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MEMORY KEEPERS: A NARRATIVE STUDY ON SIBLINGS NEVER known

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Drawing on literature relevant to the impact of sibling death, the authors examined the invisible loss of siblings never known. This article presents findings of a phenomenological study of 15 adult siblings who “storied” the psychological presence and power of a deceased infant sibling never known but who acted as memory keepers for their unknown sibling. Transcriptions of the 15 interviews were analyzed using NVivo software to support development of thematic categories. The initial 29 subthemes were collapsed into 3 overarching themes of personal loss = unacknowledged loss, continuing bonds = memory keeping, and sense-making. The participants’ experiences reflect support for unaddressed and unacknowledged loss for the phenomenon of loss of an unknown sibling. The retrospective narratives echo their perceived roles as memory keepers of their unknown siblings. For many participants, the research process itself was the first recognition of a sense of loss.

Sibling deaths carry a significant impact for surviving siblings. The grief of a sibling may be as significant, though different, as that of a bereaved parent. Some investigators (Davies, 1995; Devita-Raeburn, 2004; Packman, Horsley, Davies, & Kramer, 2006; Rosen, 1986; Rowe, 2007) have described the grief of a bereaved

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sibling as “invisible,” and this phenomenon has been given more consideration in recent literature. However, little attention has been given to possible effects of a child who has died at or near birth on the siblings who never knew the deceased child in the world of the living, but who “knew” the brother or sister through the voiced and unvoiced stories of the family. The authors propose that a portion of living siblings of a deceased infant may in fact be memory keepers (Edwards, 2005) for that child; in other words, they “hold” what some postmodernist grief theorists (Klass, Silverman, & Nickman, 1996; Kempson, Conley, & Murdock, 2008; Neimeyer, 2001) refer to as continuing bonds with and meaning reconstruction around their unknown sibling.

The purpose of this exploratory, phenomenological study is to examine, through retrospective narrative, how surviving siblings understood the loss of a sibling who died at or near birth but who was never physically known by them in their families. This article reports on the findings of this qualitative study conducted with adults who live with the internal storying of a deceased sibling whom they never knew. The study examines intrapersonal and interpersonal aspects of the unacknowledged loss of a sibling never known.

**Literature Review**

**Sibling Grief**

Sibling relationships are considered to be one of the strongest and longest relationships throughout one’s life (Hogan, 2008; Robinson & Mahon, 1997). The loss of a sibling is typically, at a minimum, the loss of a stable figure in one’s life, and often the loss of a loved companion (Rowe, 2007). Surviving siblings frequently perceive neglect from a host of their usual support systems at the time of the death. As elaborated on by Devita-Raeburn (2004), “Validation is in short supply when a sibling dies. In the broad-based group I spoke with, the ultimate equation was simple: the less validation, the more ambiguous the loss, the more frozen the grief” (p. 31). Other researchers indicate that the lack of acknowledgment about the significance of their personal loss may complicate surviving siblings’ grief (Davies, 1995; Devita-Raeburn, 2004).

Surviving siblings may live through a double trauma during the time following the death of their sibling—having lost both a
sibling and, at least temporarily, the support and attention of their parents (Packman et al., 2006). Because adults may perceive their surviving child as lacking a depth of understanding about death or a host of other reasons, the surviving siblings may be shut out of the grieving process. Of these, a significant number of surviving siblings may experience an unresolved or lifelong grief in response to the loss of a sibling (Rowe, 2007). These survivors are often thought of as “invisible or forgotten mourners” (Packman et al., 2006) within their family and community (Capitulo, 2005; Côté-Arsenault, 2003; Devita-Raeburn, 2004; Hogan, 2008; Sood, Razdan, Weller, & Weller, 2006).

Surviving siblings often experience an enduring emotional attachment thus exemplifying continuing bonds (Klass et al., 1996; Neimeyer, 2001) with the lost sibling. Siblings, like their parents and extended family, recognize that their lives have been irrevocably altered. This experience affects them so deeply that in their adulthood, because of their own encounter with tragedy, they sometimes have a greater appreciation of life and greater comfort with death and often feel able to help others in distress due to their grief journey (Hogan, 2008; Packman et al., 2006; Robinson & Mahon, 1997).

