

Candles in the Snow: Ritual and Memory for Siblings of Infants Who Died in the Intensive Care Nursery

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Objective To assess the developmental impact of surviving a sibling who dies in the neonatal intensive care unit (NICU).

Study design Fourteen (13 adults, 1 adolescent) siblings of infants who died in Dartmouth-Hitchcock Medical Center's NICU between 1980 and 1990 were interviewed. The interviews were recorded and transcribed verbatim, and prominent themes were coded.

Results Six siblings rated family communication as veiled or a family secret; 7 reported unresolved parental mourning. Eleven siblings were rated high on anxiety themes, including concerns over future pregnancy or anxiety about their mother's health. Photos and family rituals were helpful to siblings in grieving and remembering the infant.

Conclusions Although death in the NICU often has a brief course, consequences for survivor siblings can be life-long. Siblings born both before and after the death of an infant may be at risk and in need of psychological support. Family rituals and photos are important vehicles of communication, grieving, and memory for siblings and parents alike. Clinicians should allow siblings to be active participants in the infant's brief life and death. (*J Pediatr* 2009;154:849-53)

Little is known about the long-term developmental consequences for surviving siblings of infants who die in the neonatal intensive care unit (NICU), and long-term follow-up studies of these siblings are needed.¹ In sibling survivors of neonates, some themes may be shared in terms of reactions to chronic pediatric conditions. Sibling resentment, guilt, anger, and prolonged maternal grieving may contribute to similar difficulties. There may be other unique consequences as well; for example, visiting the NICU may raise specific anxieties.

Many families with an ill child tend not to communicate about the disease.²⁻⁹ Family secrets lay the groundwork for traumatic responses to the illness and death.¹⁰ Siblings may be unable to grieve until traumatic aspects are resolved.¹¹

Leon¹² found the impact of perinatal death on siblings to be determined by parental responses. These commonly include anger, guilt, sorrow, helplessness,¹³ as well as pregnancy-specific anxiety and depressive symptoms.^{14,15} Displacement of blame and anger can lead to maltreatment in the family.¹⁶ Studies have indicated that many parents are unaware of the effects of the NICU experience on siblings and lack the knowledge to assist them.¹⁷

Gold¹⁸ reported that the death of an infant may involve complicated bereavement for parents. Maladaptive mourning responses include idealization, substitution, memorialization, and refocusing on surviving siblings, with profound consequences for these children's identity and self esteem.^{4,19,20} Young adults who lost a sibling when they themselves were younger than 5 years old recalled their mothers as more protective/controlling compared with other groups.²¹

METHODS

The goal of this study was to assess the psychosocial impact of surviving a sibling who died in the NICU.

Recruitment Efforts

W. E. and G. L. sent a letter to the parents of all infants who died in the NICU at Dartmouth-Hitchcock Medical Center between 1980 and 1984. A total of 77 letters were mailed, of which 30 were returned by the postal service, and 7 responses were received. Of the 7 parents who responded, 4 had contacted their adult offspring, 1 had no adult offspring, and 2 wished not to contact their offspring. Two siblings contacted J.F.

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and subsequently were interviewed. The parent of 2 siblings from another family was contacted directly, and the 2 siblings were then interviewed.

W. E. and G. L. also mailed a letter to the parents of all infants who died in Dartmouth-Hitchcock Medical Center's NICU between 1985 and 1990. A total of 101 letters were sent, of which 43 were returned by the postal service, and 24 replies were received. Fifteen parents provided names and addresses of their offspring. J. F. sent a postcard to each of the 23 potential siblings. Sixteen siblings responded; 14 agreed to be contacted, but 4 of these did not participate despite repeated attempts to enroll them. Thus, 10 siblings were interviewed.

David J. Durand, MD, Director, Division of Neonatology, and Arthur D'Harlingue, MD, Medical Director, Neonatal Intensive Care Unit, Children's Hospital and Research Center, Oakland, California, mailed a letter to the parents of all infants who died in their NICU between 1987 and 1990 for whom addresses were available. A total of 82 letters were sent, 30 of which were returned by the postal service, and no replies were received.

Description of the Sample

Fourteen siblings (13 adults and 1 adolescent; 12 females and 2 males) from 9 families of infants who died in the NICU were interviewed. The study protocol was approved by the Dartmouth Committee for the Protection of Human Subjects and the Institutional Review Board at Children's Hospital and Research Center, Oakland. All interviewees provided informed consent.

