Florida International University FIU Digital Commons

Nicole Wertheim College of Nursing and Health Sciences Nicole Wertheim College of Nursing and Health Sciences

6-1-2018

Adolescents' Experiences 7 and 13 Months Following the Death of a Brother or Sister

Dorothy Brooten Nicole Wertheim College of Nursing and Health Sciences, Florida International University, brooten@fu.edu

JoAnne M. Youngblut Nicole Wertheim College of Nursing and Health Sciences, Florida International University, youngblu@fu.edu

Rosa M. Roche Nicole Wertheim College of Nursing & Health Sciences, Florida International University, rroche@fiu.edu

Follow this and additional works at: https://digitalcommons.fiu.edu/cnhs_fac Part of the <u>Medicine and Health Sciences Commons</u>

Recommended Citation

Brooten, Dorothy; Youngblut, JoAnne M.; and Roche, Rosa M., "Adolescents' Experiences 7 and 13 Months Following the Death of a Brother or Sister" (2018). *Nicole Wertheim College of Nursing and Health Sciences*. 35. https://digitalcommons.fu.edu/cnhs_fac/35

This work is brought to you for free and open access by the Nicole Wertheim College of Nursing and Health Sciences at FIU Digital Commons. It has been accepted for inclusion in Nicole Wertheim College of Nursing and Health Sciences by an authorized administrator of FIU Digital Commons. For more information, please contact dcc@fu.edu.



HHS Public Access

Author manuscript *J Hosp Palliat Nurs*. Author manuscript; available in PMC 2018 June 01.

Published in final edited form as: *J Hosp Palliat Nurs*. 2017 June ; 19(3): 247–255. doi:10.1097/NJH.0000000000336.

Adolescents' Experiences 7 and 13 Months Following the Death of a Brother or Sister

Dorothy Brooten, PhD, FAAN [Professor of Nursing], JoAnne M. Youngblut, PhD, FAAN [Dr. Herbert & Nicole Wertheim Professor in Prevention and Family Health], and Rosa M. Roche, PhD, ARNP-BC [Clinical Assistant Professor]

Nicole Wertheim College of Nursing & Health Sciences, Florida International University, 11200 SW 8th St., AHC3, Rm 221, Miami, FL 33199

Abstract

This qualitative study used semi-structured interviews to describe adolescents' responses at 7 and 13 months to siblings' NICU/PICU/ED death. At 7 months, adolescents were asked about events around the sibling's death; at 7 and 13 months, about concerns/fears, feelings, and life changes. Seventeen adolescents participated (13-18 years; M=15); 65% Black, 24% Hispanic, 11% White. Themes included death circumstances, burial events, thinking about the deceased sibling, fears, and life changes. Adolescents reported shock and disbelief that the sibling died; 80% knew the reason for the death; many had difficulty getting through burials; all thought about the sibling. From 7 - 13 months fears increased including losing someone and thoughts of dying. Adolescents reported more changes in family life and greater life changes in them (more considerate, mature) by 13 months; some felt friends abandoned them after the sibling's death. Girls had more fears and changes in family life and themselves. Adolescent's responses to sibling death may not be visually apparent. One recommendation from this study is to ask adolescents how they are doing separately from parents since adolescents may hide feelings to protect their parents, especially their mothers. Older adolescents (14-18 years) and girls may have more difficulty after sibling death.

Keywords

Bereavement; Child death; Sibling death; Adolescents; Sibling bereavement

In the US, more than 57,000 neonates, infants, children, and adolescents die annually,¹ most in Neonatal Intensive Care units (NICUs) or Pediatric Intensive Care units (PICUs).² Some children see their sibling in respiratory distress while others may see an injury event (car or jet ski crash) and others experience a sibling's repeated hospitalizations for a chronic condition.³ For most children, their sibling's death is a frightening, confusing, and lonely time.

Corresponding author: Dorothy Brooten, PhD, Florida International University, Nicole Wertheim College of Nursing & Health Sciences, 11200 SW 8th St., AHC3, Rm 221, Miami, FL 33199, Office Phone: 305-348-7718, Office FAX: 305-348-1697, brooten@fiu.edu.

All authors have participated in the concept and design; analysis and interpretation of data; drafting of the manuscript, and have approved the manuscript as submitted. None of the authors have any competing financial interests or conflicts of interest in relation to this work.

Adolescents' Responses

Research is mixed on responses of adolescents who have lost a sibling. Adolescence is a particularly difficult time to grieve the death of a sibling because it is a time of significant physiologic, relational, cognitive and psychosocial change. As Lancaster⁴ notes, during adolescent development, teens center on understanding their identity, testing limits and defining socially responsible behavior. Spiritual belief may be a source of comfort or viewed as a disappointment or punishment.

