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School Aged Children's Experiences 7 and 13 Months Following a Sibling's Death

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Abstract

This study described 6-year to 12-year-old children's responses 7 and 13 months after siblings' NICU/PICU/ED death. Using semi-structured interviews, at 7 months, children were asked about events around their sibling's death. At both 7 and 13 months, children were asked about their thoughts and feelings about the deceased, concerns or fears, and life changes since the death. Thirty one children (58% female), recruited from four South Florida hospitals and Florida obituaries, participated. Children's mean age was 8.4 years; 64.5% were Black, 22.5% Hispanic, 13% White. Interviews were analyzed using conventional content analysis. Resulting themes: circumstances of the death, burial events, thinking about and talking to the deceased sibling, fears, and life changes. Most children knew their sibling's cause of death, attended funeral/memorials, thought about and talked to their deceased sibling, reported changes in family and themselves over the 13 months. Fears (something happening to themselves, parents, other siblings—death, cancer, being snatched away) decreased from 7 to 13 months especially in 7-year to 9-year-olds. Seven-year to 9-year-olds reported the greatest change in themselves from 7 to 13 months. More Black children and girls thought about the deceased and reported more changes in themselves over the 13 months. School aged children thought about and talked with their deceased sibling, reported changes in themselves and their family and their fears decreased over the first 13 months after their sibling's death

Keywords

Child death; Sibling death; School aged children; Siblings; Bereavement

Introduction

Children describe death of a sibling as loss of a playmate, friend, role model and loss of the chance to be a big brother or sister (Charles and Charles 2006). Almost 2 million children experience sibling loss annually (Heron 2011); 50% have behavior problems (McCown and

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Davies 1995); 25% require clinical intervention, although few receive help (Packman et al. 2006).

Most pediatric deaths (< 18 years) occur in Neonatal Intensive Care units (NICUs) or Pediatric Intensive Care units (PICUs) (Fontana et al. 2013). Some children see their sibling in respiratory distress, cyanotic, and limp; others see the injury event—car crash, a fall from a window; others are affected by a sibling's chronic condition and repeated hospitalizations (Demmer and Rothschild 2011). Some children are allowed to visit their sibling in the NICU/PICU, others are not. For most children, their sibling's death is a frightening, confusing, and lonely time when daily routines are disrupted and access to parents for support and comfort is limited.

Theorists vary in their views of children's capacity to understand death and to mourn. Freud (1960) suggested that young children did not have the ego capacities to do the work of mourning, which is to accept the reality of the loss, experience the pain of grief and adjust to the absence of the deceased. Bowlby (1961) thought that infants as young as 6 months old experience mourning in the same way as adults. Kübler-Ross (1969) described the stages of grief as denial and isolation, anger, bargaining, depression and acceptance. Brent et al. (1996) described the concept of death as having three components: (1) universality, that all living things must die; (2) irreversibility, the physical body cannot be reanimated; and (3) nonfunctionality, a deceased body cannot perform activities like a living body can. Brent et al. commented that kindergarten-aged children have a mature understanding of universality but the majority of them do not understand the other components until the age of 10.

Lancaster (2011) noted that a child's response may not appear to fit neatly into one of Kübler-Ross' categories but children grieve. According to Lancaster, preschool children (2–5 years) do not understand that death is permanent. In this period of magical thinking, they may think death can be reversed with a wish. They may also search their homes and neighborhoods for the deceased. Changes in behaviors include fussiness, disobedience, and withdrawal from activities. Lancaster noted that school-aged children (6–12 years) are concrete thinkers with a strong sense of fairness. Those in the higher grades (4th–6th) demonstrate overt signs of depression, somatic complaints, and prolonged anger at the deceased, their parent caregivers, sometimes their peers and whatever they see as the cause of the sibling's death. Their reactions fit into some of Kübler-Ross' stages of grief including anger and depression. In Gibbons (1992) presentation of children's conceptions of death, 6-year to 12-year-olds learn to think logically and to solve problems. Death is seen as concrete, with a specific cause, universal and irreversible. Children in this age group may have an exaggerated fear of dead things and may begin to think about their own mortality. Their reactions may include anger and curiosity, or they may act as though nothing has happened. Gibbons noted that grouping children by age can be helpful in understanding general characteristics of how children conceptualize death, but cautions that each child is unique in their response.

According to parent report children whose sibling has died respond with anger, aggression, guilt, nightmares, depression, separation anxiety, fear of being alone, trouble concentrating, poor school performance, suicidal thoughts and attempts, feeling responsible for the death,

and/or the need to have said good bye to their sibling (Abdelnoor and Hollins 2004; Youngblut and Brooten 2013). Avelin et al. (2011) in a study of 25 Swedish parents found that surviving children may feel different from friends and classmates, think they are the only ones to experience a sibling's death, and feel the loss of their grieving parents. In studies with 11 South African teens (Demmer and Rothschild 2011), 19 children who lost a sibling to stillbirth (Erlandsson et al. 2010), and 10 White siblings (Warland et al. 2011) children maintained a relationship with the deceased sibling through singing favorite songs, looking at photographs, and talking or writing to the deceased, findings consistent with those of Fanos et al. (2009). Girard and Silber (2011) note that some children are afraid that others they love will die. Young children who do not understand the permanence of death may expect the deceased sibling to come back (Youngblut and Brooten 2013).