Participants ranged in age from 16 to 27 years (median age, 22 years). Thirteen were single, and 1 was married with 2 children. All participants were Caucasian. Median educational level was some college. Six participants were born after the birth and death of their sibling. Of the 8 participants who were alive at the time of the birth/death of their sibling, age at the time of the death ranged from 3 to 7 years (median, 5 years). The deceased infants had lived from a few moments to up to 30 days.

Qualitative Analysis

J.F. interviewed each individual over the phone for about 1 hour. The interviews were tape recorded and later transcribed verbatim. The interviews were semistructured, beginning with open-ended questions and moving on to more specific questions if information was not forthcoming. For example, all respondents were asked the following

- Can you tell me about what it was like growing up in your family?
- If you had questions about your sibling's illness or death, was there anyone to whom you could bring them?
- Can you tell me about your experience when your sibling was in the NICU?
- How did your parents react?

Based on the interview material, coding scales were developed to capture important aspects of psychosocial adaptation. Nine categories were created, each with 2 possible options: parental mourning (resolved/unresolved), resentment (low/high), sibling identification with brother/sister (low/high), anxiety about being sick (low/high), anxiety about future pregnancy for self (low/high), avoidance of having children (low/high), anxiety about mother's health or mother's next pregnancy (low/high), recurring nightmares (low/high), and keeping photo of deceased infant as keepsake (low/high). Three categories had 3 possible options: sibling attachment (slight/warmth/idealization), survivor guilt (low/moderate/high), and family communication about the infant's death with siblings (open/veiled/family secret).

Several interviews were selected randomly and rated by J. F. and an outside rater. When a suitable level of reliability had been attained ($\kappa > 0.90$), 10 interviews were rated. Interrater reliability was obtained on all coded scales; κ coefficients ranged from 0.71 to 1.00 (overall $\kappa = 0.98$).

RESULTS

Sibling Relationships

Unlike chronic pediatric disorders, in which the family revolves around the sick child for many years, often creating substantial sibling resentment,^{4,22} in this study, the infants died soon after birth or within a few weeks thereafter. Consequently, sibling resentment was limited. Similarly, identification with or idealization of the sibling, so prominent in many chronic illness situations,⁴ was not an issue here. Siblings who visited the NICU recalled seeing the infant in the incubator with medical apparatus in place. Many found the image confusing. One young woman, 5 years old at the time, remembered seeing her brother in his incubator and thinking that he would grow up and live in a bubble. Siblings perceived a hierarchy of privilege of involvement with the infant. They were most proud to have held the infant and, failing that, at least to have viewed the infant. One young man recalled that because he was only 5 years old, he never held his infant brother, but at least he "got to look through the window." He believed that his younger brother, 3 years old at the death, "had the hardest time with it because he was the only one that didn't ever get to see or hold him."

Those older or whose sibling had lived longer cherished memories of the time they had together. One young woman, 7 years old at the time, recalled feeling special that she was able to bring her brother a rattle and give concrete expressions of affection: "I made him a weather chart so I could tell him what the weather was outside that day." She was grateful that the medical staff "let me do what I could at the time, which was to be there and to talk to him instead of relegating me to some room somewhere . . . I think that when things went wrong and he did die, having us all together was really big. It wasn't like he died by himself. We were together, and we had this moment as a family."

Several siblings longed for the lost opportunity to have a brother or sister, feeling different from friends and classmates.

Sibling Guilt and Gratitude

Three participants expressed feelings of guilt. One young woman, 7 years old when her sibling died, wished for a sister during her mother's pregnancy and worried that it was "maybe my fault because I didn't want another brother." One young woman, who had 2 siblings die, one when she was 5 years old and the other when she was 7 years old, felt guilty that her parents had not grieved because they did not want her to witness their distress. One young woman, born several years after the death of her brother, believed that if he had not died, she would not exist, because her mother wanted only 2 children: "It is sort of lucky for me that he died, because otherwise I wouldn't have been born. I kind of feel guilty for thinking that. I shouldn't feel lucky that a infant died." Several siblings felt gratitude rather than guilt, glad they were spared sharing a bedroom or even that the family had more financial resources to direct toward them.

Anxieties

Eleven participants were rated high on 1 or more themes of anxiety. Half of the sample was rated high on anxiety over a future pregnancy. Several participants were considering adoption to avoid pregnancy risks. One-third were rated high on anxiety over their mother, concerned that she would get sick, have another ill-fated pregnancy, or disappear altogether. Fifty percent had earliest memories containing traumatic images of death or its impact on parents. One sibling recalled: "I have like a snapshot of my Dad sitting at our kitchen table when my brother died. That was my very first memory."