Adolescents' grief is profoundly personal and can be more intense, intermittent and overwhelming than that of adults. Their bereavement reactions may include bravado, denial, anger and rage, shock, numbness, nightmares, loneliness, withdrawal, survivor guilt, substance abuse, great sadness and school problems. However, they may delay or repress their grief to avoid showing strong emotions.⁵ Unlike younger children whose support system is mainly parents and family, as Barrera and colleagues⁶ note, adolescents enlarge their support system to a widening group of peers. Birenbaum⁷ found that adolescents who lost a sibling to cancer were at higher risk of developing physiologic and psychosocial symptoms than other age groups. Stikkelbroek and colleagues⁸ found that adolescents had more internalizing problems after the loss of a sibling than loss of a parent. For some adolescents loss of a sibling may facilitate psychological growth with reported feelings of being "more mature" than most of their peers. As Gibbons⁹ notes, these adolescents have come to value life and its potential more than they did before their sibling's death. Shipkey,¹⁰ studying the grief of 13 older adolescents who had lost a sibling found that bereavement was an ongoing process, interwoven with developmental tasks and adolescents' relationships with their deceased sibling, family, friends and society. In analyzing case studies. Price¹¹ noted that children also "re-grieve" losses throughout the lifespan as they are able to more fully and maturely recognize and cope with the reality of the loss.

Gender is a factor in sibling responses; girls are affected differently by loss of a sibling than boys, especially if it is a same sex sibling who died. Boys' peak of disclosure with friends does not occur until high school, while girls' peak disclosure occurs in junior high school.¹² Following a sibling death, girls demonstrate higher grief scores, more physical symptoms and depressive behaviors, while boys demonstrate behaviors of not being able to concentrate and exhibit hyperactivity.^{13,14}

Research on responses of child and adolescent survivors is heavily focused on those whose siblings died from cancer,^{15,16} with small samples,^{17,18} mainly White participants^{7,19} and methodological weaknesses. Most data are collected on parents' perceptions of surviving children's responses^{20,21} which can differ from children's responses.²² 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.^{4,23,24} Studies include deaths of newborns to 30-year-old adult children in the same sample.²⁵ There is very little research on adolescents' reports of their reactions to sibling death in the NICU/PICU. The purpose of this qualitative study was to describe 13- to 18-year-old adolescents' responses 7 and 13 months after their siblings' NICU/PICU death.

Methods

Data reported here are part of a longitudinal mixed methods study examining surviving siblings' and parents' health and functioning following the ICU death of a child.²⁶ The study was approved by Institutional Review Boards of the University and each study site. In the larger study, children whose sibling (neonate who lived 1 hour through 18 years) died in the NICU, PICU, or Emergency Department (ED) and their parents (White non-Hispanic, Black non-Hispanic, Hispanic/Latino) were recruited from 4 South Florida children's hospitals and Florida obituaries. All parents understood spoken English or Spanish. Eligible adolescents for this study were 13–18 years old 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. Adolescents were excluded if unable to participate verbally; lived in foster care before or after the death; or a parent or another sibling died in same event. This qualitative study included 17 adolescents aged 13–18 who agreed to be interviewed after parental consent.

Procedure

Clinical consultants (designated nurse or physician at the clinical site) identified families of children who died in their units and who had at least 1 surviving child between 13 and 18 years old. The project director (PD) contacted the clinical consultant weekly 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 study research assistants (RAs), and providing the project phone number and email address. One week later, an RA called the family, screened for inclusion/exclusion criteria, and determined family willingness to be in the study. For interested families, the RA set an appointment to go to the family's home to obtain informed consent and collect the data. At the home, RAs explained the study to parent(s), answered questions and obtained their signed consent for their own and their 13-to 17-year-old's participation and review of their deceased child's hospital record. The RA explained the study to eligible adolescents and answered their questions. Only the 13- to 17-year-olds who signed the assent form after their parent(s) gave consent and the 18-year-olds who signed consent for their own participation were interviewed.

Adolescent interviews were conducted in English by health professionals with advanced clinical degrees. Interviewers were trained in study interview methods and supervised to maintain interview integrity across time and adolescents. Interviews were conducted in adolescents' homes at times convenient for them and their parent(s).

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/ED 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 hours) were audio-recorded and transcribed verbatim; transcripts were compared to audio-recordings for accuracy.

Adolescent 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. 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 adolescents' experiences around the death and since then.