In addition, responses of children to a sibling's death may vary since death is viewed and responded to differently according to religion and culture (Brooten et al. 2016). In one study only Black non-Hispanic parents talked about the deceased being in heaven and/or with God (Youngblut and Brooten 2013). In research with 63 parents (33% Black non-Hispanic, 27% White non-Hispanic, 40% Hispanic), Hispanic parents viewed the child as a "gift from God" to be taken care of no matter the child's condition or prognosis (Brooten et al. 2013). Black non-Hispanic parents viewed the reason for the child's life, the extensive care needed and subsequent death as serving to bring the members of the family closer. Some parents and cultures prevent children from seeing the deceased sibling and/or attending the funeral (Erlandsson et al. 2010; Lobar et al. 2006) resulting in children's feelings of loneliness, anxiety, and jealousy (Nolbris and Hellström 2005).

The most frequent behaviors Swedish parents observed in their 7 to 12-year-old children in the first year after an infant sibling's death were crying, silence and visiting the grave (Erlandsson et al. 2010). Children were worried about the mother's health, nervous, tense and silent. In the study by Gerhardt et al. (2012), children ($n = 105$, 81% White) in elementary grades bereft of a sibling were perceived by peers as less polite, sadder, less accepted and as having fewer friends compared to classmates. In a study of 90 bereaved children aged 4 to 16 (90% White), parents reported the most behavioral problems in preschool and school aged children and the fewest in adolescents (McCown and Davies 1995). In three case studies with an Asian-American preschooler, a White 7-year-old, and an African-American teen, Price (2007) observed that children also "re-grieve" losses throughout life as they are able to more fully and maturely recognize and cope with the reality of the loss.

In a study of sibling-bereaved 6-year to 18-year-olds (90% White), girls ($n = 41$) had different types of reactions to sibling loss than boys ($n = 34$) with greater anxiety, depression, withdrawn behavior, thought problems, and attention-seeking behaviors (Worden et al. 1999). Following a sibling's death, girls demonstrated internalizing depressive behaviors while boys demonstrated externalizing behaviors of hyperactivity and not being able to concentrate (McCown and Davies 1995). Peers and teachers rated bereaved boys as sad and victimized following a sibling death (Gerhardt et al. 2012). Others found no gender differences in parents' reports of children's responses to sibling death (Youngblut and Brooten 2013).

Christ (2000), in a related study of children's development and mourning to a parent's death, found that 6-year to 8-year-olds (80% White) understood the permanence of their parents' death. In this study, children became immersed in joyful reminiscence of the deceased parent, underscoring the importance of creating a mental image of the parent. Nine-year to 11-year-olds were intolerant to strong emotions in themselves or others and escaped from short bursts of grief into activities. Information provided them with security.

In a qualitative study of 27 parents (15% White non-Hispanic, 48% Black non-Hispanic, 37% Hispanic) who had lost a child, parents reported on the surviving children's responses (Youngblut and Brooten 2013). Seventy-eight percent of their comments were focused on children 6–12 years old. White parents made the fewest comments, half about changed behaviors but none about the sibling not understanding or the sibling being in a good place. Black non-Hispanic parents commented most about children's lack of understanding about the death followed by changed behaviors and made all of the comments in the study about the sibling being in a good place. Hispanic parents commented about changed behaviors followed by lack of understanding.

Overall, research on responses of children whose sibling has died is limited and heavily focused on those whose siblings died from cancer (Gerhardt et al. 2012; Nolbris and Hellström 2005). In situations where children die from cancer, the death often occurred in familiar surroundings, allowing time for creating memories and discussing end-of-life issues with the dying child, and parents and siblings knowing health care staff over time. In contrast, infants' and children's NICU or PICU deaths may be abrupt and frightening, in environments of loud noises, bright lights, and staff who are strangers (Brooten et al. 2013). In addition, research in this area had small samples (Erlandsson et al. 2010; Warland et al. 2011), mainly White participants (Birenbaum 2000; Gerhardt et al. 2012), a wide age range of children in the samples and methodological weaknesses. Most data were collected on parents' perceptions of surviving children's responses which often differ from children's own responses (Lohan and Murphy 2001–2002; Roche et al. 2016). Many studies have recruited samples from support groups or advertisements introducing sample bias with data collection up to 20 years after the sibling's death (Lancaster 2011; Sood et al. 2006). Studies included deaths of newborns to 30-year-old adult children in the same sample (Youngblut and Brooten 2012). There is very little research on children's reports of their reactions to sibling death in NICUs or PICUs. This qualitative study's purpose was to describe 6-year to 12-year-old children's responses 7 and 13 months after their siblings' NICU/PICU or emergency department (ED) death.

