Published in final edited form as:
Am J Crit Care. 2013 November ; 22(6): . doi:10.4037/ajcc2013790.

Parents' Report of Child's Response to Sibling's Death in a Neonatal or Pediatric Intensive Care Unit

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Abstract

Background—Research on sibling death in a pediatric/neonatal intensive care unit is limited, despite many qualitative differences from deaths at home or in hospitals' general care areas and has overlooked cultural differences.

Objectives—To describe parents' reports of children's responses to a sibling's death in a neonatal or pediatric intensive care unit via qualitative interviews at 7 months after the death.

Methods—English-speaking (n = 19) and Spanish-speaking (n = 8) parents of 24 deceased infants/children described responses of their 44 surviving children: 10 preschool, 19 school-age, and 15 adolescent. Parents' race/ethnicity was 48% black, 37% Hispanic, 15% white. Ten siblings died in the neonatal unit and 14 in the pediatric intensive care unit. Semistructured interviews in parents' homes were audio recorded, transcribed verbatim, and analyzed with content analysis.

Results—Six themes about surviving children emerged. Changed behaviors were reported by parents of school-age children and adolescents. Not understand what was going on was reported primarily by parents of preschoolers. Numbers of comments in the 4 remaining themes are as follows: maintaining a connection (n = 9), not having enough time with their siblings before death and/or to say goodbye (n = 6), believing the sibling is in a good place (n = 6), not believing the sibling would die (n = 4). Comments about girls and boys were similar. White parents made few comments about their children compared with black and Hispanic parents. The pattern of comments differed by whether the sibling died in the neonatal or the pediatric intensive care unit.

Conclusions—Children's responses following a sibling's death vary with the child's sex, parents' race/ethnicity, and the unit where the sibling died. Children, regardless of age, recognized their parents' grief and tried to comfort them.

Almost 2 million children face a sibling's death each year.[1] Death may bring loss of a playmate, confidante, and/or role model[1] and loss of grieving parents who are left with little emotional energy for their children.[2] Half of these children have behavior problems,[3] 25% requiring clinical intervention, yet few receive help.[4] Research on children's responses to a sibling's death has focused on children of siblings with cancer who live day-to-day with the

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FUNDING DISCLOSURES
This study was funded by grant number R01 NR009120 from the National Institute of Nursing Research, National Institutes of Health.

siblings' cancer treatments. In neonatal intensive care units (NICUs) or pediatric intensive care units (PICUs), children may never see or touch their newborn siblings before death. Some see their siblings shot, hit by a car, or fall from a window. They may see their siblings in respiratory distress, cyanotic, bleeding, or unresponsive before transport to the PICU. These differences suggest that children's responses also may differ. This study's purpose was to describe parents' reports of children's responses 7 months after a sibling died in a NICU/PICU in 3 racial/ethnic groups.

Children's responses to a sibling's death in a NICU/PICU are largely unknown. In 1 study,[5] children of stillborn siblings felt different from friends and classmates, isolated and excluded from their families. Parents distanced themselves; children lived with relatives for a time after the death.[5] Reporting memories 10 to 20 years old, adults whose siblings were stillborn or died in a NICU recalled feeling grief, sadness, disappointment, and helplessness; wanting to see and hold the deceased; thinking they had caused the siblings' deaths or prevented their parents from grieving.[6]

Most studies of children's responses focus on siblings' cancer deaths. In 1 study[7] that primarily included white children, behaviors varied with the child's age. Preschool children experienced nausea, bed-wetting, trouble sleeping, and hyperactivity. School-age children were unhappy, sad, or depressed and experienced aches/pains, nausea, and day wetting. Adolescents were sad, unhappy, depressed, hyperactive, moody, and had aches/pains, nausea, trouble sleeping, nightmares, and daydreams.[7] South African adolescents reported shock, devastation, confusion, fear, and intense pain after older siblings' deaths.[8]

Children's responses to the sudden or violent death of a sibling included prolonged grief, bereavement, and psychological and health impairments. Adult children reported greater guilt, shame, and rejection after sibling suicide than after an accidental death.[9] Lohan and Murphy[10] found that adolescents had multiple grief reactions and behavioral changes up to 2 years after their siblings' sudden or violent deaths.