At the 7-month interviews, adolescents were asked about events around the time of the sibling's death, their thoughts and feelings about the deceased, concerns or fears, and life changes since the 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 – adolescents' perceptions of the cause of the deceased sibling's ICU/ED admission and death, experiences with the deceased sibling before and after ICU/ED admission, how they found out about the death; 2) Time after the Death – what their parents, family and friends did after the death; the adolescent's experiences with the funeral and other related activities around that time; things that were frightening or scary about their sibling's death; who or what has helped them deal with the deceased sibling; whether they kept something of the deceased sibling's; themselves and their lives at home, at school, in their family, with their friends; relationships with their parents, brothers, and sisters (as applicable) now and if/how things have changed.

At the 13-month interviews, the same adolescents 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 helps them deal with them; whether they think about or talk with the deceased sibling, and how they feel; themselves and their lives at home, at school, in their family, with their friends; their relationships with their parents, brothers, and sisters (as applicable) now and if/how things have changed.

Data Analysis

Conventional content analysis procedures were used to allow codes and themes to come from the data rather than imposing preconceived categories.²⁷ The investigators and 3 PhD educated nurses with relevant clinical and cultural expertise individually read and re-read 6 transcripts and made notes on potential initial codes. Then, these individuals came together as a group to discuss and compare their individual thoughts and notes about each of the 6 transcripts. Through this discussion, the group created and agreed upon a set of codes with operational definitions. Two members of the group separately used these resulting codes and operational definitions to code each of the transcripts, and then met to compare their coding and resolve any coding inconsistencies.

Results

Sample—The 8 male (47%) and 9 female (53%) adolescents had a mean age of 15.1 years (SD=1.98); most were Black non-Hispanic or Hispanic. (Table 1). Mean age of the 6 female and 7 male siblings at death was 102 months (SD=90.3) or 8.5 years; only 2 (15.4%) were first-borns. Causes of sibling deaths (8 PICU, 2 NICU, 2 ED, 1 home after extubated) were infections (4), congenital heart defect (3), genetic conditions (2), and 1 each from umbilical cord strangulation, motor vehicle crash, gunshot, and drowning. On average, the 12 mothers were younger than the 6 fathers. Most parents were Black non-Hispanic or Hispanic and partnered with high school or higher education; 23% of families had annual incomes below \$25,000; and 84.6% had 1 or more additional surviving children.

At 7 months, themes included learning about the sibling's death, disbelief that the death had happened; getting through the viewing, funeral services and/or burial events; beginning to return to normal functioning and concerns for others in the family; and continuing a relationship with the deceased sibling. At 13 months adolescents shared thinking about and talking with the deceased sibling, and changes in themselves, their parents and friends since the sibling's death. See Table 2 for differences by time point in types of themes by age and gender.

Seven Month Themes

Learning about the sibling's death and disbelief—Most adolescents were at home (65%) or at the hospital (35%) at the time of the sibling's death. They were told of the death by mothers (35%), fathers (18%), other family members, neighbors or the police. Almost all (80%) of the adolescents knew the reason for the sibling's death. One adolescent wasn't sure of the cause of the death and one chose not to talk about this. Three adolescents were with the siblings when they died.

I saw when he died -- he couldn't breathe underneath the machine--he wasn't moving, they unplugged the machine (13-year-old). I saw him dead, yeah -- held him (14-year-old). Lady next door -- your daughter got killed -- she got hit by a car (17-year-old). They [doctors] didn't know what happened to him, nothing, they didn't know (18-year-old).

I did see him when they, um, was working ... they had the paddles -- but it was already too late (18-year-old).

The majority of adolescents reported shock and disbelief that the sibling had actually died. They were distressed that they hadn't had time to say good bye and they would never see the sibling again. They reported being in great distress at seeing the sibling in the ICU, waiting for the sibling to die and seeing the sibling in the casket. For the few that reported concerns for something happening to their parents or siblings, the concerns were focused mainly on the health of the mothers.

"It was more like, I can't believe this is happening" (18-year-old).

They waited to take him off life support until we were there (18-year-old).

When I saw him ... he didn't look the same; ... it was like in a blink of an eye, you see him alive and then in like another second you see him lying on a bed, and oh, my God, like how did this happen -- a matter of like an hour or not even, all of this just happened (18-year-old).

Getting through funeral services & burial events—Most adolescents (82%) reported going to a viewing, funeral or memorial service for the deceased sibling. They participated by singing; reading scripture, stories or poems; and sharing memories of the sibling. Many families had a gathering after the funeral or memorial service described as "a party" by the adolescents with eating, drinking, dancing, and a DJ for one family. Younger children played with others at the gathering. The party was held at a hall or a similar venue. Candle lightings were common at the deceased's home, the site of the death and repeated on the date of the death (e.g. 4th, 7th) in each subsequent month. Balloon releases were common at the grave site or home of the deceased. Remembrances (get-togethers) were also held on the deceased's birthday and the anniversary of the death. Adolescents found these events difficult to get through.