Method

Participants

Data reported here are part of a longitudinal mixed methods study that examined surviving siblings' and parents' health and functioning following the ICU/ED death of a child (Youngblut and Brooten 2010–2016). In the larger study, children whose sibling (neonate who lived 1 h through 18 years) died in the NICU, PICU, or ED and their parents (White non-Hispanic, Black non-Hispanic, Hispanic/Latino) were recruited from four South Florida children's hospitals and Florida obituaries. All parents understood spoken English or

Spanish. In the larger study eligible children were 6–18 years of age and English speaking, lived with the mother during pregnancy (neonatal deaths) or sibling before the death; lived with the same parent(s) since the death and in age-appropriate grade in school. Children were excluded if unable to participate verbally; lived in foster care before or after the death; or a parent or another sibling died in the same event.

Sample—Most of the 31 school-aged children were Black non-Hispanic and female (Table 1). Sibling mean age at death was 61.4 months ($SD = 73.93$); 26.3% were first-borns. Causes of the 19 sibling deaths (7 NICU, 8 PICU, 4 ED) were prematurity (6), brain trauma (4), respiratory failure (4), cardiac abnormalities (2), and 1 each from cancer, lupus, and infection. On average, mothers were younger than fathers. Most parents were Black non-Hispanic or Hispanic with some education beyond high school; 36.8% of families had annual incomes below \$25,000; 89.5% were two-parent families, and 47.4% had one or two surviving children. For data analysis, children were categorized: 6-year-olds ($n = 10$), 7-year to 9-year-olds ($n = 11$) and 10-year to 12-year-olds ($n = 10$).

Procedure

This study was approved by Institutional Review Boards of the University and each clinical study site. Our clinical consultants identified families of children who died in their units and who had at least 1 surviving child between 6 and 12 years old. The project director (PD) contacted each clinical consultant every week to obtain names of eligible families. At 6–7 weeks after the death, families were sent a letter (in Spanish and English) explaining the study, identifying the research assistants (RAs) on the project, and providing the project phone number and email address. About 1 week after the letter was sent an RA called the family, screened for inclusion/exclusion criteria, and ascertained whether the family was willing to be in the study. For those interested, the RA then set an appointment to go to the family's home for the data collection visits. At the home, the RAs again explained the study to the parent(s), answered any questions and obtained their signed consent for their own and their children's participation and review of their deceased child's hospital record. The RA explained the study to the eligible children, answered their questions, and obtained their signature on an assent form. Children were not asked to participate if the parent did not give consent for the children to participate. Only children who signed the assent form after their parent(s) gave consent were interviewed.

Two of the three RAs were fluent in Spanish and English, and one RA was intimately involved with the Black and African American cultures in South Florida. Child interviews were conducted in English by the RAs who were health professionals with advanced clinical degrees. The RAs were trained in study interview methods and supervised to maintain interview integrity across time and children. Interviews were conducted in children's homes at times convenient for children and their parent(s). Data for this qualitative study included the 31 children aged 6–12 who agreed to be interviewed with parental consent.

Measures

A standardized protocol with core questions and probes was developed based on the literature and parents' comments about their children's responses in our previous study on

parent's health and functioning after the NICU/PICU death of an infant or child. The protocol was reviewed by parents and persons who had lost a sibling and revisions incorporated. Interviews (1.5 to 2 h) were audio-recorded and transcribed verbatim; transcripts were compared to audio-recordings for accuracy.

Children's interviews focused on the experience of having a sibling die in the NICU/PICU/ED—their perceptions of what it was like for them around the time of death and what life had been like for them since the death. All interviews were conducted by one of the RAs assigned to the family. Open-ended, conversational-style interviewing techniques with a semi-structured interview guide followed by probes to elicit more specific information were used to gain a full description of the siblings' experiences during the time around the death and since then.

At the 7-month interviews, children were asked about events around the time of the sibling's death and their thoughts and feelings about the deceased, concerns or fears, and life changes since the death. To elicit the child's story of their sibling's death, the 7-month interview began with the opening question, "Tell me about your brother's or sister's illness and death". Follow up questions and probes addressed: (1) Time around the Death—children's perceptions of the cause of the deceased sibling's ICU/ED admission and death, experiences with the deceased sibling before and after the admission, how they found out about the death; (2) Time after the Death—what their mother, father, family and friends did after the death; the child's experiences with the funeral and any other related activities around that time; things that were frightening or scary about their sibling's death; who or what helped them deal with the death; and (3) Time before the interview—whether the child thought about or talked with the deceased sibling, what they thought about, what they talked about, and how they felt; whether they kept something of the deceased sibling's; themselves and their lives at home, at school, in their family, with their friends; their relationships with their mother, father, brothers, and sisters (as applicable) now and if/how things have changed.

At the 13-month interviews, the same children were asked about their thoughts and feelings about the deceased, concerns or fears, and life changes since the 7-month interview. The 13-month interview began with: "Tell me about yourself, your family, and your life now". Follow-up questions and probes addressed the time since the last interview—things that were frightening or scary now and who or what helped them deal with these scary things; whether they thought about or talked with the deceased sibling, what they thought about, what they talked about, and how they felt; themselves and their lives at home, at school, in their family, and with their friends; their relationships with their mother, father, brothers, and sisters (as applicable) now and if/how things have changed.

Data Analysis

Using conventional content analysis, the investigators and three PhD-educated nurses with relevant clinical expertise individually read six children's transcripts and developed initial codes. Together, the group discussed the six transcripts and decided on the codes and their operational definitions. Using these resulting codes, two PhD-educated nurses individually coded the interviews, and then met and compared their coding and resolved any coding inconsistencies.

