story. Families communicate in many
ways around the death of a child, some very openly, and some more subtly. All forms of
communication though are an interaction between people, where the memory carried on is jointly
constructed and negotiated to bear a particular meaning.
SUMMARY AND CONCLUSION

“I would hope that first of all there would be memories, whatever the memories are. Like you know you think about a scrapbook or pictures so you can make it real. Because I wasn’t born so I can’t experience it firsthand, but you know you look back at you know at great-grandparents or things that happened when you were a baby that you were too young to remember, that there would be memories. Whatever that is, if it’s a diary, or written, or pictures, and just acknowledgement so when somebody says to me tell me about your family that it’s okay to talk about it.” ~Sarah, whose sister Jessica died as a baby before Sarah was born.

Why are some topics taboo? Such things, once discovered, inform us about the culture in which we live. If the death of a child is difficult to talk about, tension must exist between families who suffer such a loss and a community that discourages their telling of that story. This chapter tells us not only how families communicated about the death of a child, but what they communicated. If we understand some of the themes communicated about the loss to subsequent siblings, we might better understand people’s motivations to share that story. The loss contributed to respondents’ understandings of who they were, as individuals and as a family, unique from other families. The rituals were symbolic reenactments of those same lessons from the stories.

Memory-work is done in social interaction. We construct memories through our exchanges with others, depending on the parts of the story that actors wish to highlight. Sharing memories connects individuals to a community, their family and larger culture, providing identity (Middleton and Edwards 1990; Miztal 2003). In this chapter, I described the ways in which the families represented in this study constructed the memories of a child who died. The
respondents in my study never personally knew their sibling who died while they were alive as the respondents were either not yet born at the time of the loss or were too young to remember.

Finding out was only the first step. Having ‘always known’ about a brother or sister did not guarantee that the topic was openly discussed in the family. Communication styles in families represented in this study varied from very open to extremely secretive. Silence however, did not mean that there was not a story. Families constructed together stories and lessons from those stories through their narratives and rituals.

Memories are stories shared and constructed between individuals. Some of the participants had heard the story often enough to be able to recite certain details. “Through the repeated recall of the family’s past – usually via oral stories which are told at family get-togethers – those who did not experience past events first hand can also share in the memory” (Erll 2011: 306). Those stories inform individual and familial identities and inform behaviors such as learned coping styles.

It is difficult to tell a story, whether of oneself or another, without there being a moral component in it. Indeed, the very manner in which the story is told, its mode of ‘emplotment’ [White, 1978], implies a moral stance; one has made a narrative choice, to tell this sort of story rather than that, and this choice often issues from the most fundamental beliefs, values, and ideals that one holds (Freeman 1991: 98).

Family constitution, and constellation are all ways that familial identities are informed by the sharing (or not sharing) of deceased members’ memories. Memories inform individual identities, to whom we are related, how we came to be, or certain shared personal traits. And memories as stories are lessons, perhaps opportunities to model how to cope with adverse events.

Remembrance rituals allow the bereaved to honor their loved ones and to maintain some connection to them, thus maintaining the bereaved person’s identity in relation to the person who
died (Toller 2008). Grave tending or visiting, especially on significant dates, was a recurrent theme among the participants. Besides rituals, the stories that are shared through keepsake objects and photographs affirm the life that once existed (Blood and Cacciatore 2014; Riches and Dawson 1998). Pictures mostly, but also other memory items, were available in their childhood homes for many of the participants to be cherished. They served as a means to connect to the sibling who died. Now adults, some of the participants still had such keepsakes in their own possession or continued their own rituals. Rituals are a symbolic retelling of the story (Mitztal 2003). In the next chapters, I will discuss the relationships that developed as a result of the shared construction of these memories, and the meanings those relationships held for the participants in the study.
FOUR

“There but not there”: Symbolic Relationships with Siblings Never Known

Jennie is a 24 year old young woman who was born after her parents lost a 4 year old boy. Jennie’s older brother Eric had a rare blood disease which ultimately led to a cardiac arrest. Two years after Jennie was born, she had another sibling, this time a sister. Jennie’s sister Rachel was diagnosed with the same rare blood condition that Eric had. Jennie grew up wondering if her friends’ siblings had g-tubes also. When Jennie was seven years old, Rachel also had a cardiac arrest and died suddenly, at least that was how it felt to Jennie. So, from age seven on, Jennie’s parents raised her as an only child. But, even before Rachel died, Jennie felt she knew about death. She always knew about her brother Eric, a sweet four year old who loved to snuggle. Pictures were around and her parents often told her stories about him. Every year on his birthday, they would light a candle and go to the cemetery to release balloons with messages on them. These traditions continued after Rachel passed as well. On Christmas, Jennie’s parents would still hang stockings for Eric and Rachel and each of the children would have a new ornament hung on the tree. As a family, they would talk about what things would be like if Eric and Rachel were still alive. Jennie misses the companionship she imagines she would have had with a sibling. In Jennie’s words, Eric and Rachel are still with them. She still talks to them and senses their presence. She keeps special objects – a blanket of Eric’s and one of Rachel’s favorite toys as precious keepsakes to remind her of them. She also feels they have influenced her in a positive way. Her daily mantra is “No excuses.” She feels that since she is able to live and
her siblings were not, there is nothing she cannot do in their honor. “Instead of living one life, I live three.”

In the last chapter, I talked about how families do memory-work through their interactions, namely through narratives and rituals. This chapter addresses what ensues from the memory-work, symbolic relationships with siblings never known. Clearly, Jennie feels connected to her siblings. They are part of her life as sources of inspiration, and spiritually as protectors. While at age seven she was old enough to have her own memories of her sister Rachel, she had to rely more heavily on outside resources to construct memories and images of her older brother Eric. Jennie is one example of participants who developed a relationship with her sibling never known, and her images of and interactions with Eric and Rachel are but one kind of theme that emerged from the interviews.

The siblings of the participants, though never known to them as living, physical beings, become real through the stories told, memories shared, and rituals observed. Though no longer physically present, these deceased siblings are symbolically present, and thus capable of being one of the actors in a social interaction (Bender 2008, Cerulo 2009). Cerulo argues that many nonhuman entities (animals, God, technology, memories, the dead) can be considered legitimate participants in a social interaction in that they have the ability to make things happen within the actor-network (2009:534). For example, prayer is an interaction with an imagined other shown to provide emotional solace to victims of abuse (Sharp 2010). One aim of my study was to explore the influence of the loss of a child in a family on members of the family who did not have a lived relationship with the deceased child. In other words, did an imaginary relationship develop between the participants and their siblings? What did those imaginary others look like and what did they mean to the participant? In this chapter, I describe symbolic relationships that developed
between the participants and the memories and images of their deceased siblings. In the next chapter, I address the various meanings that participants attribute to the loss of their sibling(s) never known to them.

What informs the participants’ symbolic images of their deceased brother or sister? I argue since family is the context in which we do much of our meaning making after loss (Nadeau 1998, 2001), that the participants’ families mediated larger cultural images of what it means to be or have a sibling, and who are the dead. For example, another symbolic image held by many is an image of God. “The construction of images of God, like the construction of images of self and other, arises from a mix of interpersonal relationships, cultural context, language and the personal unconscious” (Stone 2004: 2). For example, “God as mother or God as father” would rely on social images of mothers or fathers and would be bound and determined by a culture’s available variety of ideas of gender. God as father could be patriarchal, authoritative, or punitive. God as mother could be nurturing and comforting (Stone 2004). In other words, symbolic images are formed by our interactions with others but limited by the cultural symbols at large. Interactions with God through written or spoken prayers have been studied to better understand the effects on people’s coping (Grossoehme, et al. 2011, Sharp 2010).

As opposed to culture being understood as something exotic or unique to certain groups, Swidler approaches culture as something that is used by individuals to make sense of their experience, a context, often with a variety of options within which to frame meaning (2001: 5). Culture is “the publicly available symbolic forms through which people experience and express meaning,” (Swidler 2001: 12), providing a repertoire of resources to guide individuals as they create meaning (Swidler 2001: 24-25). In this case, interactions with family members (as described in Chapter 3) helped mediate larger cultural influence as participants gave meaning to
their experience of having a brother or sister whom they never personally knew. To place this study in a cultural context, the participants generally represented Midwestern Americans. Recall that demographically, though largely female, this study of 49 respondents had a nice representation of low to upper-middle class.

Like Jennie, many of the participants in this study feel they have a relationship with their siblings even though they never knew them, though a few did not describe it as a ‘relationship.’ However, each of the respondents acknowledges some type of bond or relationship by the mere fact that they responded to my query for participation in this study. In this chapter, I describe the different categories of imagined relationships, and the numerous ways that participants interacted with the imagined other. Although at some level all bonds are constructed via social interactions, I conclude this chapter by discussing how the bonds I address in this dissertation – the ones people have with a dead person they have never met (constructed bond) – both differ from and are similar to the kinds of bonds people have with dead people they once knew (continued bond). Bereaved persons continue bonds with deceased loved ones as part of their adaptation to loss (Field et al. 2004, Klass 1993, 1997, 2006, Neimeyer 2001, Weiss 2001, Worden 2009). For persons who never knew the decedent in life, their constructed bond is always symbolic and their grief expression, if there is one, is diluted.

**RELATIONSHIPS WITH A DECEASED SIBLING**

A symbolic other is one who exists figuratively in our minds. Dennis Klass found in his work with bereaved parents that ongoing interaction with the inner representation of their deceased child brought solace in the parents’ grief experience (1993). The inner representation is the symbolic image that the bereaved parents hold of their deceased child. The parents in his
study symbolically related to and interacted with their deceased children (1993: 345).