I don't know what they call it, but we had that party, not for like happiness but, I guess sorta to help deal with it ... (14-year-old).

I was just like staring at the casket and then when they rolled him down ... I cried for like a few minutes and then I just stopped; I just couldn't breathe anything out anymore (18-year-old).

I just kinda walked around; I had a friend with me but I was kind of in shock, I didn't really ... I was just walking around really (18-year-old).

I felt like that wasn't him, like who is that, like ... and then I touched him and he was just cold and I was like no, no, no, no, no -- it just didn't feel real and I didn't want to accept it either -- that can't be him (18-year-old)

Every fourth of the month we all do a candlelight 'cause that's like the day of the month [deceased died], so is like every month ... is like how long she's been dead (14-year-old). They [parents] light a candle like twice a day -- morning and evening -- they still do it to this day [7 months post-death] (18-year-old).

Seven (54%) of the deceased siblings were cremated. For most families, the siblings' ashes were placed in urns in the parent's bedrooms or family living rooms surrounded by pictures, clothing, and belongings of the deceased sibling. For a few families the sibling's ashes were scattered in a place the sibling enjoyed.

Beginning to return to normal functioning and concerns for the family members

Adolescents reported that music, talking with friends, going to the gym, dancing, looking at pictures, religion, talking to the deceased, and a camp for children who have lost loved ones helped them deal with the sibling's death. For 2 adolescents, nothing helped. What didn't help most were adolescents staying alone and triggers that reminded them of the deceased sibling including looking at pictures of the sibling, looking at the empty crib, and listening to songs sung at the sibling's funeral or memorial service.

Everybody been dead will come back eventually and be like ... everlasting life; is our religion so that also makes me happy 'cause I know I'll see him again (14-year-old).

This um camp where you go into the woods ... this where I actually made the memory box; they let you write little notes and send them up in balloons. You also gather....in age groups; it was amazing (14-year-old). When we sing the song that was played at [deceased's] funeral "I was there" by Beyoncé, I barely listen to that song anymore or if I look ... look at his crib inside mommy's room and ... I get teary eyes -- just leave (15-year-old). I find that nothing helps, like sometimes I cry and I just can't....get out of like the funk that I am feeling, I just can't, there's like no getting out of it, like I try (18 year old).

Most adolescents (71%) reported positive changes in themselves since the sibling's death including being happier, nicer and more considerate of others, more mature and having closer ties to their family. Others were less happy; they laughed and played less. They were worried when their parents went out, and one experienced rushes of depression and talking less to other people.

... like before, I've always wanted to help people but not as much as I want to now; so now I doing a whole bunch of community service and work ... working with organizations and stuff (14-year-old). So now I'm just like, more focused; I know like, in the future I wanna help. The other day we are talking with my friend, "we should go to a hospital to visit people;" I'm like, "no ... I can't do that right now" (17-year-old).

I'm a little bit nicer; like I'm a little bit more conscious of people's emotions (15year-old). I really changed a lot, like I'm maturing; I'm becoming a better man towards the world and towards myself (18-year-old).

It [sibling's death] just made me ... think that life is short -- to be always thinking that you're blessed to live this life that you are in right now (18-year-old).

I stopped talking to a lot people, um I don't have a lot of friends anymore, like I'm ... really impatient now, with people. I get mad really, really easily now (18-year-old).

When asked about relationships with parents, siblings and friends, most adolescents reported being concerned about changes in their mothers. Overall mothers were spending more time with them now, talking to them more and were described as "less mean." One mother reportedly was not the same, with a quiet sadness. Another mother cried a lot; another no longer cooks, an activity she enjoyed before the sibling's death. Only one comment was specifically regarding fathers, saying he now demonstrates emptiness.

She [Mom] hugs me a little more ... uh, talks to me, tells me to talk to her (13-yearold). We spend more time with our mom; I don't like her home by herself 'cause my momma getting old; she's 50 (13-year-old).

I worry all the time whenever like, my parents go out and I don't know; like I'll um, wake up and my mom is not upstairs. I'll freak out and I'll have to figure out where

they are (18-year-old). I worry ... more about my mom -- I was like oh, my God, what if [she] goes to kill herself -- 'cause you know, maybe she wanted to be with [deceased sibling] or something (17-year-old).

Adolescents reported becoming closer to their remaining siblings except for one younger sibling who had now developed anger issues. While many adolescents reported no changes in relationships with friends, a number felt friends didn't understand the situation and weren't there for them. One adolescent had not mentioned the sibling's death to friends believing it was a private matter not to be shared.