Results

At 7 months, themes included circumstances of the sibling's death (cause, where they were, who told them), funeral services and/or burial events, thinking about and talking with the deceased, fears, and life changes. At 13 months children shared their feelings about the deceased including thinking about and talking with the deceased, their fears, and life changes. See Table 2 for differences by time point in types of themes and Table 3 for gender and race/ethnicity differences.

Seven-Month Interviews

Circumstances of the death—Almost all children provided a reason for the sibling's death. Four children weren't sure of the cause of the death and one child chose not to talk about this. Only one child was with the sibling when she died. Most children were at home, in school, in another hospital wing, or at a relative's home at the time of the death. Most were told of the death by mothers (68%), their fathers (19%) or other family members (13%) including grandparents, aunts and uncles.

“They were trying to get the tube so they can put it back ... in his throat but it was ... too late, so he died”. (6 yrs)

“My parents told me that her brain couldn't exist ... anymore so she had to go to heaven.” (6 yrs) “She had surgery and she had a heart attack in the surgery... she died on my birthday.” (7 yrs) “Well he had an infection in his lung; my mom and my dad were in the room ... with the lady doctor and ... the lady said, ‘now we'll pull the plug’ and my mom say, ‘yes.’ ” (9 yrs) “They say some chromo—some are missing; he needed more of that you know to live”. (11 yrs)

Funeral services and burial events—Most children reported going to the sibling's funeral or funeral service. They recalled music, singing, speeches about the deceased and playing with other children who attended. Older children were given roles to greet family and friends who came to the service. A number of children reported a family gathering after the funeral service or burial. Celebrations were held on the deceased's birthday and the anniversary of the death.

“It was in a funeral home ... my pastor at my church came and he was like preaching ... Everyone had on a shirt of my brother. At my mama's house is a gathering; it was cooking; they was talking, having fun, joking around, drinking and stuff and, like inside, they was watching TV, dancing and all a that; then people was eating and having a good time.” (8 yrs) “It was very nice. It had the music, all the Goddess music.” (9 yrs) “I read a scripture and then I wrote this thing that I had made; it's kinda like a poem I guess”. (12 yrs)

Some children whose siblings were cremated reported a service and others did not. Many had a family gathering. A few children saw only pictures of their deceased siblings and were told how they looked. Siblings' ashes were placed in the parent's bedroom or family living room surrounded by pictures, clothing and toys of the deceased.

“They went and there was a line; [deceased] was in a little bed and they were in a line, um like ... saying goodbye to her. Some even went more times—and went and said goodbye and they kiss her and hug her and then, when we went home, we were very, very sad. We have a little box that [deceased] in Mom and Dad’s room. In a box that you can’t open; they closed it so you can’t open it because [deceased] will be thrown out ... and splatter all around.” (8 yrs) “We doesn’t ... listen to music or do ... or watch TV for a whole week because my dad say that it will mess up the transition of him becoming spirit to a angel”. (10 yrs)

Thinking about and talking with the deceased—Almost all of the children reported thinking about their deceased sibling, crying and feeling sad about the death (Table 2). Many children reported thinking about the things they did with the sibling or had planned to do including bathing, feeding, changing diapers, and things they would have done as their sibling grew older. Some children were sad they didn’t get to see the sibling “person to person”. Others were afraid their mother would become pregnant again and the baby would die, forcing them and the family to experience the situation all over again.

“Um, when she have a baby ... the baby I think is going to be dead again”. (6 yrs)

“Um, I’m thinking that she (deceased) was here right now with me.” (6 yrs) “Sad because I don’t have her here; I can’t feel her, I can’t hug her, I can’t kiss her, I can’t talk to her, I can’t hear her voice, but happy because I know she’s enjoying there with all her new friends and playing there and stuff like that.” (8 yrs) “I wish this would start it over and I would a went with him and tell him to watch out, there was someone coming. Because he had loud music so he didn’t hear the car, I guess.” (9 yrs) “Sad ... when he’s alive I was so happy... I never see a tiny ... my tiny brother like this before. Yeah, really tiny like a mouse”. (10 yrs)

“I usually listen to songs, songs that remind me of him. I just be playing it over and over and so it ... won’t make me sad. It’s like a slow sad song like, ‘I will always love you.’ ” (10 yrs) “I went and prayed and, you know, asked God, um, why did he passed ... you know, try to thank God that he at least lived for some time and got to see him, you know. Some kids didn’t even get to see them when they are so ... we are really grateful for that”. (11 yrs)

Most younger children but fewer 10-year to 12-year-olds reported talking to their deceased sibling. They talked about what they were doing, the sibling’s birthday, going to the park and other places they had gone with the sibling or had planned to go and about their parents. They also talked to the deceased in prayer and at the graveyard.