Continuing Bonds and Meaning Reconstruction

Grief theories have now evolved to present-day postmodernist perspectives, focusing on continuing bonds and meaning reconstruction (Gillies & Neimeyer, 2006; Goldsworthy, 2005; Kempson et al., 2008; Klass et al., 1996; Rothaupt & Becker, 2007). Significant loss results in the disruption of the template and the meaningful order of one’s life (Brownlee & Oikonen, 2004; Neimeyer, Prigerson, & Davies, 2002). According to Neimeyer, Baldwin, and Gilles (2006), such losses require efforts to find meaning in the loss, to reconstruct one’s identity in the face of being the survivor, and to attempt to find something beneficial that came as a result of the loss.

Methods

Study Design

The study was conducted to describe the lived experience of the loss of a sibling never known among a sample of surviving adult
siblings. A phenomenological descriptive design, collecting data through face-to-face interviews with a purposive sample of volunteer participants, was used to elicit their subjective experiences and interpretations (Polit & Beck, 2004; Rubin & Babbie, 2008). The research questions were the following:

1. What is the lived experience of growing up in a family that has lost a child at or around birth?
2. What is the impact of the lived experience of a lost sibling never known?

Sample and Sampling Procedure

With the exception of two, all interviews were conducted primarily on campus in a small Wyoming university town of approximately 27,000. One of the other two interviews was held in a neighboring town in Wyoming, and another was conducted with an attendee at a national grief conference.

To recruit potential participants, an 8 × 11 flyer was posted around the university campus for approximately 4 months. The flyer requested participants for a research study on the experience of living with the loss of a sibling who was never known. The flyer was also posted at a national conference resulting in the recruitment of one participant. Using the same content of the flyer, e-mails were delivered to all University of Wyoming campus e-mail subscribers. Within the purposive participant pool, there was a snowball effect as an interviewee would recommend others to the study. Additional interviewees were located through word of mouth. Criteria for inclusion in the study included a person over 18 years of age, s/he having experienced a family loss of a sibling at or near birth, and completion of a consent form. Approval for this study was obtained from the Institutional Review Board (IRB) at the University of Wyoming for Human Subjects Research.

Instrumentation

Two instruments were developed. First, a brief demographic form was formulated that asked each participant to provide the following: current age, gender, religious background, where they grew
up, and ethnic background. Second, a series of open-ended prompt questions were developed to encourage elaboration in response to the unknown sibling grand tour questions (the two main research questions).

Data Collection

Data were collected through completion of the demographic form and semistructured face-to-face interviews. Interviews were audio-taped and were approximately one hour in duration. They were transcribed verbatim.

Data Analysis

Data collected from the demographic questionnaire were analyzed by descriptive statistics. Interviews were transcribed and data were uploaded to NVivo, a qualitative software program. NVivo allows researchers to organize transcribed material into thematic categories, which then allows for easy referencing during analysis. In large qualitative studies, NVivo has been shown to improve the efficiency of analysis by allowing more sophisticated comparisons between themes than with manual methods (Auld et al., 2007). Further, NVivo increases flexibility and heightens specificity of qualitative findings (Bazeley, 2002).

After uploading the interview transcriptions, the researchers identified thematic categories through an inductive stage of open coding (Padgett, 1998). Twenty-nine subthemes were identified through a process of constant comparison until saturation or the point where no new information was found (Strauss & Corbin, 1998). NVivo quantified participant responses in each thematic category.

Findings

Nineteen respondents were interviewed. Four interviews were excluded from the data analysis. Two interviews were not recorded due to a technical malfunction; therefore, the data obtained were not available for analysis. Two interviews were sufficiently different from the focus of the study (near- or at-birth sibling loss) as to warrant exclusion as one participant’s sibling was removed from
the home and did not die, and one interviewee’s mother had an early pregnancy miscarriage. The final sample consisted of 15 interviews.

**Demographic Information**

Ten women and 5 men, ranging in age from 22 to 60 years old, participated in the study. Twelve were White, non-Hispanic; 3 had other ethnic backgrounds. Other demographic information such as religion, location of upbringing, number of siblings, birth order, and gender of deceased sibling, is shown in Table 1.

**Qualitative Analysis**

Analysis conducted through the NVivo program highlighted 29 subthemes. Each of the thematic categories was identified through an open-coding, constant comparison process. NVivo recorded the number of references/responses to each theme specific to each transcript. When the subthemes were analyzed, seven primary themes evolved as most significant and inclusive of the 29 subthemes. These primary themes were communication, impact/effect, lack of acknowledgment/validation, loss, memory keeping, personhood, and sense-making. Finally, the seven primary themes were again re-analyzed and further collapsed into three overarching themes: (a) memory keeping/continuing bonds, (b) personal/unacknowledged loss, and (c) sense-making. In reporting study results, when names are used or quotations from participants are presented, pseudonyms are used to ensure anonymity.