I choose my friends wisely now -- 'cause I realize that people that you choose as your friend are not your real friend 'cause ... when something happen they're not your friend no more (14-year-old). My friends like, they really surprise me, 'cause at the time, they weren't like, there for me; they wouldn't like ... I don't know, even text me; and I understand that maybe it was awkward for them but like ... I needed them (17-year-old). The emotional dynamic for the family has strengthened but like, um, my friends has actually weakened -- growing more distant with my friends ... I feel like they are not there for me (18-year-old).

My sister -- we've gotten really closer (15-year-old).

Continuing a relationship with the deceased sibling—All 17 adolescents reported thinking about their deceased sibling ranging from several times a day to "sometimes." Seven (41%) reported talking to the deceased sibling about what they did together, the adolescent's day, and how much the sibling was missed. Eighty two percent of the adolescents reported keeping items of the deceased sibling including clothes, shoes, perfumes, toys, book bags, games and pictures. One adolescent kept the sibling's bedding.

My sister loved the Sponge Bob, so she has Sponge Bob sheet set. I kept that; I sleep with it ... sometimes I put it on my bed or I'll take it off -- put it beside me (14-year-old).

I once wrote a letter to him (18-year-old).

One time I told my mom I was sitting in the room and I felt somebody like, touching my shoulder, but it was nobody in the room with me; I was just watching TV. My sister one time left her phone on -- the music ... her [deceased's] favorite song ... was playing on my sister phone; my sister don't even have her... that song on her phone. My mom say, "that just [deceased]; it's [deceased] her ... her spirit is (17-year-old).

13-Month Interviews

At 13 months adolescents shared thinking about and talking with the deceased sibling, and changes in themselves, their parents and friends since the sibling's death.

Thinking about and talking with the deceased—All of the adolescents reported thinking about their deceased sibling from "sometimes" to "daily." Thoughts centered on what they would be doing together if the sibling was alive and memories of what they had

done together. Triggers reminding adolescents of the sibling included seeing babies or young children on TV or on the street. Only 4 adolescents reported talking to the deceased sibling as though the sibling were alive. For these adolescents, conversations centered on what they had done together.

It's certain things that ... like, make me think about him -- games, TV shows -- now, it's happening more often than it used to when he passed away (18-year-old)

Changes in themselves

All but 3 of the adolescents described themselves as "fine" to "great" at 13 months following the sibling's death. One adolescent acknowledged "not being over it yet" while another was "coping" with the death, and another was doing "all right." All but 2 adolescents reported changes in themselves including becoming stronger, more mature, more independent, more cynical, a better person, more open minded and sympathetic, and reacting to people and events with less stress.

I'm not really over it right now, but like, I'm getting used to it (14-year-old). I don't feel in touch with the fact that he passed away; I look at his grave and it's not like ... I know it's him, but I just don't wanna realize it I guess (18-year-old).

There were fewer frightening things or concerns reported at 13 months for the 13-year-olds. Most concerns were general concerns or fears of snakes, cockroaches, heights, and test taking in school. For the older adolescents, concerns about losing someone or thoughts of dying in general were common. The 2 adolescents whose sibling had died in a car crash named car crashes as a fear.

Death really scares me (14-year-old). I think it's losing someone else ... that's like, the scariest thing for me (18-year-old).

Changes in family members & friends

The majority (79%) of adolescents reported a change in their relationship with their mother since the sibling's death. Most reported closer, more positive relationships with mothers and stronger family relationships. Communications with parents had increased since the sibling's death. For 2 adolescents the relationship with their mother had deteriorated because of the mothers' stress and reactions. For those adolescents who had a remaining sibling, relationships with the remaining siblings remained the same or became better.

I feel like my parents talk to me more as an adult. I can believe my mom that she'll always have my back because she ... she's putting more effort into treating me in a better way (13-year-old).

At 13 months after the sibling's death, most adolescents reported things at school now remained the same as did their friends. One student had changed schools since the family relocated following the sibling's death. One adolescent reported changing friends since they had been a bad influence on her. Another commented that her 2 friends were now there for her.

I have two friends who help me with it and they talk about it 'cause -- my friend had a brother who died but she didn't really know him (14-year-old).

Discussion

This is one of few studies reporting adolescents' own responses to a sibling's NICU/ PICU/ED death in a largely minority sample. Most studies have largely white samples,^{7,19,28} are parents' reports of children's responses,^{20,21} and are from children whose siblings died of cancer.^{15,16} Collecting data at 7 and 13 months post death allowed a view of changes in adolescents' thoughts and behaviors not possible in cross sectional studies.

Three adolescents were with their sibling in the ICU at the time of death; the majority was at home. It is not clear whether being present at the time of death in the ICU would be helpful to adolescents since resuscitation efforts and removal of life support can be difficult even for adults.