Participants in my study also describe symbolic relationships, but with siblings they never knew in life. In chapter three, I talked about how families constructed memories of the child who died together through stories and rituals. This chapter explores the resulting relationships with deceased siblings never known for the respondents and how those are socially constructed and culturally bound. I asked all respondents if they felt they had a relationship with their brother or sister who died. There were a few cases where I did not directly ask about relationship, but the participant had already made a statement which in essence answered the question. While some of the respondents clearly and quickly responded, many gave more elaborate answers which I could not easily classify as a simple yes or no. I did not give a definition of relationship to the participants but allowed them to interpret that in their own way.

The following are the three themes that emerged of the images of the participants’ deceased siblings; spiritual, familial, and legacy. For many of the participants, the image of their sibling or the description of their connection to their sibling fell into more than one of the categories described further below even if they appear to be competing images. Spiritual images relate to religious beliefs in an afterlife, either presently experienced or hoped for in the future. Familial images draw on ideas of what it means to be family or to be a sibling. Legacy images referred to notions of what ensued personally for the respondents from the sibling’s passing.

**Spiritual**

A spiritual image of their brother or sister would be a spirit of some sort, either presently felt or one that the respondent felt they would meet one day in an afterlife. These images come from stories told by their parents and relied on respondents having a faith tradition that allows for an afterlife.
**Guardian Angel.** Frequently respondents used the term “guardian angel” to indicate a caring spirit when they described their sibling and felt some type of force that had the power to intervene, protect or bring about positive outcomes. Participants believed these spiritual beings would watch over and possibly intercede in the lives of the respondents or their loved ones. Again, these were often stories that began in their childhood, but bound by a larger culture. If the respondents did not belong to a culture, religion, or faith tradition, that endorsed spirits or an afterlife, they would not have the cultural tools to activate such an image or would reject such images as ones that countered their own belief system (Swidler 2001).

*I feel he is one of my guardian angels. And I can’t tell you even why I think that, but you know how you feel a presence of something that’s positive in your life; that time you know you are going across a bridge and there’s this huge accident and for some reason if you had been ten seconds earlier you would have been in it. Or you know. So I do believe that he is a guardian angel that watches over me and I don’t know why I even think that.* ~ Cathy, whose brother Donald died at the age of two from an accidental fall. Donald died before Cathy was born.

*I always felt when I was growing up was that she was my special guardian angel. That she was always looking over me. That she would keep me out of harm’s way. You know ‘cause...*

**M:** Uh huh. Is she still that for you today?

*I think so. Yeah. You know I still feel her presence you know ‘cause I’m kind of a spiritual kind of person. And so I know she’s around, and I know that she was you know*
there to greet my parents when they passed. You know, and so there was you know a
great big old party. ~Alice, whose sister Emma died at the age of 10 from Cerebral
Palsy. Alice was a year old when her sister passed.

Well, I don’t necessarily think I have a relationship. I just know they’re there. ~Alexis had
two sisters die from a rare genetic illness. Alexis was two years old when her first sister
died at age 3 months, and then almost four years old when her next sister died at only a
week of age.

Nicky, below, demonstrates how her previous image of her sister as a guardian angel does not fit
into her current culture of medicine and reason so her symbolic image has changed as Nicky has
reconstructed herself and her relationship to her sister.

I’m a doctor now and um I guess I’m less emotional than I used to be, and I don’t know if
that’s all the training that kind of trains it out of you and um... I don’t know, now I just
see it as a kind of unfortunate event that occurred... I mean I believe in God, but I don’t
think I’m as religious as my mom is. So I just kind of see that as a cute story that she told
me. ~Nicky, whose older sister died approximately 9 hours after birth. Nicky was
named after her sister, and was told as a child that her sister was her guardian angel.

Spiritual – Future Relationship. In addition to a present-day apparition of sorts,
participants described another way they experienced a spiritual connection to their sibling,
through the notion of a future relationship, in ‘heaven’ or some celestial afterlife. Again, such an
image depends on a cultural/ religious system that provided the possibility of life after death.
No, not really. I know I will see him again in heaven, but other than that not like a current relationship, no. ~Deborah, whose older brother Carl died at age 14 from bone cancer. Deborah was only a year old at the time of his death.

I know we all come here for a purpose; some you know longer than others, but I guess she had other work to do in the heavens above. And I just hope and pray that I see her again one day. ~Janelle, age 39, whose sister Melissa died at 7 months from an irregular heart. Janelle was born after Melissa passed.

For me, I just can’t wait to meet him someday, you know. ~ Macy, whose twin died shortly after they were born.

She is still my sister, my sister that I will meet sometime. ~Kathryn, age 29, whose sister Jasmine died at age 1 day, unexpectedly but from presumed prematurity. Jasmine died before Kathryn was born.

But I think I will someday see them. I believe in heaven and they are there and I think someday I will have a chance to meet them and maybe figure out why this all happened. ~Kiley, who had three siblings die before she and her living sister were born. She had an older brother who lived to almost 8 months, but then died due to complications from
prematurity and she had a brother and sister who were twins, who died very shortly after their birth also from prematurity.

**Interactions with Spiritual Symbolic Others.** Respondents expressed different ways that they interacted with their ‘guardian angels’, from having conversations in their head, invoking their presence for protection through prayer, or wondering if they were watching over them. These are varying expressions of the symbolic spiritual bond.

*I think about him a lot and I wonder if he is watching over me right now or is seeing (my daughter). I have a 2 and ½ year old and if he sees her and things like that.*

~Macy, age 28, whose twin brother died 12 hours after they were born.

*I would say someone to talk to in times of trouble, you know in my head.*

~Andrea, age 39, whose brother Robert died at about 1 ½ months of age from leukemia.

Andrea was not born when her brother died. *This was in response to the question, “Who is your brother to you today?”*

*So I went (to her gravesite) and I had a little conversation with her. I took my younger brother that I now have custody of and he got to say goodbye because he had never seen it either.*

~Teresa, whose older sister Briana died a few hours after birth.

Teresa’s younger (half) brother Brian grew up knowing about Briana from their mother but Teresa lived with her father who revealed very little information about her.
I still think of her on occasion. Like I said, my mom would pray to her because she said, “Well she never sinned so that means she is in heaven. She is a saint”. So there are times when I am feeling a little desperate about my children. I’m like, “Okay, I hope you’re up there praying for these nephews that you have.” — Maureen, whose sister Peggy died from Down’s Syndrome and other complications at 1 ½ years.

Maureen was 6 months old when Peggy died.

The spiritual theme included both an image of their sibling being a celestial presence that was watching over the respondents at times, and/or a spiritual form that they would one day meet when the respondents themselves pass away. Interactions with the spiritual images of their brother or sister who died, the ‘guardian angels,’ included prayer, talking to their siblings, or a felt sense of another presence being near.

Familial

Another theme that emerged among the categories of symbolic images of the deceased sibling never known was one that evoked the notion of family or family history. Stories which counted the sibling as part of the family or social and cultural definitions of what family meant constructed and informed these bonds. In our culture, a sibling is a “companion, protector, or simply a solid figure in the child’s world” (Rowe 2007: 195).

Family. Many respondents stressed that they had a brother or sister, even if they never knew them in life. They pointed out the shared DNA, the genetic, biological link to their sibling. They might distinguish the genealogical connection from an emotional or spiritual connection. The image of some of the siblings never known was also simply a name on a family tree.
No, no I don’t see myself as having a relationship. Because she was like I said, she was never talked about. She was never an active part of the family. I mean she was… she has a name; you know she was born into the family, but it’s not somebody who was an active part of the family. You know it’s… she’s somebody that’s there but not there. ~Suzanne, whose sister Julia died at age 6 months from a respiratory illness and her parents never talked about it. Suzanne pieced together later that her mother was expecting her when Julia died.

I always thought of him as my big brother. That’s kind of… that’s kind of weird. I don’t have a relationship but I always felt like I have a big brother. ~Brenda, whose brother Richard died from an accidental fall at age 5, years before Brenda was born.

Um he’s just a brother that I don’t know. No relationship. Somebody that I didn’t know, but feel like because of mom’s discussion I was talking about, that I somewhat know him. I feel like I should know him but I don’t. ~Grace, age 50, whose brother Hank died 36 hours after his birth.

I guess she kind of fits in my mind the same way my grandparents who passed away before I was born. They are part of my family in the sense that they are related by blood, but they are not a person that I have a personal relationship with. ~Eileen, age 28, whose sister Regina died two days after birth.

My mother’s grief. Beyond the name on the family tree, another familial symbolic image of their siblings was the resulting emotion from the sad story, the history that puts their family
together in a particular way. This image of the deceased sibling was the felt grief, the tangible emotion left behind and still witnessed even by members of the family who never knew the child who died.

Who are they to me today? Again, I think it’s just um... I didn’t know them. They’re my mother’s grief, which bothers me. ~ **Paige, age 52, who lost two siblings to Cystic Fibrosis before she was born, Vicky age 5, and Jack age 2 months.**

Um... oh golly, I really haven’t given her much thought. She’s not what I would consider a part of my life. Um...you know, just I guess I would consider her a painful part of my parents’ life. ~ **Carrie, age 53, whose sister Martha died when only a few days old from prematurity. Carrie was not yet born when Martha died.**

I just think of Abigail as like just sadness you know. ~ **Allison, age 27, whose sister died from unknown complications after a few weeks. Allison was not yet born when Abigail died.**

I never met her or knew her at all. I just kind of feel the pain because I sometimes see it in my parents. ~ **Jason, age 31, whose sister Shelly died at age 3 in a drowning accident before Jason was born.**


Interactions with familial symbolic others. Respondents who described a familial bond also expressed their relationship with their sibling in ways socialized to honor family. Many respondents describe their own rituals to remember or honor their sibling’s memory, especially if modeled for them when they were growing up. Most often it was the cemetery that would be a place that made the respondent feel close to their sibling, especially, but not always if they were included in a grave tending ritual in their childhood. Again, families mediate culture in giving meaning to our experiences.

On her (Gwendolyn’s) birthday, my mom and dad always went to the gravesite and on Memorial Day they always... Well, we still go even though my parents have passed away. ~Caroline, whose sister Gwendolyn died at age 9 from pneumonia.