**MEMORY KEEPING/CONTINUING BONDS (100%)**

Storying of circumstances surrounding one’s unknown sibling was important to all participants, suggesting a form of memory keeping. Edward (age 37) indicated that his sibling’s death did not leave him with a sense of loss. He, nevertheless, wanted to “tell the story” of his sibling’s birth/death. Many of the stories (80%) were couched within medical contexts. Darcy (age 37), whose brother died after 5 days from encephalitis, described the agony storied by her mother who was on the same hospital floor as the infant: “They didn’t feed him or anything, you know...[S]he describes him crying. She heard him crying that whole...
<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Age at sibling's death</th>
<th>Birth order of living sib.</th>
<th>Gender of deceased sibling</th>
<th># of brothers</th>
<th># of sisters</th>
<th>Place of growing up</th>
<th>Religion</th>
<th>Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darcy</td>
<td>F</td>
<td>37</td>
<td>2</td>
<td>Oldest</td>
<td>M</td>
<td>1</td>
<td>2</td>
<td>Rural WY</td>
<td>None</td>
<td>Mixed</td>
</tr>
<tr>
<td>Sarah</td>
<td>F</td>
<td>47</td>
<td>11</td>
<td>2nd</td>
<td>F</td>
<td>3</td>
<td>2</td>
<td>Rural CO</td>
<td>Catholic</td>
<td>Hispanic</td>
</tr>
<tr>
<td>Jenny</td>
<td>F</td>
<td>53</td>
<td>Unborn</td>
<td>Only child</td>
<td>M</td>
<td>0</td>
<td>0</td>
<td>Northeast</td>
<td>Unitarian</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Denise</td>
<td>F</td>
<td>22</td>
<td>4</td>
<td>Oldest</td>
<td>M</td>
<td>0</td>
<td>1</td>
<td>Rural WY</td>
<td>Christian</td>
<td>Asian American</td>
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<tr>
<td>Catherine</td>
<td>F</td>
<td>46</td>
<td>28 mos.</td>
<td>Oldest</td>
<td>F</td>
<td>2</td>
<td>2</td>
<td>Rural Iowa</td>
<td>Protestant</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Berta</td>
<td>F</td>
<td>26</td>
<td>Unborn</td>
<td>2nd</td>
<td>M</td>
<td>0</td>
<td>1</td>
<td>Poland</td>
<td>Catholic</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>David</td>
<td>M</td>
<td>60</td>
<td>2 y.o.</td>
<td>2nd born</td>
<td>M</td>
<td>2</td>
<td>3</td>
<td>Rural WY</td>
<td>Buddhist</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Zach</td>
<td>M</td>
<td>49</td>
<td>Unborn</td>
<td>Youngest of 4</td>
<td>M</td>
<td>1</td>
<td>1</td>
<td>Denver, CO</td>
<td>Agnostic</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Melissa</td>
<td>F</td>
<td>28</td>
<td>Unborn</td>
<td>5th of 6</td>
<td>F (Stepsister)</td>
<td>1 full brother; 1 stepbrother; 1 half-brother</td>
<td>1 full sister</td>
<td>Rural WY, SD</td>
<td>None</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Allen</td>
<td>M</td>
<td>41</td>
<td>Unborn</td>
<td>4</td>
<td>F</td>
<td>3</td>
<td>0</td>
<td>Salt Lake City, UT</td>
<td>None</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Steven</td>
<td>M</td>
<td>35</td>
<td>Fraternal twin</td>
<td>Oldest</td>
<td>F (Twin)</td>
<td>0</td>
<td>1</td>
<td>Suburban Los Angeles, CA</td>
<td>Protestant</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Elena</td>
<td>F</td>
<td>27</td>
<td>8</td>
<td>Oldest</td>
<td>M</td>
<td>2</td>
<td>0</td>
<td>Rural Northern Plains</td>
<td>Catholic</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Abby</td>
<td>F</td>
<td>48</td>
<td>About 3</td>
<td>Oldest</td>
<td>M</td>
<td>2</td>
<td>2</td>
<td>Rocky Mts.</td>
<td>Mormon</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Edward</td>
<td>M</td>
<td>37</td>
<td>Less than 1 y.o.</td>
<td>2nd</td>
<td>F</td>
<td>0</td>
<td>0</td>
<td>South Texas</td>
<td>Eastern Orthodox</td>
<td>White, non-Hispanic</td>
</tr>
<tr>
<td>Sandra</td>
<td>F</td>
<td>24</td>
<td>Oldest</td>
<td>Unborn</td>
<td>F</td>
<td>0</td>
<td>1</td>
<td>Iowa</td>
<td>Christian</td>
<td>White, non-Hispanic</td>
</tr>
</tbody>
</table>
time...[S]he’s glad now to have heard it, because she never held him or saw him.” For 12 of the 15 participants, there was an implicit or explicit knowledge of being a primary “memory keeper” within their families for the deceased sibling. “I’m probably the one that’s the least willing to let her be forgotten” (Catherine, age 46).