Most adolescents attended a funeral or cremation service for the sibling but expressed difficulty getting through the experience. Some walked around in disbelief; some participated by singing, reading poems or scripture at the service. Adolescents seemed to have a perspective on the "gathering" or "party" that followed the funeral as something to help family and friends deal with the death. Elaborate and often lengthy gatherings after death of a family member are common and anticipated events following Black/African American funerals.²⁹ African Americans also maintain a stronger continuing bond with the deceased.³⁰

In this largely minority sample, 100% of the adolescents thought about their deceased sibling at 7 and 13 months. Fewer reported talking with their deceased sibling, especially at 13 months. However, at 13 months, some adolescents reported having difficulty believing and coping with their sibling's death. Adolescents' thoughts about the deceased sibling were triggered by previously shared activities, the deceased's belongings, and preparations to bring the baby home that now stood empty, findings consistent with earlier studies in younger children.^{19,20}

While fears decreased for the 13-year-olds from 7 to 13 months after the death, fears increased for the 14- to 18-year-olds. For the older adolescents fears were about accidents, losing someone or thoughts of dying in general. Except for the 17- and 18-year-olds, there were more reported changes in family life from the 7th to the 13th month after the death. Most family changes focused on mothers who were now communicating more with the teens, spending more time with them, and being less strict. Adolescents who had remaining sibling(s) reported becoming closer to them. A number of adolescents felt that their friends abandoned them when they needed them after the sibling's death. While some recognized that their friends may not have known what to say or do, it was hard for the adolescents to deal with at a time in their development when peers are so important.⁴ Most of the abandonment and changes in friends occurred at the 7th month interviews.

Adolescents also reported more changes in themselves from the 7th to the 13th month after the sibling's death. Adolescents reported becoming more mature, more considerate, and wanting to become involved in helping others in some way. For a number of adolescents, the sibling's death served as a motivator to do better in school and in the future.

Girls, compared to boys, reported talking more to the deceased sibling at 7 months, had more fears at both 7 and 13 months, and reported more life changes in the family and themselves at both the 7 and 13 months after the sibling's death. These findings are consistent with those of Worden and colleagues¹² who found that girls have different reactions including greater anxiety to a sibling's death than boys.

Clinical Implications

Adolescents are negatively affected by their sibling's death, even for a newborn they haven't met. These effects continue through 13 months for many. Parents may need help to understand that the adolescent's behaviors are likely to change after a sibling's death and to expect episodes of crying, separation or loneliness and often changes in school grades, activities and friends. For health care providers, adolescents' responses to a sibling's death may not be visually apparent. Asking adolescents how they are doing separately from their parents is important since adolescents may hide or minimize their feelings to protect their parents. Asking adolescents about their health, somatic complaints, anxiety, depression, and changes in activities, school progress and friends is likely to yield important information about the adolescent's progress. Ask adolescents about their fears for the wellbeing of their family and themselves. Referral to support groups for adolescents who have lost a sibling may help as well as support groups for parents.

Study Limitations

The distribution of adolescents' race/ethnicity in this study (89% minority) did not allow examining themes by racial/ethnic group. The limited number of families with low incomes also made it difficult to consider differences by socioeconomic status. Almost all of the adolescents in this study had at least one surviving brother or sister, preventing investigation of the experiences of adolescents whose only sibling had died. Findings may not apply to White non-Hispanic adolescents and/or those from other racial/ethnic groups (e.g. Asian, Native American) not included in this study.

Future Research—Research extending beyond 13 months after the sibling's death is needed to determine the pattern of adolescents' responses over time. Samples with greater numbers of Hispanic adolescents would help our understanding of ethnic and age differences in adolescents' responses. Studies of adolescents' responses and parents' reports of their adolescent's responses would provide data to identify similarities and differences in these perspectives.

Acknowledgments

Funded by grant # R01 NR012675 from the National Institutes of Health, National Institute of Nursing Research.

References

- Kochanek, KD., Murphy, SL., Xu, JQ., Tejada-Vera, B. Natl Vital Stat Rep. Vol. 65. Hyattsville, MD: National Center for Health Statistics; 2016. Deaths: Final data for 2014.
- Fontana MS, Farrell C, Gauvin F, Lacroix J, Janvier A. Modes of death in pediatrics: differences in the ethical approach in neonatal and pediatric patients. J Pediatr. 2013; 162(6):1107–1111. DOI: 10.1016/j.jpeds.2012.12.008 [PubMed: 23312685]