Gwendolyn died before Caroline was born.

I wouldn’t say I have a relationship, but I always say I have a sister. I have gone myself to the gravesite. And I have talked out loud, which seems kind of silly. ~Jason, whose sister Shelly died in a drowning accident prior to Jason or his brother being born.

Participants described the family tree image of their siblings in less emotional terms and the bond was more matter of fact, a simple fact of biological connection. However, participants expressively describe the familial image of their sibling as an emotion. The child never known, still not believed to be known, is described as a resulting, lingering sadness, ‘my mother’s grief.’ Interactions with the familial image of their sibling were usually through participation in some type of memorial, cemetery visits, or other symbolic means to honor or remember their sibling.
**Legacy**

Legacy was a theme that emerged which indicated some sort of inheritance from the sibling who died before the respondent was alive or old enough to know them. For some, the legacy was clearly positive; the respondents felt more valued by their parents and attributed that directly to their parents’ experience of having lost a child. For others, the legacy was less positive, or at times even negative. They were left with the burden of living the life their sibling could not, to carry on where they left off. They sometimes felt compared to their deceased sibling. A symbolic sibling rivalry is difficult to live up to due to the idolization of the dead child.

*I mean I do, because you know in just a way because she is part of the family you know. You know families have great experiences and they have terrible experiences together, but you somehow find a way. I mean she saw experiences in her young life and experienced something in my parents’ early marriage that I kind of feel like, okay I took off where she left off, you know? So I do feel connected, but I’m sure not to the degree that you know obviously my brother and sister do.* ~ Kim, whose sister Jenny died at age 4 unexpectedly during surgery due to an unexplained illness years before Kim was born. Kim’s older brother and other sister were alive at the time.

*I live my life every day for them because they couldn’t, and that’s just the philosophy of life that I have. I try not to you know make excuses for things that I do. I try to do it in memory of them because they didn’t get a chance to do it. So instead of living one life I live three I guess.* ~ Jennie, 24 years old, whose older brother Eric died before she was born, and younger sister Rachel died when Jennie was 7 years.
I mean if they wouldn’t have had those losses they wouldn’t have known how precious my brother and I were. ~Edie, whose parents had stillborn twins years before Edie was born.

Interactions with inherited symbolic others. Many respondents attributed a certain drive and or motivation to their siblings’ memories. Whether respondents saw the drive as a burden due to a competitive rivalry, or based on a positive philosophy of not taking life for granted, respondents reported that their siblings’ legacy inspired them at times in either small daily decisions or in major life decisions. Such lessons usually emanated from stories told to them by their parents, or from their own understanding of what it must mean to lose a child in our society. In our modern society, Americans consider it a tragic and out of order death for someone to lose a child (Rando 1986).

Colleen finds it difficult to live up to an idealized brother.

I think as far as my mother goes I always you know I was always trying to live up to expectations, to be you know on the same level as he was. ~ Colleen, whose brother died in war when Colleen was a toddler at home.

Janie did not take life for granted because of her awareness of her brother’s premature death and her parents’ loss.

I remember when there was one time when I got asked to do something that was probably not real wise and all my friends were trying to talk me into it and I said no I can’t. I have
older parents; number one and I said I had a brother who died. I don’t know. I am like 16 and explaining this to people! ~Janie, age 61, whose brother Dennis died before she was born when he was 3 weeks old.

Nicky also knew not to take life for granted and took extra precautions at the time of her own delivery of a baby.

   Even when I was in the delivery room, I remember my OB said to me, well you’re negative for Hemolytic Strep and I said I don’t care if I’m negative. One death in the family is enough. I understand there’s a risk of allergic reaction. I want the drugs and they just looked at me and went, “oh, okay.” So, I got antibiotics. ~Nicky, whose older sister died approximately 9 hours after being born from a respiratory illness that Nicky’s mother believes could have been cured with penicillin. Nicky was not yet born when her sister passed but remembers that lesson from her loss. Hemolytic Strep is a condition that can be passed from the mother to the newborn if the mother has it and is prevented by antibiotics.

Paige drew on the image of her older sister to summon bravery.

   She (Vicki) was in and out of the hospital quite a bit so my mother would always bring her up when we were going to the doctor and we were gonna be getting shots or something. She would say, “Now you think of your sister ‘cause she had to have shots in her neck and she just got shots all the time and she was so big and brave.” ~Paige, who had two siblings die from Cystic Fibrosis prior to Paige being born. Her sister Vicki lived until age 5. Paige continues to remind her own children today to be brave like their aunt Vicki was.
Beyond the varying images of their deceased brother or sister, there were many ways that the subsequent siblings in my study interacted with the symbolic other. Some had internal conversations or prayers with their sibling; others ‘felt the presence;’ while others found places, people, or objects to be reminders of their sibling. Some even felt inspired or guided in their decision making by the memory. Respondents may not have necessarily felt they had a relationship with their deceased sibling, but they still acknowledged the symbolic existence of their sibling, and thus some type of bond, by interacting in these various ways.

The bond with their siblings and the image of their siblings comes from the narratives of their youth, the ways they found out, the ongoing communication, and the rituals experienced as the respondents grew up (see chapter three). Thus the relationship that the respondents describe is socially constructed. And, I say culturally bound because cultural artifacts (Swidler 2001) informed the participants as they constructed those relationships. The culture to which they belong (in this study, Middle American), provided the participants with their ideas of spiritual beings, an afterlife, what family means, what it means to have a sibling, and how to grieve or honor ancestors. The images, spiritual, familial, or legacy, though distinct, often coexisted within one respondent.

What is unique about the symbolic image of a dead sibling? Why, if a person already has images of a God, or saints, or angels available to them spiritually, or other ancestors in their family tree, do these subsequent siblings construct and utilize images of their deceased brother or sister? Dorothy Rowe (2007) argues that “remembering a dead sibling and the circumstances of that sibling’s death is a way of somehow keeping the person alive” (200). I argue that the same is true even for a sibling never known, due to our notions of what a sibling should be – protector or lifelong companion (Davies 1999, Rowe 2007) as well as our ideas of the innocence of children.
“Thus we might come to idolize a god, a saint, or some famous figure. If our first clear vision of the all-encompassing evil of the world comes with the death of someone we love then that person can become the innocent perfection that must be preserved” (Rowe 2007: 201). The subsequent siblings in this study also preserve the innocence of their siblings through their constructed symbolic relationships.

CONTINUED BONDS VERSUS A CONSTRUCTED BOND WITH SYMBOLIC OTHERS

While all bonds are socially constructed, through our interactions with others and informed by the culture in which we live, the bonds that I describe in this study are unique. These are bonds with a symbolic other, never known in life. In current grief studies literature, a ‘continuing bond’ is one where the bereaved continue a relationship with their deceased loved one as part of their adaptation to loss (Klass 1993, Neimeyer 2001, Worden 2009). In this section, I compare the continuing bond phenomenon with the constructed symbolic bond.

Historically and following the Freudian model, theorists believed the successful adaptation to loss required the severing of any bonds with the deceased. The purpose of grief work was to disengage hopes and memories from the deceased and reinvest in new relationships (Worden 2009). Experts during most of the 20th Century asserted that recovery from loss would only occur if individuals let go of the past and moved forward with their life (Neimeyer 2001). However, more contemporary grief theorists recognize that it is both typical and healthy for the bereaved to maintain a connection to the loved one who died (Klass 1993; Neimeyer 2001; Worden 2009). Rather than severing the relationship, relocating the memories and thoughts of their loved one to a symbolic, emotional, and psychological location, can provide comfort and
solace to the bereaved (Klass 1993; Worden 2009). This phenomenon is referred to as continuing bonds.

Just as other people do in response to the death of a significant loved one, many of the respondents I interviewed found ways of constructing attachments to their deceased brothers and sisters; however they are dependent on others for the memories. A bond is established when the unknown lost person becomes real and is integrated into one’s life story, personality, or identity. Interactions with parents, siblings, extended family members, or even with one’s self through inner dialogue and imagination, could construct the bond. In this study, I arrived at my conclusion about whether a bond had been constructed through the answers to several questions relating to family memorialization, the “what if” question, and/or by asking the respondent directly if they felt they had any type of relationship with their brother or sister who died.

The constructed bond is distinct from a continued bond, which is an (albeit altered, but) continued attachment. This is not a continued attachment but a constructed attachment to the memory of their deceased sibling or the event of their loss that becomes meaningful to the individual’s own life story. A continued bond was once physical and, through the bereaved person’s adaptation to loss, becomes a symbolic relationship. A constructed bond is always symbolic. A continued bond begins with a state of yearning in the early days of the loss which motivates the mourner to relocate their loved one to a place where the connection continues (Worden 2009). The yearning, if it even occurs in a constructed bond, is later, diluted, and not about the physical presence of the loved one, rather about the imagined fantasy of who their loved one might have been or how the respondent’s life might have been different.

The expressions of constructed bonds, the ways that respondents interacted with their image of their deceased siblings resembles expressions of a continued bond. Field et al. (2004)
developed a Continuing Bonds Interview (CBI), a semi-structured interview tool to better appreciate a parent’s experience related to the loss of their child and ways in which they express their continued attachment. Expressions of continuing bonds as categorized by Field et al. resemble many of the interactions as described by participants in my study, from sense of presence, talking with the deceased, feeling drawn to certain places where they feel close to the deceased, being influenced or inspired in decision making, to creating and participating in memorials or special events. The interactions with a symbolic other who was never a physical presence cannot be motivated by an attempt to adapt to a loss (as it is for bereaved continuing a bond) since the participant only knew their sibling symbolically. In the next chapter, I discuss the meanings held of their sibling’s death by the participants, which sheds greater light on their motivation to maintain connections with those memories.