Within the group, six participants talked about rituals surrounding the remembrance of their unknown sibling. Gloria (age 47) captured the importance of rituals and their endurance over time: “36 years later, and every year for Lucia’s birthday, I have 6 white carnations and a single red rose... The red rose is for her red lips, and the 6 carnations are for us who lived and remember her.” Ritual activity, however, sometimes had a painful impact. Melissa (age 28), growing up with her abusive stepfather, remembered being forced every year to celebrate the birthday and visit the grave of her unknown stepsister. Yet, “I really liked going to visit her grave. You know, I really liked having that connection with her. Because I had built her up in my mind as...the one who understood me.”

Six participants (40%) engaged in fantasies about or in conversations with the sibling as a way of maintaining an emotional connection and of coping. These adult siblings used words like connecting, closeness, “feeling” the presence of the sibling, “gaining a different perspective”; “I [as the twin] still feel her; I do have a memory of her. I really don’t like being alone” (Steven, age 35).

For Zach (age 49),

[There were] nights I lay in bed, and I don’t know if I would outwardly talk to him...but, I would just kind of feel, you know, “hey, I wish you were here” and still just kind of that fascination of what would life have been like had you been around. I think there’s some elements of relationship. I have no idea how to, how you describe that... [H]e’s still a part of our lives.

Melissa (age 28) lived on a ranch in the country with her severely abusive stepfather. She referred to her deceased stepsister (Tracey), whom she had never known, as one of her few friends. Melissa depended on Tracey to offer support and protection when she was being abused. She added, “I would spend...time telling her how much I hated myself... She would tell me ‘Well, you don’t have to hate yourself.... You’re a nice girl. You’re fun. We like to play.’”
An infant’s name attributed identity and memory to the sibling as a person, as reflected through the storying of the loss by all participants, especially for the two whose siblings were not named. A name appeared to provide a personal bond or connection, enabling the lost sibling’s persona, psychological presence, and significance to be more concretized. David (age 60) succinctly stated the case: “Richard never was a non-entity.” Jenny (age 53), whose parents were advised by medical personnel not to give the baby a name in case they wanted to use that name for another child in the future, reflected the ongoing presence of her deceased brother in this way:

I think it would have made it more real if he had had a name, and it would have made it more, well, validating [of] the importance, the existence, the role that he and the loss played in the family. I think all would have been impacted positively by having a name. And it would have acknowledged what some of the hopes or dreams or whatever they were attaching to that child to some extent.

PERSONAL/UNACKNOWLEDGED LOSS (93%)

In reflecting on the loss of their sibling whom they never knew, some sense of loss was clearly articulated in many different ways and by all but 1 of the 15 participants. The sorrow of loss was expressed as having less in one’s family. Several participants explicitly acknowledged a sense of grief in reflecting on the loss of their sibling whom they never knew: “it’s a kind of grief for a person I never knew” (Allen, age 41); for Jenny (age 53), “there’s still that longing, wish that I had a sibling”; and “I think of it as a loss because . . . it was a sibling that I don’t know . . . that I don’t have . . . . You’re a different person for it” (Elena, age 27). Allen (age 41) captured the essence of the experience with a few succinct words: “I would use yearning as . . . the feeling. For something that can’t be.”