- 3. Demmer C, Rothschild N. Bereavement among South African adolescents following a sibling's death from AIDS. Afr J AIDS Res. 2011; 10(1):15–24. DOI: 10.2989/16085906.2011.575544 [PubMed: 21852964]
- 4. Lancaster J. Developmental stages, grief, and a child's response to death. Pediatr Ann. 2011; 40(5): 227–281. DOI: 10.3928/00904481-20110412-09
- 5. Malone P. The impact of peer death on adolescent girls. J Soc Work End Life Palliat Care. 2007; 3(3):23–37. DOI: 10.1300/J457v03n03_04 [PubMed: 18077294]
- Barrera M, Alam R, D'Agostino N, Nicolas D, Schneiderman G. Parental perceptions of siblings' grieving after a childhood cancer death: A longitudinal study. Death Stud. 2013; 37(1):25–46. DOI: 10.1080/07481187.2012.678262 [PubMed: 24600719]
- 7. Birenbaum L. Assessing children's and teenagers' bereavement when a sibling dies from cancer: a secondary analysis. Child Care Health Dev. 2000; 26(5):381–400. [PubMed: 10998002]
- Stikkelbroek Y, Bodden D, Reitz E, Vollebergh W, van Baar A. Mental health of adolescents before and after the death of a parent or sibling. Eur Child Adolesc Psychiatry. 2016; 25(1):49–59. DOI: 10.1007/s00787-015-0695-3 [PubMed: 25786705]
- 9. Gibbons MB. A child dies, a child survives: the impact of sibling loss. J Pediatr Health Care. 1992; 6(2):65–72. [PubMed: 1573530]
- Shipkey N. Impact of sibling death on older adolescents. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2009; 69(8-B):4669.
- Price SK. Social work, siblings and SIDS: conceptual and case based guidance for family system intervention. J Soc Work End Life Palliat Care. 2007; 3(3):81–100. DOI: 10.1300/J457v03n03_07 [PubMed: 18077297]
- Worden J, Davies B, McCown D. Comparing parent loss with sibling loss. Death Stud. 1999; 23:1– 15. DOI: 10.1080/074811899201163 [PubMed: 10346731]
- McCown D, Davies B. Patterns of grief in young children following the death of a sibling. Death Stud. 1995; 19:41–53.
- Paris MM, Carter BL, Day SX, Armsworth MW. Research on trauma and loss-grief and trauma in children after the death of a sibling. J Child Adolesc Trauma. 2009; 2(2):71–80. DOI: 10.1080/19361520902861913
- Gerhardt CA, Fairclough DL, Grossenbacher JC, et al. Peer relationships of bereaved siblings and comparison classmates after a child's death from cancer. J Pediatr Psychol. 2012; 37(2):209–219. DOI: 10.1093/jpepsy/jsr082 [PubMed: 21946038]
- Nolbris M, Hellström A. Sibling's needs and issues when a brother or sister dies of cancer. J Pediatr Oncol Nurs. 2005; 22(4):227–233. DOI: 10.1177/1043454205274722 [PubMed: 15994341]
- Erlandsson K, Avelin P, Säflund K, Wredling R, Rådestad I. Siblings' farewell to a stillborn sister or brother and parents' support to their older children: a questionnaire study from the parents' perspective. J Child Health Care. 2010; 14(2):151–160. DOI: 10.1177/1367493509355621 [PubMed: 20200194]
- Warland J, O'Leary J, McCutcheon H. Born after infant loss: The experiences of subsequent children. Midwifery. 2011; 27:628–633. DOI: 10.1016/j.midw.2010.06.019 [PubMed: 20702010]
- Fanos JH, Little GA, Edwards WH. Candles in the snow: ritual and memory for siblings of infants who died in the intensive care nursery. J Pediatr. 2009; 154(6):849–853. DOI: 10.1016/j.jpeds. 2008.11.053 [PubMed: 19342063]
- Youngblut JM, Brooten D. Parent report of child response to sibling death in a neonatal or pediatric ICU. Am J Crit Care. 2013; 13:474–481.
- Roche R, Brooten D, Youngblut JM. Comparison of parent and sibling perceptions of surviving sibling"s health following ICU death of a brother or sister. Int J Nurs Clin Pract. 2016; 3:185. [PubMed: 27683673]
- 22. Lohan J, Murphy S. Parents' perceptions of adolescent sibling grief responses after an adolescent or young adult child's sudden, violent death. Omega (Westport). 2001–02; 44:77–95.
- Rosenberg A, Postier A, Osenga K, et al. Long-term psychosocial outcomes among bereaved siblings of children with cancer. J Pain Symptom Manage. 2015; 49(1):55–65. DOI: 10.1016/ j.jpainsymman.2014.05.006 [PubMed: 24880001]