In summary, studies of children's reactions to a sibling's death from cancer, suicide, and accidental causes describe feelings and behaviors that vary with children's ages. Findings are limited by almost exclusive focus on white families,[11] widely varying "child" ages (some were adults), and ignoring whether children were born before or after their siblings' deaths.[6] Childhood responses reported up to 20 years later most likely are altered by intervening events and matured understanding of death.[12,13] Contribution of the NICU or PICU environment to children's reactions is unknown. This qualitative study is an analysis of parents' comments regarding their 2- to 19-year-old children's responses 7 months after a sibling died in a NICU or PICU.

Methods

Qualitative data reported here are from a longitudinal mixed methods study examining health and functioning of parents and family members after the death of a child in a NICU or PICU. The study was approved by institutional review boards from the university and each recruitment site (4 hospitals, Florida Department of Health). For the quantitative portion, parents whose children died in the NICU or PICU were identified by hospital collaborators and through death records from the state's Office of Vital Statistics. Letters describing the study (in Spanish and English) were sent to families. Interviewers called to screen for inclusion and exclusion criteria, describe the study, answer questions, and schedule an interview in the parents' home where written consent was obtained. All parents understood spoken English or Spanish, had a deceased neonate (singleton pregnancy) living more than 2 hours in a NICU or a deceased child (newborn-18 years) hospitalized at least 2 hours in a

PICU. Exclusion criteria included the following: child in foster care before hospitalization, suspected child abuse, and parent's death in the illness/injury event. At 7 months after the death, 63 parents of 47 deceased infants or children were individually interviewed about events around their child's death and afterward.

Procedure

Semistructured parent interviews were conducted in English and/or Spanish by using a standardized protocol at 7 months after the death. Parents received $25 for their 1.5- to 2-hour interviews. Two "grand tour" statements—"Tell me the story around your child's illness and death" and "Tell me about life since the child's death"—and associated probes were developed from the study's purpose, literature, and investigators' clinical expertise, then reviewed by our clinical collaborators for face validity, understandability, and level of language.

Interviewers were trained in study interview methods and supervised to maintain integrity across interviews. Interviews were audio recorded and transcribed verbatim. Transcripts were compared with audio recordings for accuracy and entered into Atlas.ti. The investigators and a racially/ethnically diverse group of 6 PhD nursing students used an inductive approach to thematization on 6 transcripts. Two English speakers and 2 bilingual Spanish speakers coded the interviews, using the resulting overarching themes and operational definitions. All transcripts were coded independently by 2 coders in the language of the interview. English and Spanish coders compared and discussed their coding to maintain consistency across languages. Any coding inconsistencies were discussed until consensus was reached. Text in the "surviving children's responses/actions" or "surviving child relationships" overarching themes was analyzed for subthemes by following this same process.

Results

Sample

At 7 months after a sibling died in the NICU or PICU, 27 parents commented on responses of 44 of their 48 children (≤19 years old) who lived with them (Table 1). One father and 18 mothers were English-speaking; 4 fathers and 4 mothers were Spanish-speaking. Most parents were high school graduates (93%), employed (85%), Catholic or Protestant/Christian (77%), married/partnered (63%), and lower income (63%). Half of the 24 deceased siblings were infants; 46% died of congenital or chromosomal anomalies.

Themes

Parents' comments clustered into 6 themes: changed behaviors (38%), not understanding what was going on (23%), maintaining a connectedness with sibling (14%), not enough time to be with sibling and/or say goodbye (9%), believing that the sibling is in a good place (9%), and not believing that the sibling would die (6%) (Table 2).

Changed behaviors included children not talking, being distant from parents, crying, and avoiding activities/things shared with their sibling.

> The 16-year-old, I feel him to be a bit distant—as if he doesn't want to be around me. It's like he is in his own world.
>
> She [14-year-old] doesn't want to talk about him. She ignored him because she was angry he was sick. She thought if he put his mind to it your mind could overcome everything. Then she felt guilty when he passed.

> One of my kids [6-year-old] told me they didn't want me to go out because I may leave them—and I'm like what are you saying—and my daughter says, "because [deceased] left us."

Not understanding what was going on included children's behaviors and comments demonstrating lack of understanding about death and associated activities.

> "When can I [4-year-old] see my sister? I wanna play with my sister. When she going to wake up so we could play?" I told her she was going to be sleeping for a long time. She said, "ok—I'm going to tell my sister bye." They were just touching and kissing her. Then later—"why we left her at the church all by herself? Why they put my sister in the dirt?"

Maintaining a connectedness with sibling was demonstrated by children's behaviors, words, and dreams.