“I’m just talking to you and I know you’re in heaven but I am not ... and I know God is protecting you. And I know that you’re burned up but you are still my brother.” (6 yrs) “I think he is playing with me; he’s in the house every time and he goes wherever we go. I talk about when he grows up and what is he gonna do.” (7 yrs) “I even wrote notes in one of his books. I was sending notes so he can maybe read them. I was just, um, writing in a book and leaving the book open so he can

read it ... since he can't touch anything. When I go to his room, I feel his presence ... and talk about my day". (9 yrs)

Keepsakes and triggers: Children talked about keeping the deceased's clothing, toys, ashes in a charm or necklace, and diaries. Several children slept in the deceased's bed where they felt close to him/her. Children identified triggers that reminded them of their deceased sibling: watching TV and sports that they once did together, seeing the bed that had been prepared for the baby, the empty infant car seat, the sibling's toys, pictures and ashes. One child was reminded of the sibling when the wind blew on her face; for another, the trigger was flowers.

"I go to sleep in her room ... 'cause I keep it warm; it's my job and the cat's." (6 yrs) "Actually her bed is now mine." (8 yrs) "This was her bed." (10 yrs) "Is some kind of necklace; is a cross." (7 yrs). "We have a box for her." (10 yrs) "We all kept something in a box—the blanket he slept on, his cap, like that". (11 yrs)

Fears—The majority of children reported having fears and worries 7 months after the sibling's death (Table 2). Most worried about something happening to their parents and other siblings including somebody taking them away, them passing away, getting a terminal illness or Mom going crazy. Fears for themselves included someone snatching them away and getting hit or stabbed. The children coped with their fears mainly by "talking to Mom and praying" (6-year-olds), "praying, talking to Mom, and playing with living siblings" (7-year to 9-year-olds), and diversions such as TV, listening to music, writing and "talking to Mom" (10-year to 12-year-olds).

"When I have my lights off, it's like I am alone, and when I'm asleep—like bad [people]—hunting for the baby but the baby is not really there. And if the baby is not there, they try to hunt for me". (6 yrs)

"Somebody would take me—or snatch me away." (6 yrs) "I worry that, sometimes that he be dead and sometimes he won't come back to life." (7 yrs) "That somebody else will take them [parents] away." (8 yrs) "When he was here, he ... is like he was putting a shield over our house and protecting it, and we still have that shield because now he's an angel. He can protect us anytime. Because I didn't wanna lose another family or another person." (9 yrs) "Like ... they [parents] might like pass away or ... or catch something like cancer. Sometimes I cry in the room by myself and then my Mom be calling me, and saying [deceased] is sleeping." (9 yrs) "Like maybe I might get hit or stabbed or shot". (10 yrs)

"She [Mom] might go crazy". (10 yrs)

"Every time when my mom is pregnant, somebody dies". (10 yrs)

"I think that I didn't have nothing to do with that ... (crying) but I keep on thinking that it was something what I did that caused him his death, and I'm scared that my mom wants baby but it will happen again". (10 yrs)

Life changes (family members and self)—More 6-year-olds (80%) reported changes in their parents or siblings than 7-year to 9-year-olds (27%) and 10-year to 12-year-olds

(40%). Changes in family life included taking more trips for fun, doing more things together, and parents spending more time with them. Some children reported their mothers remained sad and easily upset.

“I told [sister] not to talk to her, and daddy not to talk to her so she (mom) can calm down.” (6 yrs) “That day [of the death] we had to sleep with mom and dad because um, they wanted to sleep with us and then ... we could sleep in our own bed because they were like sad.” (8 yrs) “They [friends] said, ‘You’re strong. You’re my first friend that I’ve met who’s been through the stuff that you’ve been through.’ Makes me feel good; I take it as a compliment.” (10 yrs) “Oh well, mom was really depressed and she didn’t really like to do anything for like, 3–5 months; very long time to get better but, you know, she is feeling better now. Oh, I did get worried more ... want to keep safe and Mom more overprotective, like when I come from school, she told me to walk home, keep the phone in my pocket and put it on sound so ... she could hear its ringing and stuff.” (11 yrs) “Because she was like crying the most, like I thought that she was gonna do something really bad or something, and I just thought ... that she wasn’t gonna take it as well as she’s taking it now. Well, mommy is not really like, mad at us anymore ... like, before she use to be like, kinda straightforward with everything, like strict, and now she like ... fun”. (12 yrs)

Most children (60–64%) reported life changes in themselves 7 months after their sibling’s death. Changes included new activities such as drawing, sports, having new friends, better relationships with other siblings, and being more considerate of others. Others reported negative changes: going fewer places, worrying about the deceased, having less fun in general.

“Well, my life changed ... by my brother gone because I ... I saw him at the hospital and now it’s like he just disappeared [cremated]. And I am still his big sister but it’s like he’s gone, he disappeared, and I don’t have a brother. I don’t have a sister...”. (6 yrs)

“Without my brother I have less fun. I don’t have that much fun with my friends like I used to have; my sisters don’t play with me that much anymore”. (6 yrs)

“I sleep less”. (7 yrs)

“I don’t know what’s wrong. I try to be good and I keep on being bad”. (7 yrs)

“Don’t go outside. And when [deceased brother] was born I would go outside with him every day to show him plants and animals that’s outside there, but now I don’t ... because it remind me ... [deceased brother]”. (10 yrs)

“I dye my hair; it looks like what [deceased] had.” (10 yrs) “Um, more considerate about life and, you know, try not to take it for granted, because anytime, God can take that away from us.” (11 yrs) “Well, um, I’m doing better in school because ... like he’s my motivation now”. (12 yrs)

13-Month Interviews

Thinking about and talking with the deceased—At 13 months children continued to think about and talk with their deceased sibling (Table 2). Some were thinking about the sibling less often but thinking about happy times with the sibling. Two children, one 6-year-old and one 8-year-old, reported they no longer thought about the deceased sibling.