- 24. Sood AB, Razdan A, Weller EB, Weller RA. Children's reactions to parental and sibling death. Curr Psychiatry Rep. 2006; 8(2):115–120. [PubMed: 16539886]
- 25. Youngblut JM, Brooten D. Perinatal and pediatric issues in palliative and end-of-life care from the 2011 summit on compassionate care. Nurs Outlook. 2012; 60:343–350. [PubMed: 23036690]
- Youngblut, JM., Brooten, D. National Institute of Nursing Research, NIH, R01 NR012675. 2010– 2016. Children's responses to sibling death in the NICU/PICU in 3 racial/ethnic groups.
- 27. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005; 15(9):1277–1288. DOI: 10.1177/1049732305276687 [PubMed: 16204405]
- 28. Girard GA, Silber TJ. The aftermath of adolescent suicide: Clinical, ethical, and spiritual issues. Adolesc Med State Art Rev. 2011; 22:229–239. [PubMed: 22106737]
- 29. Brooten D, Youngblut JM, Charles D, Roche R, Hidalgo I, Malkawi F. Death rituals reported by White, Black, and Hispanic parents following the ICU death of an infant or child. J Pediatr Nurs. 2016; 31(12):132–140. [PubMed: 26639773]
- Laurie A, Neimeyer R. African Americans in bereavement: Grief as a function of ethnicity. Omega (Westport). 2008; 57(2):173–193. DOI: 10.2190/OM.57.2.d [PubMed: 18680889]

Demographics of Adolescents and their Parents.

Variable		Adolescent	s (N = 17)
Age (years)	M (SD)	15.1 (1	1.98)
Sex [n (%)]	Female	9 (53	%)
	Male	8 (47	%)
Race/ethnicity [n (%)]	Black non-Hispanic	11 (6:	5%)
	Hispanic	4 (24	·%)
	White non-Hispanic	2 (11	%)
		Mothers (n = 12)	Fathers $(n = 6)$
Age	M (SD)	38.1 (6.10)	43.8 (7.06)
	Range	31 - 50	34 - 52
Education [n (%)]	< High School	5 (41%)	1 (17%)
	High School Graduate	2 (17%)	2 (33%)
	More than High School	2 (17%)	2 (33%)
	College degree	2 (17%)	1 (17%)
	No Response	1 (8%)	
Race/Ethnicity [n (%)]	Hispanic	4 (33.3%)	2 (33.3%)
	Black non-Hispanic	7 (58.3%)	2 (33.3%)
	White non-Hispanic	1 (8.3%)	2 (33.3%)
Partnered [n (%)]	Yes	9 (75%)	4 (67%)
	No	3 (25%)	2 (33%)
Total Family Income [n (%)]	< \$25,000	3 (23%)	
	\$25,000 - \$49,999	3 (23	%)
	\$50,000	3 (23	%)
	No response	4 (31	%)
Number living children [n (%)]	1	2 (15	5%)
	2	2 (15	(%)
	3 or more	9 (70	9%)
Sibling's age at death (months)	Range	0.03 - 2	26.00

Author Manuscript

Brooten et al.

Table 2

Gender.
and
e Group
Age
Adolescent .
by
Death b
Sibling
Post
Aonths
13 N
and
Themes at 7 and

								Life Cl	Life Changes	
	Thin	Thinking	Tall	Talking	Fœ	Fears	Fan	Family	Š	Self
Age Group	7 mo	13 mo^{d}	7 mo	$13 \text{ m}_0 a$	7 mo	$13 \mod^{a}$	7 mo	13 mo^{d}	7 mo	13 mo^{d}
13 yr olds $(n = 5)$	5 (100%)	4 (100%)	3 (60%)	1 (25%)	5 (100%)	3 (75%)	3 (60%)	4 (100%)	2 (40%)	2 (50%)
14-15 yr olds (n = 6)	6 (100%)	6 (100%)	4 (67%)	2 (33%)	4 (67%)	6 (100%)	4 (67%)	5 (83%)	4 (67%)	6 (100%)
17-18 yr olds (n = 6)	6 (100%)	4 (100%)	2 (33%)	1 (25%)	3 (50%)	3 (75%)	5 (83%)	3 (75%)	5 (83%)	4 (100%)
Total	17 (100%)	14 (100%)	9 (53%)	4 (29%)	12 (71%)	12 (86%)	12 (71%)	12 (86%)	11 (65%)	12 (86%)
Gender										
Boys $(n = 8)$	8 (100%)	6 (100%)	3 (38%)	2 (33%)	6 (75%)	4 (67%)	4 (50%)	4 (67%)	5 (63%)	4 (67%)
Girls $(n = 9)$	9 (100%)	8 (100%)	6 (67%)	2 (25%)	8 (%68)	7 (88%)	7 (78%)	8 (89%)	6 (67%)	8 (100%)

 a^{2}_{3} adolescents (one 13-year-old girl and two 18-year-old boys) were lost to data collection at 13 months