**SUMMARY AND CONCLUSION**

The essence of grief is the crisis of meaning that ensues for death’s survivors (Neimeyer 2001). How do you make sense of the death of a child? As children are extensions of identities and immortality for parents (Becker 1967), the challenge is all the greater for parents who have lost a child. As Berger and Luckmann (1966) have taught us, it is in interaction with others; first and foremost our families of origin, that we create, negotiate, and construct meaning. This study attempts to understand the meanings constructed in families surrounding the death of a child. The perspective is from the members of the family who did not personally know the child who died, siblings who were either too young or were born subsequent to the loss. Those members of the family are initially reliant on the other family members, especially their parents, to provide them with memories and meanings for the life and loss. What ensued however were constructed
symbolic images of who their sibling is now. Once established, subsequent siblings carried on the presence of the symbolic other by interacting with their memories or images of their brother or sister who died.

In the following chapter, I categorize effects on respondents’ personalities that they attribute to the experience of having lost a sibling (although they never knew the sibling). I demonstrate those effects to be similar to findings from other studies regarding the impact on children and adolescents whose brother or sister died (and was known to them). I discussed a similar parallel in this chapter, where respondents reported continuing bonds expressions who never knew their deceased loved one in life. However, since there was not a lived bond to continue, I have renamed the phenomenon a constructed bond with a symbolic other. This constructed bond is dependent on interactions with others who knew the decedent in life who then shared memories and the story of the loss. This constructed bond does not appear to be an adaptation to loss such as in a grief experience, but instead an effort to make meaning of one’s family history and life story. The construction of the relationship is in actuality a result of other’s (most notably, the parents’) grief expressions.

Sociologically, this study reinforces Berger and Luckman’s (1966) idea that our realities are constructed, including our understanding of the world and who is in it. The dead siblings in this study, though never known in life, become real for the participants. The concept of constructed bonds with symbolic others could be applied to other symbolic relationships that we have. Some people have a relationship with God which is dependent on interactions with other people (usually parents) in their construction of an image. Other relationships, such as ancestors, or deceased or absent parents, also rely on stories told by family members who knew the person. But the sibling relationship is unique, as is the symbolic constructed relationship with a deceased
sibling. Interactions with others, the sharing of family history and negotiation of memories, especially within our family of origin, result in constructed relationships, which in turn influence our identity and development of self-concept as I will discuss in the next chapter.
CHAPTER FIVE

“NO PURPLE HAIR”: Meaning of the Loss for Subsequent/Surviving Siblings

Janie, now age 61, was born subsequent to her parents’ series of miscarriages and an older brother who, born prematurely, died at about 3 weeks of age. After Janie’s older brother died, it was about three years before Janie came along, full-term and healthy. She always knew about her older brother Dennis, especially from her mother, who frequently told Janie and her younger sister how valued they were. Janie recalls the story of her own infancy as relayed to her. Her mother, having had difficulty carrying a pregnancy to term, had a drawer full of preemie sized handmade knitwear. Janie, being a “whopping” seven pounds by comparison, had to have all the feet cut out of her little outfits in order to fit in them!

Growing up, Janie thought often of what it might be like to have an older brother. Born to older parents, Janie and her sister were unusual for the time and community in which they grew up. Most of her friends had many siblings. She recognizes that because of that, she may have longed for more siblings anyway, but as she says, she had a real person she could grieve for. In her mind, Dennis would have been the ideal big brother. As a child, she imagined that he would have helped her to be a better baseball player or helped her when she was in Advanced Chemistry. To compensate for a sibling that she missed, for a period of time, she had an imaginary friend – a green and purple spotted dog named Frito.

Dennis became most real for Janie when she herself experienced a perinatal loss. She followed in her own parents’ footsteps by naming her son and keeping his memory alive in her
own family. She also felt like she got to know Dennis through her mother’s eyes in her mother’s final years, as they would reminisce together.

Janie states that her parents admitted being protective and directly attributed it to the losses that they experienced before blessed with Janie and her sister. Janie, even as an adolescent, recalls refusing to participate in “something not real wise” claiming that her brother had died. “No, I just think it was more of a responsibility to do well for my parents because they had a loss, so I wanted to do well in school and not get in any trouble. You know what I mean? Not have purple hair.”

Janie, like other respondents in the study, had a bond with her older brother Dennis, even though she never knew him in life. Through the stories shared by her parents, Janie had her own memories of her brother. Like other grievers, Janie tries to find meaning in the loss. For Janie, Dennis’ short life affected who she grew up to become – empathic, more responsible, and appreciative of life. In this chapter, I will first summarize some of what we know about sibling grief. Second, I will describe the themes that emerged regarding reactions experienced by respondents in this study who never personally knew their sibling who died. Third, I will share the themes related to how the respondents make sense of the loss. Finally, I will categorize ways that respondents’ felt their identities influenced by their sibling’s death.

SIBLING GRIEF

“Siblings’ identities are intricately connected because they share similar histories, so that when one sibling dies, the survivors essentially lose part of themselves” (Devita-Raeburn, as cited in Packman, et al. 2006). We expect the sibling relationship to be our longest lasting relationship (Davies 1999). So, when a sibling dies, the impact on surviving siblings is multi-
layered. They have lost someone who shares an insider look at their own unique family. They have lost a relationship that should have figured strongly in the survivor’s sense of self (Riches and Dawson 2000: 83). Surviving siblings often describe positive growth as a result of the loss experience; report feeling more mature, having greater appreciation of life, being more empathic, and having better coping strategies in relation to other adolescents (Davies 1999, Packman et al. 2006). However, their parents’ loss often overshadows their loss (Davies 1999), which is further compounded by a loss of security and predictability (Buckle and Fleming 2011). Things they formerly took for granted – “Children do not die;” “Parents can fix everything;” are threatened. Some studies have provided insight into the experience of surviving siblings and the impact on their identities. But, what of siblings who were too young to remember or were not even born when their brother or sister died? What motivates them to have any type of bond or interact with the memory of their sibling?

**GRIEVING FOR A SIBLING NEVER KNOWN**

I asked most of the participants if they felt they ever grieved their brother or sister who died. Sixteen felt that they did grieve, at some point in their life, either when they first learned of the loss or were at an age where they understood what it meant for them personally. For others, grief was not how they described their reaction to the loss of a sibling they never knew. They did not feel that they ever knew what it was like to have their brother or sister in their life, so didn’t experience the loss directly. While “grief” was not how most of the participants labeled what they experienced, below are the categories or themes that emerged that describe the respondents’ emotional reactions to the loss, their indirect grief. If grief is a reaction to loss, it is important to
identify who the death of a child might affect. In this case, not only were those present at the
time of the death affected, but those not yet present were *indirectly* affected.

*No Reaction*

A few of the respondents did not describe any emotional reaction to the story of the loss. They generally did not have much information about their sibling nor did their families talk much about the sibling who died.

*No, no. That was just not part of my life ever.*

~Emily, age 47, whose two eldest brothers died very shortly after they were born. The boys were not named to Emily’s knowledge, nor does she know the circumstances of their deaths. After Emily’s parents lost their first two children, they went on to have five surviving children. Emily was the second youngest.

*I mean how do you miss something you never had? ~Samantha, age 57, whose brother died at 6 weeks of age from SIDS. Samantha was around 1 ½ years old when her brother died.*

*Sadness*

Others described sadness, either when they thought about the loss or even became tearful during the interviews.

*I think I can clearly remember coming across the newspaper article. I was kind of in some stuff I shouldn’t have been into… In a bedroom up on the shelf. I forget what I was looking for but I’m sure it was something that nobody had told me to go in there and get. I was sort of being nosey… And I do remember sitting on my parent’s bed reading it.*
That's a very clear memory of first getting that information and absorbing it. I think I probably did feel pretty sad at that point. ~Leah, age 62, whose sister Tina died at 1 month old from complications due to prematurity. Leah was not yet born when Leah died and she was around 10 years old when she discovered that she had an older sister.

Oh this is weird, I have another brother. So I don’t think I ever have grieved it. But talking about it obviously makes me sad, or makes me think about it. ~Barbra, age 56, whose brother Jonathon died shortly after birth from uncertain causes. Barbra was 11 months old at the time of her brother’s death. She became tearful during the interview which she said was the first time she recalls ever crying about Jonathon’s story.

Guilt

Some of the respondents felt guilt or responsibility for being the surviving child.

I know I had a really hard time for a few years like when I was a teenager. On my birthday like I would be like, well I’m here and he’s not and it’s not like fair and I just felt really guilty and everything. ~Macy, age 28, whose twin brother Cole died 12 hours after they were born, complications from prematurity.

Teresa, below, described a feeling of joy that her sister was spared a difficult childhood. Teresa felt that she (Teresa) was likely stronger, better able to handle the adversity of one estranged parent, and one very emotionally distant parent. And, while she says “joy,” she describes a burden of responsibility that she felt by being the surviving child.
I do feel that you know she is a part of my family and I do feel love for her, and in the event that some miracle would have happened and both of us would have been here, I do feel that we could be related. But then there are times, because of my childhood, that I feel joy for her that she passed away and she didn’t go through a lot of things I went through. And I do feel that way. I feel you know.... Maybe she would haven’t been as strong as I was to get through some of the hurdles I had in my life and maybe that’s why it was decided that she needed to go home earlier than later. ~Teresa, whose sister

Briana died shortly after birth. Teresa was born about a year after Briana’s death.

**Empathy for Parents or Sibling who Died**

While ‘grief’ was not how most of the participants described what they experienced many described feelings of empathy – for their parents, for their sibling who died, or generally for the story of loss.

*I think as a mother myself, all I can remember is just relating to that fear, that pain.*

~Kathryn, age 29, whose sister Jasmine died from complications related to prematurity shortly after birth. Kathryn was not yet born when her sister died.

I always worried about if she was loved you know, being away from home.  ~Sarah, whose sister Jessica died around 9 months of age from Down Syndrome and heart complications. Jessica lived in a convalescent hospital for her short life. Sarah was born subsequent to Jessica’s death.
Longing for Sibling

Many were able to imagine what it was that they lost through their sibling’s death. It was this ‘what if’ that they mourned. Each of the participants were asked, if they did not go into the story on their own, if they ever thought about what life might be like if their brother or sister had lived. This was clearly not the first time most respondents had thought about the ‘what if’ question.