Thirteen out of 15 participants found no acknowledgment or validation for their experience of loss as “no one named it” (Steven, age 35). Most participants were only able to label their experiences in relationship to the unknown sibling as a loss when reflected on retrospectively. For 8 participants, the research recruitment flyer (“well, actually, that’s me,” Sandra, age 24) and/or the interview itself raised consciousness about an unrecognized
sense of loss. Abby (age 48) stated, “I don’t think I realized that I felt a loss until right now.” Perhaps Zach (age 49) described the quintessence of the experience/unacknowledged loss when he said,

[I]f you’re not around when that child dies, people don’t think it has any connection to [you]…. So people just don’t look at it as a loss for you because how can you lose something you never knew about? But it’s the loss of a relationship.

SENSE-MAKING (93%)

Fourteen participants engaged in attempting to make sense of their sibling’s death relative to their own lives. The psychological/spiritual presence of the unknown sibling was perceived by all participants as having a lifelong impact in various and different ways. Most experienced a presence of loss or sadness for self or parents. Three participants referenced some feeling of guilt for being the child that lived. Fears about the risk of having one’s own children or of experiencing a similar devastating loss were noted by 4 participants.

For most participants, there were questions about how life might have been different if their sibling had lived. Eleven participants indicated that their sibling influenced their relationships with other people or with other family members. Two participants talked about a strained relationship with the sibling who was born after the unknown sibling, indicating that the next-born sibling had been overindulged by parents. Elena (age 27) spoke of her next-born sibling, a special-needs child, with a sense of affection and appreciation, adding that he would not have been born had it not been for the unknown sibling’s death. Two participants noted some lack of ease with or understanding of women which they felt would have been different if their sister had lived.

For Catherine (age 46), her sister’s death and subsequent death of a loved grandmother provided her with a comfortableness with death, serving her well in her capacity as a hospital chaplain. For 4 participants, career choice that in hind sight was a reflection of loss of their sibling represented a kind of sense-making connected with the residual effects of loss. Zach (age 49), whose brother had significant damage from a “forceps’ delivery,” knew that Gary would have had multiple handicaps had he lived. He reported
being “borderline obsessive” with thoughts and questions about Gary for 2 to 3 years. He decided on a career in education and presently works with developmentally delayed children. Jenny (age 53) eloquently described it this way: “I certainly had the sense that my feeling of being led to grief work [career path] was about having carried grief for a number of events [including my brother’s death].”

**Discussion**

Storying is a human predilection as we attempt to make sense of significant events in our lives (Neimeyer, 2006). Storying in this study served as a conduit to remember and connect to the unknown sibling in the process of attempting to make meaning of the sibling’s death. The stories within the findings of this exploratory study reflect the previously unappreciated power of an “unknown sibling” who has died at or near birth on the living sibling and that sibling’s self-identity as the “memory keeper.” The complexities of the phenomenon are woven throughout the participants’ stories.

According to Rowe’s study (2007) on sibling loss, not having known the sibling does not mean that a child is unaffected by the deceased sibling; the sibling is still a part of the family. She stated, “[T]he fact that there was once someone like me but not me is something to puzzle over and take into account” (p. 184). The narratives in this study echo their overwhelming perceptions of themselves as “memory keepers” of the unknown sibling, often reflecting a sense of loss at not having known their siblings but having a continuing and strong personal connection with the sibling.

Death of a neonate is the loss of anticipated roles for family members (Werner-Lin & Morrow, 2004). Elements of loss or grief are reflected throughout the interviews (93%). The dynamic of loss for these participants appears to mimic or parallel to some degree the experience of loss of siblings who have suffered the death of a sibling that was known in this life. Studies of sibling loss (Devita-Raeburn, 2004; Hogan, 2008; Packman et al., 2006; Rosen, 1986; Rowe, 2007; Sood et al., 2006) demonstrate the invisibility of sibling grief, even for siblings known. Siblings of unknown siblings experience a similar lack of invisibility.
Cacciatore, DeFrain, and Jones (2008) reported results of their study of the ambiguity surrounding stillbirth through a retrospective, anonymous compilation of group responses of a range of family members. Study methodology is unclear, and the actual number of sibling responses and their place in the family constellation is not reported. However, our findings support their tentative conclusions that the death of a stillborn baby is “invisible” and highly ambiguous, as there is no physical presence of a relationship. Yet often there is a significant psychological or spiritual presence of the infant that did not survive. This experience for living siblings is in keeping with Boss’s (2004) construct of ambiguous loss—a loss that is unclear and that lacks external validation. Indeed both studies confirm the struggle of surviving siblings of an unknown sibling with respect to defining the enduring relationship with their deceased infant sibling, a relationship that is unnamed and unacknowledged by the outside world. This intrapersonal struggle within a cultural void perhaps represents an experience of disenfranchised loss (Doka, 1989).