> One nurse gave my oldest son [16-year-old] a guardian angel pin—so he wears the guardian angel. Everybody is like—who's that—"oh, this is my brother—he hangs out with me now." He is starting to play football. He wants a shirt with his brother's picture on it to wear under his jersey.

> My 12-year-old, he'll start feeling down—and he'll say, "let's sing one of [deceased's] songs or let's go get some of [deceased's] art and look through his book"—it's just something about his brother.

> My daughter [6-year-old] . . . says she dreams of her sister and she can hear her. Now she is saying her sister is always with her.

Not enough time to be with sibling and/or say goodbye was expressed by older children.

> I regret not letting her [14-year-old] stay in the room. She was adamant on seeing him before we left.

> He [9-year-old] regrets not having spent more time with his sister. He regrets not carrying her, not being with her—he stopped being himself.

Children's belief that the sibling is in a good place was described by black parents.

> My oldest [10-year-old] said, "my sister is in heaven—I know she haven't done no sin. I know she is much better running and playing."

> They [3- and 5-year-olds] got to see her when she was a month and a half. They got a chance to touch her and everything. When I say, "where is [deceased]," they say, "she is in heaven with God." So every time they see a star or an airplane—they are like—there is [deceased].

Not believing that the sibling would die. Some adolescents denied the seriousness of the sibling's condition before and after the death.

> I kept warning them [11- and 14-year-old], you know, he's sick – he's very sick. I think they were almost immune to hearing that—almost taking it for granted—ah, he'll be ok.

> I just don't think my daughter [14-year-old] ever felt her brother was gonna pass away.

Child's Age and Sex

Most parents' comments (78%) were about school-age children (6–12 years old) and adolescents (13–19 years old), averaging 1.6 comments about adolescents and 1.4 about school-age and preschool children. The most common theme about adolescents was changed

behaviors, followed by maintaining a connection and not believing sibling would die (Table 2). Almost half the comments regarding school-age children were about changed behaviors. Parents described preschoolers (2–5 years old) as not understanding what was going on, followed by maintaining a connection, and believing that the sibling was in a good place. Half of parents' comments referred to girls, most commonly about not understanding followed by changed behaviors. Most comments regarding boys were about changed behaviors.

Parents' Race/Ethnicity

White parents made the fewest comments, half about changed behaviors, with none about not understanding or the sibling being in a good place. Black parents commented most about lack of understanding followed by changed behaviors and made all comments about the sibling being in a good place. Hispanic parents commented about changed behaviors followed by lack of understanding.

Unit Where Sibling Died

Parents whose child died in the PICU made more comments about their surviving children overall (64% vs 36%) and per child (1.7 vs 1.2) than did parents whose child died in the NICU. The PICU-group parents commented about their child's changed behaviors and maintaining a connection. They also made all comments about children maintaining a connection and not believing the sibling would die. The NICU-group parents commented about lack of understanding followed by changed behaviors.

Discussion

Seven months after siblings' NICU/PICU deaths, parent comments about their children's responses clustered into 6 themes: changed behaviors, not understanding what was going on, maintaining a connectedness with the sibling, not enough time to be with the sibling and/or say goodbye, believing that the sibling is in a good place, and not believing that the sibling would die. Overall, the "changed behaviors" theme contained the most reports from parents. Only parents of preschoolers did not report behavior changes. Otherwise, some type of behavior change was seen in each child age and sex group, parent racial/ethnic group, and NICU/PICU group. Crying was common. Parents reported finding school-age children and adolescents crying alone, sometimes for hours. They also described crying breakdowns at family events or holidays.

Study parents felt that their older school-age children and adolescents were distancing themselves. Perhaps children needed time alone to think about the sibling's death or, as Avelin and colleagues[5] suggest, needed relief from their parents' grief. Even pre-school children were aware of their parents' grief and pain and tried to reassure or comfort them—"It's gonna be ok, Mommy. I love you, Mommy." Parents reported their school-aged children dreaming about the sibling, not wanting to talk about their sibling or do activities enjoyed with the sibling, and not wanting parent(s) to leave, fearing they might never return.

The "not understanding what was going on" theme contained the second most comments from parents, primarily about preschoolers and death, a concept that matures as children age.[12] Study parents reported their preschool and young school-age children wanting their deceased siblings to get up and play with them and wondering when they were coming home, despite attending the funeral. None of parents' comments about adolescents were in this theme, as expected developmentally.[12]

Parents' comments about "maintaining a connection with the sibling" included wearing t-shirts with the sibling's picture and special pins, talking to their sibling, and looking at

books and pictures important to the sibling. Parents in other studies also reported activities to maintain a connection with the deceased.[10] In another study, children included deceased siblings in drawings of their families,[14] perhaps indicating that continuing connection.