*I don’t know if that hadn’t happened I may have wanted to have an older brother and sister anyway. But I had a real person that I could sort of grieve for.* ~Janie, age 61, whose brother Dennis died around 3 weeks of age from complications due to prematurity. Dennis died before Janie was born.

No I don’t think so. You know, um.... I mean we talked about her and I always wondered what it would have been like to have a sister. Sometimes I’d be jealous of my friends that had sisters or you know had a sibling who was a little closer. But I wouldn’t really call that grieving. ~Nicky, age 38, whose sister Nicky (yes, same name) died a few hours after birth from a rare disease. Nicky was not born yet and was bestowed her sister’s first name.

*Another sibling.* For most though, the ‘what if’ was simply imagining what a sibling, or another sibling, would have meant to them or their family. The sibling would have been an advisory, an emotional support person. They longed for them when they were children, when they were growing up, and as adults. The respondents missed their sibling’s presence now as they took on care of their elderly parents, or imagined nieces and nephews that could have been.
This longing comes from our social and cultural notions of what a sibling means: companion, advisor, shared caregiver for parents (Davies 1999, Rowe 2007).

*I know that my three brothers adore me and my sister sometimes adores me, but to me it is just one more person I would have loved and they would have loved me.* ~**Madelina,** age 42, whose parents had a stillborn son before Madelina was born.

*I think for myself more so around the last four or five years, I just turned 31 and you know I’m not married yet and I feel like she would have been kind of the person like “what’s your problem with girls” like let’s figure this out type of deal.* ~**Jason,** whose sister Shelly died in a drowning accident at age 3 before Jason was born.

*You know also when I became an adult; you know my mother went in the hospital for something. I was like oh I wish; you know I wish they were here to help me deal with this.* ~**Andrea,** age 39, whose brother Robert died from Leukemia around 1½ months old. Andrea was not born when her brother died and has one other sibling, a much older half-sister.

*I mean of course I wonder what it would have been like, especially now that we’re caring for an elderly parent. I'm like, “Oh I wish I had her now.”* ~**Violet,** age 56, whose sister Denise died when she was only 2 days old from a heart defect. Violet was not born when her sister died.
**Idealized Sibling.** For some, it was easy to imagine a sibling with whom they would have been closer to than their living siblings, either because they would have been closer in age or because the idealized sibling would have been easier to get along with.

*I did that frequently throughout my life, um I think especially naturally like when you’re fighting with your surviving siblings you think oh gosh it’s ‘ I wish I had another sibling.’ It’d be much better you know. ~ Anna, age 32, whose brother George died from Spina Bifida when he was 4 ½ years old. Anna was born after George died.*

*Well I thought that immediately, you know, when we found out about the picture that, “Wow, you know there would have been.....”All of us siblings were very close. There was no more than two years apart and with her in the picture that would have been like one year between her and then my next sister above us. So it would have been like, “Wow, we would have been really close.” And my oldest sister that’s right above me and I... we weren’t so close, so I thought....I mean we weren’t like friends or like we didn’t play a whole lot together, and um, I thought, “Wow, that might have been fun having her just, you know, one year above me.” ~ Suzanne, whose sister Julia died from a respiratory illness at age 6 months. Suzanne was not yet born (but was in utero) when Julia died.*

**Different Family Trajectory.** Several put a lot of weight on the child who did not survive, in terms of the continued trajectory for their family and themselves as individuals. In addition to the positive qualities due to the legacy of their deceased sibling, several also mentioned negative consequences, such as the attribution of the breakup of their family to the loss, or the death or unhappiness of one of their parents.
I don’t know. I would like to think it would have been better. I mean I would have liked to think like maybe things wouldn’t have been so negative, and so angry. Had there been another girl around maybe that might have tamed my dad from being as vicious as he was. But it’s hard to say. I would like to think it would have made things better.

~Allison, whose sister Abigail died from ‘complications during pregnancy’ shortly after her birth. Allison had an older brother Curtis. Abigail died several years before Curtis or Allison were born.

I think my dad would have lived much longer. I think my mother would have been much happier hopefully. After he died, she died you know, emotionally. She really did. She was just a shell of herself I’ve been told by other people. I think there would have been much more good times together. ~Colleen, age 71, whose older brother Harold died in war.

Colleen’s father died from heart disease right after Harold’s body was returned to the family.

My dad …committed suicide. And my mom always attributes it to this situation and that he could never get over the loss… So when I was nine he committed suicide. .  ~Sarah, age 49, whose sister Jessica died around 9 months of age from Down Syndrome and heart complications. Jessica lived in a convalescent hospital for her short life. Sarah was born subsequent to Jessica’s death and Sarah’s father died when Sarah was only 9 years old.
I would like to think that life would be different and that my parents would have maybe stayed together. You know my dad blames my mom and mom just kind of says, “Well your dad wasn’t here. There is nothing new about that.” —Jason, whose sister Shelly died in a drowning accident at age 3 before Jason was born.

The categories of reactions ranged from no reaction to sadness, guilt, and longing, similar to reactions for persons who directly experience a loss. While the intensity might be lesser than a mourner who knew the individual who died, I still list these as themes of grief, as they were all respondent responses to a loss. Whether it was how the family would have gotten along differently or better, or whether they as individuals would have had another (often presumably better) support person, the participants longed for many ways that life would have been different had their brother or sister lived. The loss of these indirect grievers is generally unacknowledged.

MAKING SENSE OF THE LOSS

There is a post-modern, constructivist approach within the interdisciplinary field of thanatology which places meaning making as the central process for grievers in their adaptation to loss (Neimeyer 2001). While this was a loss of which most of the respondents were always aware and accustomed (37 out of the 49) thereby not requiring a re-adjustment of their reality, I wished to explore the respondents’ thoughts on the meaning of their sibling’s death as indirect grievers. I asked them each, “How do you (if you can) make sense of your brother or sister’s death?” Two distinct themes emerged from that question and other parts of the interviews that were coded under the category ‘understanding of the death cause/meaning of the loss:' spiritual and science. In our culture, science and religion (often concurrently) offer scripts for understanding death. Spiritual scripts, most notably found in religions, offer not only a
connection to a belief community larger and longer lasting, and hence a sense of immortality, but also a literal or symbolic belief in immortality (Becker 1973, Seale 1998). Science too offers an explanation for death. “In modern society there are active efforts to construct most deaths as ‘natural’ by controlling premature death, resisting deliberately imposed death … and relieving the suffering of dying. All of these things, if not prevented and controlled in these ways, would introduce uncertainty, resulting in a designation of death as ‘unnatural” (Seale 1998: 54).

**Spiritual**

Some were able to leave their questioning to a higher power. While I didn’t directly query about participant’s religious affiliation, for some, their belief system or life philosophy clearly allows for unexplained events. They were able to live with the mystery, trusting that a reason exists, but that they do not have to fully understand at this time. They might speculate (spared from a worse, future accident, would not have been strong enough), but were comfortable not truly knowing.

**God’s Plan.** Respondents talked about their faith when explaining why their brother or sister had to die. As in chapter 4, these meanings, based on stories told by their parents, also relied on respondents having a faith tradition that allows for an afterlife.

*I believe things happen for a reason…that our family had to experience that. There was a reason.* ~Cathy, age 60, whose brother Donald died at the age of 2 from a head injury.

*About the death part of it? That’s always just been. She’s my sister and she just happened to pass away… Like God was ready for her, so.* ~Kathryn, age 29, whose sister Jasmine died from complications related to prematurity shortly after birth. Kathryn was not yet born when her sister died.
"I think for me it’s just a safe thing, you know that happened for a reason. Maybe God was keeping her from another horrible accident. So… that’s kind of what my family has kind of held onto as well. ~Jason, whose sister Shelly died in a drowning accident at age 3 before Jason was born.

I guess the spiritual side of me feels like, um, you know he fulfilled his life duties, and you know he’s gone on to be a constant in our family and protector in other ways. ~Anna, age 32, whose brother George died from Spina Bifida when he was 4 ½ years old. Anna was born after George died.

Punishment. Some even felt there was some universal punishment involved. A variant of the first category under spiritual meaning, ‘God’s Plan,’ this allowed for mystery and depended on some spiritual belief system. However, since it had a distinct negative element, I categorized it separately.

To get the concept that a child that was innocent and did nothing wrong and this happened, how is that? I couldn’t reconcile the thoughts together. .. That was so contradictory I couldn’t understand. You know it was a punishment. ~Madelina, age 42, whose parents had a stillborn son before Madelina was born.

I just felt it was unfair that I had lost this person and I didn’t understand you know. And I didn’t grow up in a very religious family, but I did spend some time with some friends
who had religious families and at one point I actually thought I was being punished in some way. ~Teresa, age 36, whose sister Briana died a few hours after birth. Teresa was not born when her sister died.

She (mother) always thought it was punishment for like giving up the baby that they had in high school. ~Allison, whose sister Abigail died from ‘complications during pregnancy’ shortly after her birth. Abigail died several years before Allison or her brother were born. Allison considered her family to be closed communicators around the topic of Abigail’s life/death, but Allison also learned that her parents had given up an even older sibling for adoption. Allison said this was an even more closed topic, but believes her mother attributes Abigail’s death to her (the mother’s) decision to give up her first child.

Both sub-themes under spiritual, God’s plan and punishment, rely on the respondents belonging to a culture that allows for a higher power, an afterlife, or some other transcendent belief. Such explanations offer not only meaning, but solace in the face of an out of order death.

**Science**

Others, or even some of the same people at different points in the interview, also found science and technology in their search for meaning when contemplating the reason for their sibling’s death. Many respondents also lamented that it probably would not have happened today due to advances in science and medicine.
Well, I mean I feel like you know it was a health issue. I mean I, you know I feel like I can make sense of it. ~ Andrea, age 39, whose brother Robert died from Leukemia around 1 ½ months old. Andrea was not born when her brother died.