Half of the participants had repetitive nightmares signaling their preoccupation with death. One young woman, born after her sibling's death, had dreams of "being in graveyards and there being zombies—generally death-related things." Some dreams reflected parents' inability to help in the face of danger. One sibling, 7 years old at the time, recalled a repetitive dream in which "bad guys were chasing me." She remembered her father explaining her brother was very sick. She responded with the following unsettling words: "Well, you can fix that. You can fix anything!" That comment has always stuck with her father.

Another sibling reported persistent anxiety. She explained: "My guess is when you are 3 years old and you see your Dad crying, you definitely realize that your parents aren't all powerful." Loss of the normal childhood illusion of the omnipotent parent is detrimental to a child's sense of safety and security in the world.

Family Communication

Six participants reported problematic family communication, creating a climate of family secrets. Those whose

sibling had died before their own birth had particular difficulty obtaining information about the death. One participant, 7 years old at the time, recalled her father telling her there was something wrong with her baby brother. She had seen people in wheelchairs and on crutches, and so "just assumed that meant he's going to be in a wheelchair." The siblings depended on parents for information. Some siblings felt that their parents had avoided the topic to protect them, but they did not find that helpful. Several siblings found children's books useful. One young woman, 5 years old when her brother died, recalled: "My Mom gave me a book called 'Freddy the Leaf.'²³ It's about a leaf that goes through different seasons and then falls off the tree. Still to this day I read the book. It explains death and gives you something to picture; as a little kid you really don't know what the heck is going on."

Unfortunately, siblings seemed not to have discussed the topic with each other, but each struggled alone. One participant, who had siblings die when she was 5 years old and 7 years old, said that the subject still is not mentioned in her family. She is now able to find comfort talking about it with her boyfriend "because he listens."

Parental Mourning

Fifty percent of siblings believed their parents had never mourned the loss. Siblings tried to find one parent to help in their own grieving. Guilt and blame caused problems, both individually and for the relationship. One sibling was told that her grandfather blamed her father for her sibling's preterm birth because her father had abused her mother. After the infant's death, the father drank heavily and eventually left his wife. He bought a house right next to the infant's gravesite. "He asked my sister when she died if she would be buried there . . . What do you say to that?"

Some parents apparently attempted to deny the loss with a replacement child.²⁴ One young woman recalled that within a year of the death, her parents took a foster child into their home. Another participant, 7 years old at the time, recalled that in high school there was a troubled young man who "became like their son, and he still is." Many participants felt that counseling would have helped their parents. There was little indication that the parents had received significant support. As one participant noted: "They had somebody talk to them briefly, but after they got home, there was nothing."

Rituals

Most siblings reported their families visited the grave at regular intervals, such as the infant's birthday, anniversary of the death, and holidays. Some families placed an ornament on the Christmas tree or planted flowers in the yard to remember the infant. Some buried the cremated infant's ashes in the backyard with a memorial marker; in some cases, seeing this marker was the sibling's introduction to the loss. One young woman, born after the loss of 2 infants, described the field behind her home where there was a small stone inscribed

Table. Sibling age, birth order in relation to deceased infant, and major rated themes present (X)

Sibling age, years	Years born before (+) or after (-) infant's death	Family communication veiled/secret	Parental mourning unresolved	Global anxiety	Sibling anxiety/future pregnancy	Sibling anxiety/mother	Photo keepsake	Nightmares
27	+7	X	X	X	X	X	X	X
25	+7			X	X		X	
23	+5, +7*	X	X	X		X	X	X
16	+3, +7*			X	X	X	X	
24	+5	X	X	X		X		X
24	+5			X	X		X	
22	+5			X	X	X	X	
22	+3		X	X				
22	-3	X	X	X	X			X
18	-3		X	X				X
18	-2						X	X
24	-1	X	X	X	X		X	X
18	-1	X					X	
18	-1, -1†						X	

*Two infants died.

†The deceased infants were twins.

with all of the siblings' names and birthdays. As a child, this encouraged her to talk with her parents about what had happened: "I would go into the garden and, as soon as I could read, I probably asked them. I'm sure they told me, because I remember knowing from a young age." Her family celebrates their December birthdays by putting candles in the snow: "We each light one for them."