“Well, I think about that he should never die and he should have lived and this should never happen”. (6 yrs)

“I feel sad. I didn’t get a chance to hold him”. (6 yrs)

“Not really [think about the deceased]”. (8 yrs)

“Well, I feel great and I’m happy because he is in a better place, and he’s inside our house—his ashes in a container”. (8 yrs)

“I think about her a lot of times ‘cause sometimes I find stuff that she wrote for me, like a journal. She had diary ... I read it—Just when my Mom says it’s ok.” (8 yrs)

“I’d be daydreaming in class; think about him, how me and him and my other brother be playing with the action figures.” (9 yrs) “Um, I feel like he’s like, right next to me, hearing me”. (10 yrs)

At 13 months after the sibling’s death, 70–78% of the children indicated that they talked with the deceased sibling. More 10-year to 12-year-olds reported talking with the deceased sibling (70%) than at 7 months (40%), while fewer 6-year to 9-year-olds reported doing so at 13 months. “I tell her that I miss her; I imagine she’s giving me a hug. Sometimes I ... I’m somewhere, I feel like, this little wind blowing or something, and feel it is her.” (8 yrs) “We talk about funny things”. (10 yrs)

“I talk to her like, I say like, wish she were here and stuff”. (10 yrs)

Fears—At 13 months fewer children reported fears, especially the 7-year to 9-year-olds. The type of fear for children 6–9 also changed from fears of family members dying or being taken away, or being snatched away themselves at 7 months to fears of cockroaches, the dark, monsters, and falling off a cliff at 13 months. One third of the 10-year to 12-year-olds reported fears of losing family members or something happening to themselves and potentially having to experience the same situation again. Children coped with their fears by using direct action. The 6-year to 9-year-olds dealt with their fears by killing cockroaches, keeping the lights on, and talking with Mom. The 10-year to 12-year-olds talked with their parents and used diversionary activities such as watching TV.

“Fears: spiders and roaches. I face my fears, kill the roaches.” (6 yrs). “I don’t have any dreams about him now”. (10 yrs)

“Scary and frightening thing happen to me right now, what will happen to my family?” (10 yrs)

“My mom getting pregnant again”. (10 yrs)

Life changes (family members and self)—Children reported fewer changes in their parents or their surviving siblings compared to 7 months with the greatest decrease in the 6-

year-olds, from 80% at 7 months to 33% at 13 months (Table 2). “Me and [my brother] are fighting over the [new] baby. He says our baby sister (living) is ... his; but I get the important baby, the dead one; yeah, the one who’s up there ... in heaven”. (6 yrs)

“Actually I seen mommy and daddy fight now. It’s something they used to do and now they’re doing it again”. (6 yrs)

“They [parents] feel like, um, spend more time with me now.” (6 yrs) “My family is happier [at 13 months]”. (10 yrs)

Most of the 6-year-olds (67%) thought they had changed since their sibling’s death, up slightly from 60% at 7 months post-death. About one-third of the 7-year to 9-year-olds reported changes in their lives, down from 64% at 7 months. They reported that, overall, things were returning to the time before the sibling’s death. They were back to their sporting activities, happy, eating healthy and had stopped crying about the deceased since God was now caring for him/her. More 10-year to 12-year-olds reported changes in themselves at 13 months, 80 vs. 60% at 7 months. For them, life was better; they talked more with their parents and friends and were more considerate of others. A number of children reported their grades declined after the sibling’s death but improved over the 13 months post the death.

“I’m much gooder in school. I am eating healthier. I don’t have problems sleeping anymore.” (7 yrs) “Um, I’m alone and I have no one to talk to”. (10 yrs)

“I’m happier, I laugh more. We talk about things like that and whenever I am sad, like when I think about [deceased], I go to her [mom] and, you know, talk to her about it. The therapy that I got, she helped us become closer together”. (10 yrs)

“I ... doesn’t ache, like I can focus much in school. I ... I’m actually happy now; he’ll be always in my heart but I will do this so I can get my college degree and something.” (10 yrs) “Usually I ... I’ll care about myself a little bit before and they [friends] were like the rest of it, but now they are like the whole thing that I care about, because I count my friends as my family, so if I lose them, then I feel broken inside and another piece of my heart is gone”. (10 yrs)

Race/Ethnicity and Gender

More Black non-Hispanic children (95–100%) reported thinking about their deceased sibling than Hispanic (86–71%) or White non-Hispanic children (75–75%) at 7 and 13 months after the death, respectively (Table 3). They also reported more fears and changes in themselves at 7 months than did Hispanic or White non-Hispanic children. Girls reported fewer fears and thinking more about their deceased sibling than boys did at 7 and 13 months after the death. Girls also reported talking with the deceased sibling more at 13 months than the boys. Reported changes in parents and other siblings were about the same for boys and girls at 7 months but not at 13 months when girls reported fewer changes. Girls reported more changes in themselves at 7 but not at 13 months than boys did.