To me it was just a birth defect. In my eyes, it was just something wasn’t right; something didn’t form right or something, and he just didn’t make it. That’s just all the reason I have for it. ~ Grace, age 50, whose older brother Hank died 36 hours after birth from fluid on the lungs. Hank died before Grace was born.

I mean from a medical standpoint it’s very kind of black and white to me. As far as diagnosis, um, you know the reason why he passed away. It all makes sense. ~ Anna, age 32, whose brother George died from Spina Bifida when he was 4 ½ years old. Anna was born after George died.

Meaning making for their brother or sister’s death appeared to primarily fall into two categories, either one that relied on some faith system or one that relied on science. Oftentimes, participants were able to use both means for their explanations for the untimely death of their sibling. Anne Swidler approaches the study of culture as something that is used by individuals to make sense of their experience, a context, often with a variety of options in which to frame their meanings (2001: 5). Hence, in our Middle American culture, science and religion often coexist peacefully in one person’s framework and meaning making. Both cultural scripts, however, apply more easily to a “natural death, occurring at the end of a long life, free from suffering, and akin to falling asleep” (Seale 1998).
EFFECT ON RESPONDENT’S IDENTITY

Throughout the interviews, there were times that it was clear that the knowledge of their sibling’s life and death affected the respondents’ identities. The respondents talked about being more responsible, more empathic, appreciating life more. Or they may have felt compared to their deceased sibling. These themes are not unlike effects of sibling loss for children who lost a sibling and were old enough to know and remember their brother or sister, direct grievers. The reactions to the loss, though not directly experienced, nor even labeled by many of the respondents as ‘grief,’ led me to describe the subsequent siblings as ‘indirect grievers.’

Responsible

Like, Janie at the beginning of this chapter, other respondents talked about feeling more responsible in response to their parents’ previous loss of a child.

And you know I’ve always like grown up just telling them (her parents) where I’m going, like I have nothing to hide from them... you know why wouldn’t I live my life as I’ve had the opportunity to and they (her siblings) didn’t. ~Jennie, age 24, whose older brother Eric died at age 4 and younger sister Rachel died at age 5. They each had a rare blood disease. Jennie was not born when Eric died and was 7 years old when Rachel died.

Empathic

Being more empathic was a very common response among the participants. For those whose sibling had a special need, even though the respondent did not grow up with them, they developed sensitivity to others who were differently abled. Or, because they were able to identify with their own parents’ grief, they find themselves especially sensitive to grievers.
So you know it made me a little I guess growing up aware. You know when I would see a special needs child in a stroller you know I wouldn’t just like gasp, you know and look away. You know I would go over, and I still do it and say “hi how are you?” ~**Alice, age 50, whose sister Emma died from Cerebral Palsy at age 10. Alice was only a year old when Emma died.**

That I always tried to the most supportive to the people who I thought needed it, which really I think is my mom. I think the reason I didn’t talk to my dad or my brother so much about it is... I don’t know why. I just never got the feeling they needed to talk about it, but I was always the person who to this day... still brings it up to my mother and we talk about it.  ~ ~**Nicky, age 38, whose sister died a few hours after birth from a rare disease. Nicky was not born yet and was bestowed her sister’s first name.**

**Appreciate Life**

Also, like Janie, several respondents talked about the positive impact of being “held a little closer” as a result of the loss. They understood that their parents cherished them perhaps a little differently than parents who, although loving, might take for granted the opportunity of parenthood. And, the respondents, in turn appreciated life and their family.

*I mean if they wouldn’t have had those losses they wouldn’t have known how precious my brother and I were. ~**Edie, whose parents lost twins prior to Edie or her brother being born.**

*They had someone else prior to me and I’m sure the things they want for me, they wanted for her. You know my parents, they’re just the best parents all the way around so I’m sure*
they did the best that they could do in the little time that she was here. ~ Janelle, age 39, whose sister Melissa died from a heart defect at age 7 months. Janelle was not yet born when Melissa died.

Career Choice

A few respondents were able to directly relate the path to their current profession to the story of their sibling.

I really do think it’s because of that situation that has drawn me to (my work) and my passion for (my work)… keeping the family together… You know, just providing that support for families. ~Sarah, age 49, whose sister Jessica died around 9 months of age from Down Syndrome and heart complications.

One of the reasons I got into the physical therapy world is because he went through significant physical therapy you know back in the day and he loved his physical therapists, and my parents always spoke highly of them. ~ Anna, age 32, whose brother George died from Spina Bifida when he was 4 ½ years old. Anna was born after George died.

Compared to Sibling

A few of the respondents talked about the burden of feeling compared to an idealized child. They tried to live up to the image and expectations that they imagined their parents had for the deceased child.
I think more my feeling was always that he was the better child, and I was told one time (that) the wrong child died. I am not sure, that might have been said in a fit of anger. I don’t know. ~Colleen, age 71, whose older brother Harold died in war.

My initial thought was, “Hey, I would have had a sister; it would have been both of us.” But my dad put a down to that. He said, “If Brandy would have been born, you wouldn’t be here.” I was like, “Awesome. Thank you…” Which kind of made me harbor some feelings that I wasn’t really the one that they wanted. But that’s okay. I’m here. I do great things. ~Teresa, age 36, whose sister Briana died a few hours after birth. Teresa was not born when her sister died.

Respondents found their identities impacted in a variety of ways that they attributed to the experience of growing up in a family that lost a child, even though they never personally knew the child who died. Being more responsible, having greater empathy for others, appreciating life, or feeling compared to their deceased sibling were all themes under effects on respondents’ identities. Several even credit their chosen career, their professional identity, to the story of their deceased sibling.

SUMMARY AND CONCLUSION

In modern times, by our American standards and expectations of medicine, it is difficult to make sense of the death of a child. While the death of an infant or young child is difficult to make sense of, the respondents were all able to share their meanings of the loss. Having not been alive or old enough to be aware of their sibling’s death, the respondents’ answers to the meaning making question is good evidence that individuals do not grieve in isolation. Their interpretations
of their siblings’ deaths came about through interactions with others, the narratives and/or rituals from their childhood and the resulting symbolic relationships discussed in chapters 3 and 4. Their explanations or understanding of the cause of death came from the stories shared with them, often from several parties. According to Nadeau’s (2001) research, storytelling is the most commonly used strategy for families to make sense of their loss. The respondents’ current answer to “how do you make sense of your brother or sister’s death” is their present understanding of why their brother or sister died. Memories constructed in relation with others take the past to make sense of the present using available cultural scripts.

In this chapter, I talk about the experience of losing a sibling never known: what that ‘grief’ was like, how respondents made sense of the death, and the effects on their personalities. The siblings who were very young or born subsequent to child loss in a family appear to have some commonalities with grieving siblings old enough to remember their brother or sister, both in terms of their grief reactions and the effect on their identities. And, as it is for other grievers, meaning making came about through social interactions, framed in a cultural context. Hence, I categorize their experience as an indirect grief; a muted, yet significant version of grief.

Grief is the natural response to loss, which includes emotional, physical, cognitive, social, and spiritual reactions (DeSpelder and Strickland 2005). Typical responses include, among many other reactions, sadness, longing, guilt, and anger and there is no set duration for grief symptoms from the time of loss (DeSpelder and Strickland 2005). The respondents in this study described many of the typical grief reactions, though perhaps not with the same intensity as a mourner who directly experienced the loss. This study offers evidence that the experience of losing a sibling, even if never known in life, is in fact a loss.
When I compiled categories of ways respondents felt their identities had been impacted by the loss, I noticed the similarities to findings from other studies about siblings who were older when their brother or sister died and knew their brother or sister. Some respondents reported feeling more responsible during their childhood or adolescence, much like Balk’s (as cited in Packman et al. 2006) finding that bereaved adolescents thought of themselves as more mature, with higher moral values or Davies’ (1999:181) finding that sibling-bereaved children placed a greater value on life. Forward and Garlie (as cited in Packman et al. 2006) also found bereaved adolescent siblings to report taking fewer risks. And, similar to siblings who were alive and aware of their ill sibling’s trials preceding death (Kramer, as cited in Packman et al. 2006), these subsequent siblings also felt that their deceased sibling’s story increased their own capacity for empathy. And, finally, the few respondents who felt compared negatively to their deceased sibling shared that in common with older surviving siblings as well. Davies (1999: 200-201) also found that some sibling bereaved children did not feel that they were good enough when compared to their deceased sibling, either perceiving that their parents lost their favorite child or that they as survivors were not enough to make their parents happy. Surviving children inherited their parents’ dreams for their brother or sister who died.
CHAPTER SIX

CONCLUSION

When I was growing up, my father often told stories about our family; great grandparents, and aunts and uncles I never knew. He came from an Irish heritage where storytelling is an art and a cherished form of entertainment. Once, as we were sitting up late in the summertime on our back deck, I can clearly remember him telling me that some people believed that the way you lived forever was by your loved ones continuing to tell stories about you. I was probably only nine or ten and that thought blew my mind. Immortality? Like heaven? Then, I had a lot to remember in order to keep all of these ancestors alive.

Fast forward a few decades and I now work as a Bereavement Coordinator for a pediatric hospice. I meet with families after they lose a child. I witness as they struggle to make sense of the loss and learn who they are as parents, siblings, and as a family. I see them find ways to ‘keep their child (who died) alive’ through pictures, stories, memorial services, and special causes in honor of their child. As a grief support specialist, I have encouraged openness in families, normalized their desire to keep mementoes on display or rooms intact from the day that the child lived in it, and helped them connect with other families who have lost children and are seeking ways to cope with their loss and adapt to their new reality. I only see these people for a short time. I wondered what about the long term? What about subsequent family members? Where do they fit in and how do they connect to this significant event in their family story? This study contributes to knowledge about family meaning making after loss over the long term from the perspective of someone who only indirectly experienced the loss. It is from the perspective of someone who is inside the family but was outside of the experience of the loss when it happened.
Bereavement refers to “the basic fact or objective reality of loss” (Doka and Martin 2010: 17). This is a study about bereavement. The participants in this study lost a sibling, though never known to them in life. This study explored their grief, a person’s “response and reactions to the loss” (Doka and Martin 2010: 17). While indirect grieverers, the participants in this study shared their reactions to a unique loss, for most of them, a loss that occurred before they were even born.