Comments in the "not enough time" and "not believing sibling would die" themes may reflect children's feelings of guilt, regret, and anger. A sample of these comments includes feelings of not being kind enough or not spending enough time with the sibling and thinking the sibling didn't try hard enough to get better. Children may say "You still have me" to keep parents from forgetting about them or to comfort their parents. Parents did not report the acting-out behaviors—arguing, being stubborn and/or sullen, demanding attention—that parents of bereaved 4- to 16-year-old children (90% white) in another study[3] reported. Perhaps this difference is due to the timing of the data collection or to the sibling's helpless and frightening appearance in the ICU. Adolescents' disbelief that their siblings would die may reflect the sense of invincibility common in adolescence. In other studies, disbelief has been expressed by parents and grandparents,[15] but not children.

Parents' reports about girls and boys were slightly different. Most comments about girls were about changed behaviors and not understanding what was going on. One mother noted, "I believe she [15-year-old] understands but she just doesn't want to accept that he is not coming back." Almost half of the comments about boys reported changed behaviors. Although not seen in this study, Malone[16] noted that girls may be more affected by the death than boys.

Children's responses in this study differed with the parents' race/ethnicity. White parents made considerably fewer comments (1.3/child) about their children than did black and Hispanic parents (both 1.5/child). At least half of the comments by white and Hispanic parents were about their children's changed behaviors, followed by "maintaining a connection" for white parents and "not understanding" for Hispanic parents. Comments by black parents were not predominantly in one theme but distributed across themes. The most common theme was "not understanding" followed by "changed behaviors." Most notably, only black parents made comments about "believing the sibling is in a good place." This may reflect beliefs by blacks in a "higher power" and "miracles" noted by Bullock.[17] One black 6-year-old asked his parents not to worry about his brother because "He is in a good place."

Parents of siblings who died in the PICU made substantially more comments (1.7/child) on average than did parents of siblings who died in the NICU (1.2/child). The theme with the highest number of comments for NICU-group parents was "not understanding" followed by "changed behaviors;" none commented about "maintaining a connection" or "not believing that the sibling would die." For PICU-group parents, the highest was "changed behaviors" followed by "maintaining a connection," with other comments spread across the remaining 4 themes. Perhaps the dissimilar distributions of comments between NICU and PICU groups reflect an important difference between the units. All children whose siblings died in the PICU had spent time at home with their siblings; whereas, children in the NICU group spent limited time with and got to know their siblings only within the NICU environment.

An important limitation in this study is that data on children were obtained from parents. Parents' perceptions have been reported to diverge from the children's reports of their thoughts and feelings,[18] especially for older school-age children and adolescents. Sometimes, parents reported what their children had said. However, parents' factors like depression, stress, and feeling overwhelmed may affect what parents perceive about their children. Children's factors also may play a part. Attending school and participating in outside activities decrease the time children spend with their parents. Older school-age

children and adolescents may share their true feelings with friends rather than parents, consistent with developmental expectations.[12] However, they may withhold or minimize their feelings to shield their parents from additional pain and to comply with the advice of others to “be strong” for their parents. Collecting data directly from children after a sibling’s death is necessary in future research.

Conclusions

In summary, according to parents, school-age children and adolescents demonstrated behavioral changes in the first 7 months after their sibling’s death in a NICU or PICU. Young children did not understand the permanence of death. Only black parents reported their children believed the sibling was in a better place. The number and distribution of parents’ comments across the 6 themes varied by the unit (NICU vs PICU) where the sibling died, perhaps reflecting whether children spent time with their siblings at home. Children often recognized their parents’ grief and distress and tried to comfort them. As in most other studies, children’s responses are from parents’ observations of their children.

Clinical Implications

Children’s responses to a sibling’s death vary by age, race/ethnicity, and the unit where the sibling died. Parents need to know that their children’s behaviors are likely to change after the death and to expect bouts of crying, sometimes frequently and when children are alone. Preschool and younger school-age children will not understand the ramifications of death and may have unrealistic expectations about the sibling, even after participating in funeral activities. Preparing parents for this will help them to better understand their children’s behaviors and conversations. Children may revisit events around the sibling’s death as their understanding grows. Creating a memory book may help children with this revisiting. Even when a newborn dies in the NICU, children feel the loss. Some children want to maintain a connection with the deceased sibling; others want to avoid things that remind them of their sibling. Adolescents are more likely to want to maintain the connection. Whether these reactions change with time or age is not clear from this study. Children will need attention, and sometimes distance, from parents during this difficult time. Telling and showing children they are important may help with their feelings of abandonment and insignificance.