Discussion

In this study, children reported their responses to a sibling’s NICU/PICU/ED death in this mostly minority sample. Most studies have had largely White samples (Girard and Silber

2011). Most studies have had parents' reports of children's responses which can be different from reports by the children. In a recent study parents rated their children's health better than children rated their own health in the first 4 months after the sibling's death (Roche et al. 2016). Most studies of sibling responses report on children whose siblings died of cancer (Gerhardt et al. 2012; Nolbris and Hellström 2005). In situations where children died from cancer, the death often occurred in familiar surroundings, allowing time for creating memories and discussing end-of-life issues with the dying child, and parents and siblings having known health care staff over time. In contrast, infants' and children's NICU/PICU/ED deaths may be abrupt and frightening, in environments of loud noises and bright lights, with staff who are strangers. Collecting data at 7 and 13 months post death allowed a view of changes in children's thoughts and behaviors not possible in cross sectional studies.

Only one child was with the sibling in the ICU at the time of death. The other children were called out of their activities to be told. In contrast, children are often present when a sibling dies at home. It is not clear whether being present at the time of death in the ICU would be helpful to the other children. Resuscitation efforts and removal of life support may be difficult for younger children to understand.

Most children attended a funeral or cremation service for the sibling. Some participated by reading something at the service or greeting family and friends. Children described a subsequent family gathering that included cooking, talking, watching TV, dancing, and having fun. Children did not talk about the paradox of being sad at one point and having fun at another.

In this largely minority sample, most children continued to think about and talk with their deceased sibling over 13 months, which is consistent with mothers' perceptions of their surviving children after a child's ICU death (Youngblut and Brooten 2013). The proportions of children who thought about their sibling varied little by child age. A high percentage of Black non-Hispanic children and girls thought about the deceased at both time points. Almost twice as many 10-year to 12-year-olds reported talking with the deceased at 13 months than at 7 months. Younger children talked with the deceased about what the deceased was going to do in the future, suggesting they expected the deceased to continue to age, grow and develop, consistent with Brent et al.'s (1996) hypothesis that children younger than 10 often do not understand death's irreversibility. More girls, but fewer boys, talked with the sibling at 13 than at 7 months. Some children felt the deceased's presence, especially in the deceased's room. Mothers in another study also described their children feeling the presence of the deceased (Youngblut and Brooten 2013). As with parents, children's thoughts about the deceased sibling were triggered by previously shared activities, the deceased's things, and preparations to bring the baby home that now stood empty.

Overall, fewer children expressed fears at 13 than at 7 months. The focus of their fears changed from "something bad happening to other family members and themselves" at 7 months to more common childhood fears—insects and the dark—by 13 months post sibling death, especially for younger children. More 10-year to 12-year-olds and minority children reported fears at 7 months. From 7 to 13 months, the greatest decrease was in 7-year to 9-year-olds.

Children of all ages relied heavily on talking with their mothers to cope with their fears, but children over 6 years old identified a greater repertoire of strategies. In another study (Youngblut and Brooten 2013), parents reported that their younger children were more clingy, perhaps indicative of the limited types of coping strategies and focus on the mother reported by younger children in this study. Coping strategies for older children involved activities away from their parents, including solitary pursuits, findings consistent with research following death of a parent (Christ 2000). Mothers may interpret this behavior as their children distancing themselves.

Overall, less than half of the children reported changes in family life at 7 months and even fewer at 13 months. At 7 months, the proportion of 6-year-olds reporting family life changes was three times greater than that of 7-year to 9-year-olds and double that of 10-year to 12-year-olds. At 13 months, the same proportion of children in the oldest group, but many fewer children under 10 reported family life changes. The reason for this time lag in the older children is not clear. Perhaps the day-to-day tasks these older children assumed in the first 6 months were similar to their responsibilities before the death or reflected the coping mechanism of “keeping busy” seen in adults (Wood and Milo 2001). The first 6 months also were the most difficult for parents (Youngblut et al. 2013). By 13 months, the older children may have been able to begin “going on” with their parents. More White non-Hispanic than Black non-Hispanic or Hispanic children experienced family life changes at 7 months. Many of the changes at 7 months involved parents and children spending more time together as a family. Some of these changes remained through 13 months, and some reverted back to the way things were before the death. This may reflect parents’ higher distress and morbidity through 6 months post the sibling’s death (Youngblut et al. 2013) and their need for support within the family during that time.

More than half of the children recognized changes in themselves at both time points. At 7 months, many were negative, including feelings of loss, sadness, loneliness, “bad” behavior. Some children’s comments suggested an increased valuing of life, stronger motivation to do things, seeing life as more precious and fragile, and making the most of their lives. By 13 months, life had improved for most children as they resumed pre-death activities, interacted more with family and friends, and improved their grades. Although about the same at 7 months, more of the 10-year to 12-year-old children talked about changes in themselves than the other two age groups at 13 months. More Black non-Hispanic children at 7 months and more Hispanic children at 13 months described changes in themselves. The highest rate of self-change was at 7 months for girls and 13 months for boys.