Grief is clearly a social experience. Its effects ripple well beyond the immediate aftermath of loss, and extend to persons not even directly connected to the one who died. While the families represented in this study varied in their level of openness in talking about the child who died, this study describes how families use stories and rituals to construct and maintain memories. Those narratives and remembrance rituals reinforced identities and taught important life lessons. The stories helped connect the participants to their sibling, establishing the family connection, and for some a spiritual connection as well.

This is an important study as families are the locale where our initial socialization occurs, where we learn what family means and where we learn appropriate emotional behaviors, such as grieving (Doka and Martin 2010: 143).

Internalization in this general sense is the basis, first, for an understanding of one’s fellowmen and, second, for the apprehension of the world as a meaningful and social reality. This apprehension does not result from autonomous creations of meaning by isolated individuals, but begins with the individual ‘taking over’ the world in which others already live (Berger and Luckmann 1966: 130).

In other words, the meanings already established by others, and within a specific culture, contribute largely to our perception of reality. Our primary socialization occurs via interactions with our caregivers and guardians (Berger and Luckmann 1966, Doka and Martin 2010).
realities and meanings of interest to this study are: 1) the memories about a sibling never known to the participants, 2) the nature of the relationship with that deceased sibling, 3) the meaning of that sibling’s short life and death, and 4) the effect of that sibling’s (story, death, or relationship) on the participant’s identity.

As you may recall, the aims of this study were to first describe the ways in which family members collectively remember a child who has died, and then to explore the effect of that loss on members of the family who did not have a lived relationship with the deceased child. In order to accomplish those goals, I interviewed 49 adults who had a brother or sister die. The participants in the study were either not yet born or under the age of three at the time that their sibling passed away. In the previous chapters, I described, from the perspective of these adult siblings who did not have any memories of their own about their brother or sister, the various ways that families talked about or commemorated the deceased child. The participants shared the meaning of the loss of their sibling (or siblings in some cases). I conclude it is through our interactions with others that we develop memories, relationships, and meanings, with the purpose of affirming identities and sense of belonging. In the case of this study, the mourning behaviors of their parents, their parents’ communication about the deceased child, their parents’ memorializing activities witnessed by or in which the participants were included, and the meanings that their parents ascribed to the loss, primarily contributed to the participants’ own construction of their image of and relationship to their siblings. I call the concept of integrating the significance of the deceased child into the story and identity of another a ‘constructed symbolic bond.’

This study contributes to the ongoing discussion in Sociology of Death regarding death denying culture. Seale (1998) argues that rather than a death denying culture, modern society has
devised ways to incorporate the dying or bereaved through constructed imagined communities (hospice and palliative care being one such movement). “Clearly, mortality presents a greater threat to social order if it occurs frequently to people who are fully engaged in core activities of the social system, and modern society is organized in such a way as to reduce disruption at this level” (Seale 1998: 70). So, the larger culture more easily forgets children, who are not yet engaged in core activities of the social system. Nonetheless, because of the sentimental value we place on children, the idealization of their innocence (Rowe 2007), there remains a denial and reluctance to acknowledge that children do die. Our culture also values the sibling relationship, expecting it to be long-lasting, a source of companionship and protection (Davies 1999, Rowe 2007). Parents invest in children as sources of immortality (Becker 1973), and thus are particularly motivated to continue a bond with their dead children, keeping them symbolically alive. But, there remains a tension between a childhood death denying culture and families who suffer such a loss. To which cultural script do they adhere? Our culture concurrently values children and the sibling relationship, yet denies sanctioned ways to immortalize them. This study describes ways that some families have negotiated strategies to memorialize, honor, and remain symbolically connected to the child who died, each to varying degrees. The study explores the perspective of siblings who were either too young to remember or were born subsequently to their brother or sister who died, therefore were inside the family who lost a child, but outside the direct experience of the loss. The memory work within the families contributed to constructed symbolic relationships with the unknown siblings.

In this final chapter, I conclude with implications for professional practice and future research with bereaved families, as well as address limitations of this study.
IMPLICATIONS FOR PRACTICE

This study demonstrates that meaning-making after a loss occurs systemically in our families over the course of many years. Clearly the mourning behaviors of the parents affect the children, even years later. Family members not even alive at the time that a child died still feel the ripple effects of that loss. It is part of their family narrative, and consequently part of their own life story. Some perceived it to affect their parents’ marriages or one or both of their parent’s mental well-being. Others believed that they never would have been born had their brother or sister lived. Still others were acutely aware of their parents’ tendency to be protective (though nobody in this study felt smothered by that). Rather, several talked about how they felt loved and cherished as a gift their parents recognized and all the more precious after their parents had suffered the loss of a child. Nearly all of them were able to express some significant meaning that they attributed to the loss or a connection they felt to their sibling, and ways that knowledge of the loss influenced their identities.

In my work with bereaved parents, shortly after the death of their child, parents often ask about how to talk to the other children. At the time of the loss, parents often express gratitude if their other child or children are too young to understand. Since the siblings are too young to understand, the parents hope to spare them the pain of the loss. In those situations, the care team prepares parents for future discussions with their children, as the other children grow and develop to understand death and relationships differently. Many parents go on to conceive again and wonder how, or sometimes even whether, to talk about the child who died with the young children or children yet to be born.

There might be many reasons for parents not to disclose or talk in any depth about a child who died. Initially, parents might be concerned with simple day-to-day functioning and parenting
other children while grieving (Buckle and Fleming 2011). Parents may feel that their focus should be on the living and the future and not the past. After a time, hiding their feelings might become an established pattern or parents might think it unnecessary to burden their child with a sad story. Parents might avoid the topic of death in general. They may avoid talking about a painful experience for fear of appearing weak or shattering their child’s sense of protection and security (Schutz 1986). The death might have a certain stigma or suggest parental culpability leading parents to keep their shame or guilt internal. Parents have a natural instinct to protect their children and talking about a very sad event from the past might feel counter-intuitive. And, finally parents might not even imagine that the loss would matter to someone who wasn’t very old or even alive at the time of the death. This study’s findings contradict that belief however.

That is where we as professionals can be helpful. Bereavement providers or health care workers involved when a child dies can help by screening families who might need extra therapeutic support. Connecting parents and siblings with resources at the time of the loss might aid in their resumption of functioning. They can also model for families open communication and validate the loss for all family members’ present and future lives. As families begin to find their new normal, encourage them to find their own ways to commemorate their child who died, endorsing their need to find a place for that child as they move forward.

**IMPLICATIONS FOR RESEARCH AND LIMITATIONS**

As researchers, more studies about pediatric death and bereavement would continue to bring not just death out of the closet, but death of children.

Most of the participants in this study were Caucasian and female. I caution the reader about generalizing from this data. Further research including more males might yield a very
different set of responses, either about how they perceived communication around the topic of their sibling’s death, or what the meaning of the loss was for them. Also, different religious or cultural groups’ worldviews regarding the dead could greatly influence the meanings held for those surviving subsequent siblings (Hays and Hendrix 2008).

I regret not asking respondents whether they identified with any faith community so that I would have a better understanding of the faith traditions represented by this group. Many of the participants brought up their beliefs during the course of the interviews. “Spiritual beliefs and practices come to the fore in dealing with life’s end and the loss of loved ones. They address the very meaning of life and death, as well as the mystery of afterlife. They offer guidance in how family members and communities honor the deceased and comfort the bereaved” (Walsh 2004:183). Considering that religion and spirituality contribute largely to our meaning making, particularly around mortality issues (Frantz et al. 2001), future researchers of symbolic relationships might enquire about religion and its influence.

Also, as this study contributes to knowledge about family meaning making after loss, it is limited to a retrospective view in order to capture the long term patterns. It also only offered the voice of one of the family members in a system. More studies similar to Nadeau’s (1998) family bereavement study, closer to the event of loss or with multiple family members could also add to the understanding of how families grieve together, making sense of the loss or of their new identities.

**SUMMARY (Siblings Matter)**

Just as the sibling relationship is unique, so too is the grief that follows the death of a sibling. Siblings share the same family environment and biological similarities. They are also the
person we expect to have the longest relationship with in our lives (Rowe 2007). Some challenges that can accompany sibling grief during childhood include children being the ‘forgotten mourners;’ parents being emotionally absent; their grief being contingent on their developmental understanding of death; or comparisons made to the deceased sibling (Crehan 2004; Davies 1999; Riches and Dawson 2000; Silverman 2000). The death of a sibling challenges a child’s assumption that the world is just (Rowe 2007). Similarly, the knowledge that a child, particularly one who is genetically connected to you, has died might also bring into question that the world is safe or predictable (Riches and Dawson, 2000), perhaps even if that death occurred prior to your own birth. This study informs how siblings born to a family already bereft of a child work to make sense of that loss, even though indirectly experienced. Family communication strategies, from story-telling to rituals, contributed to the subsequent siblings’ constructed images of and bonds with their deceased sibling.

This study demonstrates that these individuals, siblings either very young or not even born at the time of the child’s death, do in fact attempt to make sense of the loss. They did incorporate the loss into their own life stories and many felt that the existence of, or their relationship to, their deceased sibling helped shape their identities. “Ghosts” do exist via constructed symbolic bonds and influence the behaviors and identities even of members of the family who did not know the decedent while he or she was alive. Particularly striking to me was that participants in this study often described ways in which they felt their identities were affected which were similar to effects described by siblings who were old enough to remember when their brother or sister died (Davies 1999; Packman et al. 2006). Losses not directly experienced involve a grief reaction. Symbolic relationships (constructed through our interactions with others) also influence our identities.
Within the context of our families, we make meaning and form identities (Gillies and Neimeyer 2006; Nadeau 1998). As families interact, share stories, and choose which memories, mementoes and photographs to talk about, they come to understand the cause of death and how the death changed the family. Family members also negotiate lessons from the loss (Nadeau 1998). With something as significant as the death of a child, those meanings take years, perhaps generations to form, and those meanings in turn, influence many individuals. Therefore, as I stated in the introduction to the study, it is imperative to consider loss within the family system, systems both present and future.