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Table 1

Description of the sample

Characteristic	Value[a]
Parents (N = 27)	
Age, mean (SD), y	37.2 (8.7)
Sex, No. (%)	
Mothers	22 (81)
Fathers	5 (19)
Race/ethnicity, No. (%)	
Black	13 (48)
Hispanic	10 (37)
White	4 (15)
Education, No. (%)	
< High school	2 (7)
High school graduate	9 (33)
Technical or some college	12 (44)
College graduates	4 (16)
Religion, No. (%)	
Catholic	11 (42)
Protestant/Christian	10 (36)
None	4 (15)
Jewish	2 (7)
Language of interview, No. (%)	
English	19 (70)
Spanish	8 (30)
Annual family income, No. (%)	
< $20 000	17 (63)
$20 000–$50 000	5 (19)
> $50 000	5 (19)
Deceased sibling (N = 24)	
Age, mean (SD), months	50.9 (73.63)
Age group, No. (%)	
Infants (newborn-0.99 year)	12 (50)
Preschoolers (1–5 years)	6 (25)
School-age (6–12 years)	2 (8)
Adolescents (13–18 years)	4 (17)
Sex, No. (%)	
Boys	14 (58)

Characteristic	Value[a]
Girls	10 (42)
Intensive care unit where died, No. (%)	
Neonatal	10 (42)
Pediatric	14 (58)
Length of stay, mean (SD), d	37.7 (54.94)
Cause of death, No. (%)	
Congenital or chromosomal anomalies	11 (46)
Head trauma	5 (21)
Prematurity	3 (12.5)
Infections, sudden infant death syndrome, birth injury	3 (12.5)
Seizures	2 (8)
Surviving children (N = 44)	
Age, mean (SD), y	
Boys (n = 20)	9.8 (5.38)
Girls (n = 24)	10.7 (5.21)

[a]Because of rounding, percentages may not total 100.

Am J Crit Care. Author manuscript; available in PMC 2014 May 01.

Table 2

Parents' reports of children's responses by surviving children's age, sex, and race and deceased's unit.

Characteristic	No. (%) of responses[a]						
	Total reports (N = 64)	Changed behaviors (n = 24)	Not understanding what was going on (n = 15)	Maintaining connection with sibling (n = 9)	Not enough time with sibling, say goodbye (n = 6)	Believing sibling in a good place (n = 6)	Not believing sibling would die (n = 4)
Age							
Preschool (2–5 y) (n = 10)	14 (22) 1.4/child	0 (0)	11 (79)	1 (7)	0 (0)	2 (14)	0 (0)
School-age (6–12 y) (n = 19)	26 (41) 1.4/child	13 (50)	4 (15)	3 (12)	3 (12)	3 (12)	0 (0)
Adolescent (13–19 y) (n = 15)	24 (38) 1.6/child	11 (46)	0 (0)	5 (21)	3 (12)	1 (4)	4 (17)
Sex							
Male (n = 20)	28 (44) 1.4/boy	13 (46)	3 (11)	4 (14)	4 (14)	3 (11)	1 (4)
Female (n = 24)	36 (56) 1.5/girl	11 (31)	12 (33)	5 (14)	2 (6)	3 (8)	3 (8)
Race							
Black (n = 24)	35 (55) 1.5/child	8 (23)	11 (31)	6 (17)	2 (6)	6 (17)	2 (6)
White (n = 6)	8 (12) 1.3/child	4 (50)	0 (0)	2 (25)	1 (12)	0 (0)	1 (12)
Hispanic (n = 14)	21 (33) 1.5/child	12 (57)	4 (19)	1 (5)	3 (14)	0 (0)	1 (5)
Intensive care unit							
Neonatal (n = 20)	23 (36) 1.2/child	8 (35)	10 (43)	0 (0)	1 (4)	4 (17)	0 (0)
Pediatric (n = 24)	41 (64) 1.7/child	16 (39)	5 (12)	9 (22)	5 (12)	2 (5)	4 (10)

[a] Because of rounding, percentages may not total 100.