Another participant, born after her sibling's death, recalled that the infant's ashes had been buried on their land with an apple tree planted nearby. "Every year, as far back as I can remember, on December 5th, we go outside at night and put a candle by the tree. When I was younger, my parents would talk to us a little when we were out there and explain some things. It wasn't like a serious conversation. It just became a sort of moment every year. As you grow up each time you learn a little more in a way that is unique and not overwhelming."

Participants reported their families preserving mementos: a lock of hair, a baby book, letters of condolence, photographs. How photos of the infants were handled was revealing. One participant reported that her sibling's photo was initially kept behind jewelry boxes, but now it is "out in the open."

In 7 of our 9 families (10 siblings), photos were treasured keepsakes. For participants who were not born yet or were too young at the time of death to remember their sibling, photos are their only concrete representation. For those who do remember the infant, photos become treasured reminders. The transition from the parent to the sibling as "keeper of the torch" was significant and demonstrated a passing of responsibility to remember. One sibling recalled how she handled the photo when moving: "My Dad kept it in his dresser drawer. I wanted to be closer to it, and to identify with it better. I remember taking it out of my Dad's drawer and keeping it in my dresser. When I moved, I just kind of like

took it with me. I was concerned that it would get lost in the shuffle at my parent's house. I remember thinking 'I'll just take this and it will be safe.'"

DISCUSSION

One significant finding is the participants' recollected desire for involvement with their sibling. Showing concrete expressions of caring, holding the infant, and being allowed to view the infant were highly valued by survivor siblings. The participants had found it difficult to understand the illness and death, and needed help and support at appropriate developmental levels. The occupational choices of the participants are indicative of the life-long implications of this event: 4 of the 14, who ranged in age from 3 to 7 years at the time of their sibling's death, have chosen careers in health care; 2 of them are planning to enter neonatology. One participant volunteered in the Dartmouth NICU for a few months after the interview conducted for this study.

Another major finding is the helpfulness of photographs in honoring the lost infants. Similar to the usefulness of photographs for parents grieving perinatal loss,^{25,26} in our sample these photos served important functions for the siblings as well: (1) providing a way of learning about the sibling who died; (2) providing a continuing connection with the deceased sibling, helping maintain memories; and (3) serving as a vehicle to facilitate communication between parents and surviving children at different developmental stages, triggering conversation. Photos can be viewed and put away at one's discretion. Thus they may serve as linking objects in mourning, a symbolic bridge to the deceased.²⁷ The rituals and traditions that families honor allow them to mourn and yet also to remember. Siblings inherit the responsibility of grieving as well as of honoring the dead child by not forgetting.

A limitation of this study is the small sample size. The 2 institutions involved represent vastly differing demograph-

ics, one urban, of low socioeconomic status, and highly mobile and the other rural, geographically stable, and more economically secure. Whether those families who declined to participate were still too upset or their mourning was resolved cannot be determined. We can infer that these parents made an adaptation that they are reluctant to disturb. Furthermore, unlike in chronic childhood illness, in which the parent has a lengthy relationship with the physician, death in the NICU is often precipitous, offering no lasting bond with the neonatologist. It is informative that many participating families were those who had maintained contact with the physician.

Despite the small sample size, some interesting differences in reported difficulties can be seen (Table). Participants who were alive during the birth and death of their sibling reported more open family communication, greater anxiety, and more importance of photographs as keepsakes. Of interest, one difficulty was more problematic for those born after the death of their sibling: more nightmares. Perhaps those siblings grew up in an atmosphere fraught with vague misgivings that could not be directly confronted, similar to siblings born after the loss of a child with X-linked severe combined immunodeficiency.⁷

Many families have adapted to the event and may be reluctant to reexamine the event and its consequences. It is important to arrange for these families to receive help at the time of the loss as well as over the ensuing months. The implementation of NICU sibling education and visitation programs has proven helpful in various institutions and should be developed further.²⁸⁻³⁰ Programs are available to serve families who have lost a sibling,⁹ a twin,³¹ or multiples.³² A recently published book devoted to support of families with infants in the NICU provides concrete strategies to address the needs of siblings and urges increased research into effective interventions.³³ Our findings from the present study reinforce suggestions detailed in that book; for example, some siblings treasure photos and family rituals for years, and recall and appreciate their participation in the infant's life and death. Even though the time frame of experience with death in the NICU may be relatively short, consequences for survivor siblings can be life-long. The neonatal team should consider the needs of siblings when planning family-centered care. Professional assistance can be a powerful addition to the range of coping strategies available to families. Medical providers and family members alike should consider psychological counseling to gain insight into the emotional responses to death in the NICU.

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