Limitations and Future Research

The 6-year to 12-year-old children in this study were predominantly Black non-Hispanic (64.5%) and Hispanic (22.5%). More than 36% of the families had annual incomes below \$25,000 and 47.4% had one or two surviving children. Findings may not hold with a greater proportion of White non-Hispanic, and older or younger children or those from families with a greater annual income. Children and adolescents from other racial/ethnic groups (e.g., Asian, Native American) were not included in this study.

Longitudinal research extending beyond 13 months after the sibling's death is needed to determine the pattern of children's responses over time. Additional studies of Hispanic and Black non-Hispanic children and adolescents, as well as those from other racial/ethnic groups, would help our understanding of racial/ethnic and age differences in children's responses. Comparisons of children's responses and parents' reports of children's responses would allow identification of similarities and differences in these perspectives.

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Table 1

Demographics of children and their parents

Variable		Children (<i>n</i> = 31)	
Age (years)	M (SD)	8.4 (2.15)	
Sex [<i>n</i> (%)]	Female	18 (58%)	
	Male	13 (42%)	
Race/ethnicity [<i>n</i> (%)]	Black non-Hispanic	20 (64.5%)	
	Hispanic	7 (22.6%)	
	White non-Hispanic	4 (12.9%)	
		Mothers (<i>n</i> = 19)	Fathers (<i>n</i> = 5)
Age	M (SD)	33.7 (5.25)	36.8 (5.98)
	Range	27–47	28–43
Education [<i>n</i> (%)]	<High school	2 (10.5%)	0
	High school graduate	2 (10.5%)	2 (40%)
	More than high school	11 (58.0%)	3 (60%)
	College degree	4 (21.0%)	0
Race/ethnicity [<i>n</i> (%)]	Hispanic	4 (21.0%)	2 (40%)
	Black non-Hispanic	12 (63.2%)	2 (40%)
	White non-Hispanic	3 (15.8%)	1 (20%)
Partnered [<i>n</i> (%)]	Yes	17 (89.5%)	4 (80%)
	No	2 (10.5%)	1 (20%)
Total family income [<i>n</i> (%)]	<\$25,000	7 (36.8%)	
	\$25,000–\$49,999	4 (21.0%)	
	>\$50,000	3 (15.8%)	
	No response	5 (26.4%)	
Number living children [<i>n</i> (%)]	1	3 (15.8%)	
	2	6 (31.6%)	
	3	3 (15.8%)	
	4 or more	7 (36.8%)	
Sibling's age at death (months)	Range	0.02–198.00	

Table 2

Child themes at 7 and 13 months post sibling death by child age group

Age group	Thinking		Talking		Fears		Life changes			
	7 mo	13 mo*	7 mo	13 mo*	7 mo	13 mo*	Family 7 mo	Family 13 mo*	Self 7 mo	Self 13 mo*
6 yr olds (n = 10)	8 (80%)	8* (89%)	9 (90%)	7* (78%)	7 (70%)	6* (67%)	8 (80%)	3* (33%)	6 (60%)	6* (67%)
7-9 yr olds (n = 11)	11 (100%)	8* (89%)	8 (73%)	7* (78%)	7 (64%)	3* (33%)	3 (27%)	1* (11%)	7 (64%)	3* (33%)
10-12 yr olds (n = 10)	9 (90%)	9 (90%)	4 (40%)	7 (70%)	8 (80%)	6 (60%)	4 (40%)	4 (40%)	6 (60%)	8 (80%)
Total	28 (90%)	25 (89%)	21 (68%)	21 (75%)	22 (71%)	15 (54%)	15 (48%)	8 (29%)	19 (61%)	17 (61%)

Note:

* Three children (one 6 year old and two 7-9 year olds) were lost to data collection at 13 months

Table 3

Child themes at 7 and 13 months post sibling death by child race/ethnicity and gender

	Thinking		Talking		Fears		Life changes			
	7 mo	13 mo*	7 mo	13 mo*	7 mo	13 mo*	Family 7 mos	Family 13 mo*	Self 7 mo	Self 13 mo*
Race/ethnicity										
Black non-Hispanic (<i>n</i> = 20)	19 (95%)	17* (100%)	12 (60%)	13* (76%)	17 (85%)	9* (53%)	10 (50%)	7* (41%)	15 (75%)	10* (59%)
Hispanic (<i>n</i> = 7)	6 (86%)	5 (71%)	5 (71%)	5 (71%)	4 (57%)	3 (43%)	2 (29%)	0 (0%)	3 (43%)	5 (71%)
White non-Hispanic (<i>n</i> = 4)	3 (75%)	3 (75%)	4 (100%)	3 (75%)	2 (50%)	3 (75%)	3 (75%)	0 (0%)	1 (25%)	2 (50%)
Gender										
Boys (<i>n</i> = 13)	10 (77%)	9* (82%)	10 (77%)	7* (64%)	10 (77%)	7* (64%)	6 (46%)	4* (36%)	7 (54%)	7* (64%)
Girls (<i>n</i> = 18)	18 (100%)	16* (94%)	13 (72%)	14* (82%)	12 (67%)	8* (47%)	8 (44%)	4* (24%)	12 (67%)	10* (59%)

Note:

*Three children (two black males and one black female) were lost to data collection at 13 months