Parents’ grief experience is not an isolated, individual occurrence (Buckle and Fleming 2011; Nadeau 1998; Riches and Dawson 2000). Rather, it is intimately entwined in the entire family system, including members of the family who were not yet born at the time of the death. Even years later, the parents’ reaction to the loss has implications for other family members (Davies 1999). Choices they make in their bereavement, including disclosure of the loss and stories they choose to tell or not tell, affects other family members (Carmen et al. 2010). An overarching message from my interviews has been that subsequent children, or children who were too young to have memories of their own of their brother or sister, have a deep desire to know about that sibling, to understand their parents’ and family’s feelings and understanding of the loss and to incorporate it into their own life story, preferably in some positive way. In general, they want to remember and honor their deceased sibling, grow from that loss, and uphold their sibling’s legacy.
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APPENDICES

Appendix A

The death of a child has a long lasting ripple effect on a family.

Did your parents lose a child when you were young?

I would like to talk with you regardless of whether you feel you know a lot or very little about your brother or sister who died.

I am interested in talking to anyone who is…

• 18 years of age or older
• Either was born after their parents lost a child
• Or was very young (age 3 or younger) at the time of the loss
• AND, again, no matter how much you know about your parents’ loss

What to expect:

• A short interview lasting up to one hour asking about your experience of having grown up in a family that lost a child
• A meeting at a location convenient to you
• Gratitude for contributing to a better understanding about grieving families.

How to sign up:

Contact Marcella Cameron Meyer: 513-636-4365
or e-mail marcella.cameron@cchmc.org
Appendix B

CINCINNATI CHILDREN’S HOSPITAL MEDICAL CENTER

INFORMED CONSENT FOR PARTICIPATION IN A RESEARCH STUDY

STUDY TITLE: EFFECTS OF CHILD LOSS ON SUBSEQUENT SIBLINGS

SPONSOR NAME: N/A  SPONSOR STUDY NUMBER:

INVESTIGATOR INFORMATION:

Marcella Cameron Meyer  513-300-3819
Principal Investigator Name  Telephone Number 24 hr Emergency Contact

INTRODUCTION:

You have been asked to participate in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation. It describes, in words that can be understood by a lay person, the purpose, procedures, benefits, risks and discomforts of the study and the precautions that will be taken. It also describes the alternatives available and your right to withdraw from the study at any time. No guarantee or assurance can be made as to the results of the study. Participation in this research study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may withdraw from the study at any time without penalty.

WHO IS CONDUCTING THE RESEARCH STUDY?

This study is directed by Marcella Cameron Meyer, Bereavement Coordinator at StarShine Hospice of Cincinnati Children’s Hospital & PhD student at the University of Cincinnati.

WHY IS THIS RESEARCH BEING DONE?
The purpose of this research study is to better understand the experience of growing up in a family who has lost a child.

**WHY HAVE YOU BEEN ASKED TO TAKE PART IN THIS RESEARCH STUDY?**

You are being asked to take part in this research study because you are eighteen years of age or older and you had a brother or sister die before you born, or before you were the age of three years.

**WHO SHOULD NOT BE IN THE RESEARCH STUDY?**

You should not be in this study if you have any of the following:

Younger than eighteen years of age.

Not had a brother or sister die before you were born or before you were the age of three years.

**HOW LONG WILL YOU BE IN THE RESEARCH STUDY?**

You will be in the research study for approximately one hour. Participation in this research study will involve one interview. With your permission, I may make one follow up phone call to clarify any responses.

**HOW MANY PEOPLE WILL TAKE PART IN THE RESEARCH STUDY?**

A total of approximately 40 people will take part in this study at neighborhoods surrounding Cincinnati Children’s Hospital.

**WHAT IS INVOLVED IN THE RESEARCH STUDY?**

If you agree to participate in and qualify for this study, you will be interviewed in a location convenient to you. The interview will last up to an hour and will include questions inquiring about your memories of what you have been told about your brother or sister who died and ways that your family might have remembered or honored your sibling.
WHAT ARE THE RISKS AND DISCOMFORTS OF THE RESEARCH STUDY?

There are no anticipated serious risks or discomforts expected with this research study. You may experience sadness related to the retelling of the story of your brother or sister’s death. You may end the interview at any time if these feelings are overwhelming for you.

ARE THERE DIRECT BENEFITS TO TAKING PART IN THE RESEARCH STUDY?

The information learned from this research study may benefit other families who lose a child by helping bereavement specialists better understand the experience of bereaved families.

WHAT OTHER CHOICES ARE THERE?

Instead of being in this research study you may choose not to participate.

HOW WILL INFORMATION ABOUT YOU BE KEPT PRIVATE AND CONFIDENTIAL?

Cincinnati Children’s Hospital Medical Center and/or the Investigator will take the following precautionary measures to protect your privacy and confidentiality of your research and/or medical records: Steps will be taken to ensure confidentiality for all interview participants. No respondent’s names will be used in any of the transcripts. All data will be stripped of any respondent identifiers including respondent name and name of sibling who died. All participants will be issued a study number, which will be found on all documents associated with that participant. If there are any documents containing the participant’s name or other identifying information, these documents will be destroyed when the study is complete. No identifying information will be included in the published manuscript or other materials leaving CCHMC such as at a presentation or meeting. Individual quotations may be used to illustrate conclusions, but no identifying information will be included in such quotations. Generally, results will be presented in an aggregate form. All information gathered from this study will be stored in a secure database located on a CCHMC computer, which requires a password for access. Paperwork will be kept in a folder that will be locked in a secure area.

WHAT ARE YOUR COSTS TO BE IN THIS STUDY?
There are no costs to be in this study.

**WILL YOU BE PAID TO PARTICIPATE IN THIS RESEARCH STUDY?**

There is no pay for participating in this research study.

**WHAT ARE YOUR RIGHTS AS A PARTICIPANT?**

Your participation in this study is completely voluntary. You may choose either to take part or not to take part in this research study.

If you decide to take part in the research study, you are free to withdraw your consent and discontinue your participation in this research study at any time. Leaving the study will not result in any penalty or loss of benefits to you.

If you have questions about the study, you will have a chance to talk to one of the study staff. Do not sign this form unless you have had the chance to ask questions and have received satisfactory answers.

Nothing in this consent form waives any legal rights you may have nor does it release the investigator, the sponsor, the institution, or its agents from liability for negligence.

**WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?**

For questions, concerns, or complaints about this research study or to report a research-related injury, you can contact the researcher Marcella Cameron Meyer at 513-636-4365, Cincinnati Children’s Hospital.

If you have general questions about your rights as a research participant in this research study, or questions, concerns, or complaints about the research, you can call the Cincinnati Children’s Hospital...
Medical Center Institutional Review Board at 513-636-8039. You can also call this number if the research staff could not be reached, or if you wish to talk to someone other than the research staff.

**SIGNATURES:**

I have read the information given above. The investigator or his/her designee have personally discussed with me the research study and have answered my questions. I am aware that, like in any research, the investigators cannot always predict what may happen or possibly go wrong. I have been given sufficient time to consider if I should participate in this study. I hereby give my consent to take part in this study as a research study subject. I will receive a copy of this signed form for my records.

____________________________________  __________
Signature of Subject              Date

____________________________________  __________
Signature of individual obtaining consent  Date
Appendix C

Interview Prompts:

Aim: Circumstances of Death/ Information about Child who Died

Suggested Questions:

Tell me who is in your family (of origin). And what is the name of your brother/sister who died?

How did they die?

What do you know about your brother/ sister? What was something special about him/her?

What do you think your parents (or other family members) would like people to know about him/her?

Aim: Family Commemorating or Remembering Activities / Rituals

Suggested Questions:

When do you remember first learning about (name of child who died)? Who told you?

What can you tell me about your brother or sister? What are special qualities that he/she had – that you have heard about from your parents/ or other family members?

Are there any stories that stand out in your mind about your brother/sister? How do you feel when these stories are told?

Would you say your family is open in talking about (name)? Can you give me an example?

While you were growing up, were there special things that you or your family did to remember or honor (name)?

What about special occasions/ holidays? Were there any ways in which he/she was remembered then?

Aim: Participant’s Relationship to Sibling Never Known

Suggested Questions:

How old were you or how long before you were born did (name of child who died) die?

While you were growing up, when might you think about your brother or sister? What times sort of things might make you remember them?
What about today – are there certain times when he/she comes to mind? What do you think about when you think about him/her? Do you feel like this has changed since you were younger?

This might seem like a silly question, but do you see yourself as having a relationship with (name of child who died)? Or … Who is (name of child who died) to you today?

Do you ever talk about (name)? Or … When might you tell someone that you had a brother/sister who died?

**Aim: Impact of Loss on Participant**

**Suggested Questions:**

Tell me about your experience of having grown up in a family with a child who has died.

How do you make sense of your brother/sister’s death?

Do you think that you grieve your brother/sister?

Is there anything that you would hope for other brothers/ sisters who grew up in a family that lost a child?

What do you think life would be like for you if your brother/sister had lived?

How about your parents – do you think they parented you differently because of the experience of having lost a child?

If you had brothers or sisters who were alive at the time that your sibling died, how do you think their experience was different than yours?

**Demographics:**

What is your age?

What is your gender?

What is your race/ethnicity?

Thinking about the time when you were 16 years old, compared with American families in general then, would you say your family income was far below average, below average, average, above average, far above average?