For nearly all participants, this unacknowledged loss resulted in, as noted by Zach, a loss that had no name. Lack of a defined phenomenon resulted in their being unable, except in retrospect, to label their experiences in relationship to the unknown sibling as a loss. Two participants were only able to perceive their sibling’s death as a loss to themselves after reading the flyer for the study. The concept of a loss with no name or an unacknowledged loss resounded for all but one interviewee. Such an absence of validation potentially contributes to a dialectic between the intrapersonal experience and the interpersonal experience of loss, or as referred to by Klass (2006), “a disconnect between inner and social reality” (p. 851).

Referencing the sibling’s name was an important component of storying the unknown sibling, thus attributing identity and personhood to the sibling. The two participants whose siblings were not named in this study questioned the wisdom of that decision. As noted by one participant whose sibling was not named, naming her brother may have helped in acknowledging the significance of the loss for her parents and herself.

A particular intricacy of balance is involved in rituals of bonding and letting go associated with neonatal/stillbirth deaths. Rituals, such as the naming of a stillborn baby, are, however, the
fabric in most cultures in the demarcation of critical events in life. Capitulo (2005), Hooyman and Kramer (2008), and Wretmark (1992) noted the importance for parents of naming and burying stillborn children as contributing to the ability to better integrate the reality of their loss. However, to our knowledge, the significance of naming for unknown siblings has not been examined before the present study.

Beyond bestowing a name to the infant, 6 participants referred to other rituals, such as visiting and/or placing flowers on the gravesite, that were important in remembering their sibling. Commemorative acts contribute to the maintenance of a spiritual presence of the child (Layne, 2000). Researchers (Fanos et al., 2009; Rosen, 1986) affirm the importance of ritual for living siblings as a way to maintain connection with a deceased sibling.

Just as ritual was an important part of remembering, so was an ongoing lived connection important as a way of coping with the sense of loss. With the exception of one participant, responses suggested an ongoing relationship with their unknown sibling. The notion of continuing bonds with the symbolic person who was not physically known is not specifically or directly addressed in the relevant literature, though Cacciatore et al. (2008) and Rowe (2007) alluded to the suggestion of continuing bonds with siblings even if the sibling was not known in the physical world.

The concept of continuing bonds, as explored and elaborated on by Klass et al. (1996), was a significant challenge to the previous dominant discourse that considered such a bond with the deceased as pathological (Field, 2006). Devita-Raeburn (2004) in her study on sibling loss found that living siblings “carry” a deceased sibling whom they have known throughout their lives; the deceased sibling becomes a fellow traveler. Although the notion of continuing bonds carries no inherent connotation of healthy versus unhealthy response to grief, it does refer to the fact that many people do continue a bond with the deceased person that may be beneficial to the living person (Klass, 2006). And as noted by Rowe, “Remembering a dead sibling and the circumstances of that sibling’s death is a way of somehow keeping the person alive. If no one remembers us we have well and truly disappeared” (p. 200).

In this study, three participants spoke directly about or inferred the importance of the unknown sibling as a friend or a beacon of faith and hope in a future, thus supporting the
importance of human connection in daily living. Perhaps human resiliency does not always necessitate the physical presence at some point in time of relationship with another; perhaps it is sufficient to “hold” the notion of relationship with another in the mind’s eye, maintaining a sense of importance with the other who “thinks about me.” As suggested by many religions, a transcendence of the temporal nature of being may be an enduring component of well-being.

Several siblings in this study discussed not only an ongoing relationship, but also an ongoing dialogue with the unknown sibling, sometimes for the purpose of simply dialoguing with but sometimes for solace in the face of difficult or challenging situations in life. Neimeyer et al. (2006) stated that continuing bonds with a deceased significant other person “provides a safe haven at times of threat, and a secure base from which to explore the world” (p. 716). In the case of the participants in this study, the bond and safety is with a symbolic projection (or inner representation) of the all-accepting deceased sibling, perhaps even more important than had the sibling actually lived and been known, as noted by Melissa (age 28) who was conscious that her stepsibling in fantasy may have been more of a friend to her than she would have been among the living.

The notion of continuing bonds with an unknown deceased person perhaps may be more easily located in experiences of collectives of persons. Groups of persons, such as surviving family members of Holocaust victims or certain indigenous groups, have experienced extensive collective losses of persons and/or cultures unknown to them directly. Succeeding generations perceive memory keeping as necessary to remembering and connecting (Irwin-Zarecka, 2007).

Neimeyer (2006) delineated human narratives of lived experiences into three dimensions consisting of personal, interpersonal, and cultural. This study mirrors exploration of those dimensions as the interview process facilitated access to the intrapersonal realm of loss for interviewees and its bearing on the core sense of identity for the surviving siblings. Moreover, the interviews tapped into the interpersonal realm for participants in discussing interactions within their family or community that were unable to provide external or cultural validation. The researchers granted an opportunity for these adult siblings to openly acknowledge and
discuss the sense of loss, most often for the first time. Inadvertently, the research crossed the line into “therapeutic opportunity,” as the narration of the deceased sibling allowed the storying or re-storying of the impact of the unknown sibling’s death on the family, particularly on the participant sibling. As noted by Romanoff (2001), “Even in a research setting, a narrative can and does have a therapeutic impact. In research on bereavement, the narrative process offers opportunity for both continuity and change” (p. 254).

In the case of this narrative study, the opportunity presented itself in meaning-making of the sibling’s death. The meaning that an individual makes of a significant death is at the center of coping and navigates the future of one’s well-being (Hsu, Tseng, Banks, & Kuo, 2004). The collective responses of participants speaks to the power of loss and meaning-making surrounding their unknown sibling’s place in their lives, including what lesson was to be learned or what purpose the death served for them. Their retrospective reflections on the loss of the unknown sibling embodies the “narrative construction of self, and...the (para)linguistic negotiation of changed meanings to provide a more responsive frame for holding the complexity of loss as a lived experience” (Neimeyer, 2001, p. 289).

**Implications for Practice**

Parents may be too grief-stricken to be supportive of each other or other living children after the loss of a child. Mental health professionals typically concentrate on the parental grief and family adjustment during this time too, as this is the most obvious need when presenting for help. Society at large also views the system of the entire family or the parents alone as the unit most in need of attention. Surviving siblings have reported typical responses such as “Your parents are so lucky to have you,” or “Help your parents during this terrible time” (Robinson & Mahon, 2004). Their loneliness is unique and thus deserves special attention of professionals.

The practice implications of this study for professionals working with families, either at the time of a neonatal death or at some later point in time, are significant in light of the multilevel impact of such deaths on the family. Of particular importance
when working with newly bereaved parents of neonatal death is the articulation and facilitation of bringing to consciousness the potential impact of the child’s death, not only for themselves, but also for surviving siblings or siblings yet to be born. Capitulo (2005) noted the particular susceptibility of neonatal deaths to disenfranchised grief. She reinforced the importance of clear communication and explanation between parents and children as part of the healing process. Possible referral for therapeutic intervention for families at risk needs to be considered by front-line health professionals.

In taking social and psychological histories, professionals—whether working with individuals, couples, or families—need to be mindful of taking a complete history to include questions, both factual and probing for deeper meaning regarding miscarriages, abortions, stillbirths, and neonatal deaths. The honoring of these deaths by professionals, particularly for surviving siblings, may provide the acknowledgment and validation that prompts the narratives of loss and grief, as some people may never have allowed themselves to consider the death of an infant sibling as a loss (intrapersonal) or they may never have had it validated as a loss in the interpersonal realm, much less within the cultural realm.

**Future Research Considerations**

The findings of this exploratory research suggest a beginning understanding of unacknowledged loss suffered by living siblings in response to an unknown sibling’s death at or near birth. These forgotten mourners represent a subset of surviving siblings who are memory keepers. The authors suggest a need to further investigate this unique grief and loss due to its seemingly profound effect on these siblings’ lives. This need permeates all levels from the individual to society. More extensive study of such sibling loss and the systemic aspects of family grief and loss located within infant death is indicated, including an understanding of the dynamic mechanisms in operation within a family that may result in one sibling—as opposed to another—assuming the position of memory keeper. Studies of entire families who have experienced the death of a neonate may facilitate a greater understanding of the dynamic interplay and effects of such grief on families over time—or, in other words, of the transgenerational/intergenerational impact of
these neonatal deaths. Finally, cross-cultural studies are needed to explore the nuances of similarities and differences among cultures in acknowledgment of the presence of and validation of any effects of the sibling never known to surviving siblings.

References


