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Editorial: Parent, Grandparent, and Sibling Responses to the Death of an Infant or Child in Intensive Care

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The death of a child is a devastating event for most parents and other family members¹. However, responses to a child's death vary by culture, generation, and often the age of the deceased child. For the Chinese, child death is a "bad death" and brings shame to the family². Filipino parents of a deceased child feel severe guilt after their loss³. In some Caribbean cultures young mothers are prevented from attending the child's funeral or going to the cemetery by women in the previous generation in the belief that if you "take one to the cemetery you will be taking all of your other children there as well." In other cultures, those who die as children have not sinned, securing their place in heaven⁴.

In the ethnically-diverse US, more than 43,000 children aged 18 and younger die each year⁵, most in intensive care units⁶. Friends, relatives, co-workers, and healthcare providers (HCP) often are uncomfortable with the parents after their child's death, not knowing what to do, what to say, and what would help the deceased's parents and family members. Many assume that parents and family members want to be left alone after the infant's or child's death. As a result, parents, siblings, and grandparents report feeling isolated and abandoned by those close to them when they need them most^{7–10}. Little research has been done with these US family members in the difficult first year after the child's death. What has been done has shown that studies of parents have been conducted years, even 3–7 decades¹¹, after their infant's or child's death. However, many studies have very diverse samples regarding the age of the "child" at death. In some studies, family members are responding to the death of a "child" who died in childhood (< 18 years old) and a "child" who died as an adult (19 and above), sometimes as old as 40, in the same study¹². In addition, studies of siblings whose brother or sister died during the sibling's childhood are often retrospective. Some studies postpone data collection until the sibling reaches adulthood; and some studies recruit bereaved siblings when they are adults. Very few studies have been undertaken with grandparents of the deceased child.

With funding from the US NIH National Institute of Nursing Research and the National Institute of General Medical Sciences, a body of research has been conducted on parents', grandparents' and siblings' health and functioning during the first year after the infant's or child's death in the neonatal intensive care unit (NICU) or pediatric intensive care unit (PICU) to fill our knowledge gap.

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Parent Study

Youngblut, Brooten, Cantwell, Del-Moral, and Totapally¹³ conducted a longitudinal study of 176 mothers and 73 fathers whose infant or child (N=188) died in the NICU/PICU. Parents provided data on their own physical and mental health and functioning at 1, 3, 6, and 13 months after their child's death. Mean ages were 32 (SD=8) for mothers and 37 (SD=9) for fathers; 79% of parents were Hispanic or Black (African American, African Caribbean)¹³. More than half of the deceased children were infants (63%), male (55%), and died in the PICU (55%) after treatment was limited or withdrawn (57%)^{13,14}.

Parent Physical & Mental Health.

In the 13 months after the infant's/child's death, there were 98 parent hospitalizations, 132 new chronic health conditions, and 2 new cases of cancer¹³. During this time, more mothers had severe symptoms of depression (35%) and post-traumatic stress disorder (PTSD) (35%) than fathers (24%, 30%, respectively). Depression and PTSD were more common among Hispanic and black mothers than white mothers¹³. In the first 13 months, a child death was associated with decline in parental physical and mental health.

We then examined when most parents' acute illnesses and other morbidity occurred to determine the best time for interventions¹⁵. Most parents' physical health problems occurred in the first 6 months after the death and peaked again around the anniversary of the child's death. Parents, mostly mothers, experienced more than 400 acute illnesses and almost 100 hospitalizations in the first 13 months, regardless of race/ethnicity¹⁵. On average, mothers had more physical health problems than fathers during the first 13 months after their infant's/ child's NICU/PICU death. These findings suggest that bereaved parents may need more primary health care visits in the first 6 months and again around the anniversary of their infant's or child's death.

Parent Grief.

Grief intensity declined for mothers throughout the first 13 months after their infant's/child's death. Fathers had a significant drop in despair between 3 and 6 months after the death, but the intensity of other aspects of grief remained unchanged through 13 months¹⁴. Mothers reported more intense symptoms of panic and despair, and had more difficulty concentrating and remembering things than the fathers in the same family. Feelings of panic and emotional distance from family and friends were greater for Hispanic mothers than black or white mothers. Spiritual growth was greater for black than Hispanic mothers from 1 to 6 months post child death. The level of grief from 1 to 13 months after the death was consistently higher for mothers of deceased adolescents than mothers of deceased infants. Grief was greater for mothers if their child was declared brain dead than if health care providers tried to resuscitate the child or if they had decided to stop mechanical ventilation¹⁴.

Parent functioning.

Two parent roles in the family, their relationship with the other parent and their employment, were examined. The proportion of parents with partners (72%) was about the same at 1 and 13 months post-death¹³. There were 32 new pregnancies during the first 13 months after the

death, most in the first 6 months. Most mothers (68%) and fathers (93%) were employed at the time of the infant's or child's death. Although a few mothers and fathers returned to their jobs immediately after the death, 74% of fathers returned to employment by 2 weeks, and 50% of mothers, by the end of the first month¹³.

Grandparent study

Youngblut, Brooten, Blais, Kilgore, and Yoo¹⁶ conducted a cross-sectional study on the physical and mental health, and functioning of 99 grandmothers and 37 grandfathers in the first year after death of their newborn through 6-year-old grandchild. Grandparents' mean age was 55.3 (SD=9.8), with a range of 36–77 years. Most grandparents were female (73%), black or Hispanic (62%), high school graduates (87%), married or living with a partner (63%), and employed before (68%) and/or after the death (63%).

The 115 deceased grandchildren ranged from newborn to 72 months of age. Most were 12 months old or younger (72%), male (65%), and died in the hospital (77%). Prematurity and congenital/genetic conditions were the two most common causes of death¹⁶, consistent with US national data¹⁷.

After the grandchild's death, 28% of the grandparents reported a total of 59 illnesses and 5% reported 7 hospitalizations¹⁶. Most grandparents (68%) had been diagnosed with at least one chronic health condition including mental health problems, hypertension, angina, cancer, and arthritis. Based on the severity of their symptoms of depression and PTSD, grandparents were classified as having moderate-severe clinical depression (14%), clinical PTSD (35%), or both (20%)¹⁶, higher than the 8% reported for adults 60 and older in the US¹⁸. The severity of their PTSD symptoms was significantly greater for black grandparents than white grandparents¹⁶. Severity of their symptoms of depression, PTSD, and grief also was significantly higher for grandparents who had provided some childcare for their deceased grandchild. White and black grandparents had more intense PTSD symptoms if they provided childcare for the deceased.

Grandparent Functioning.

Most grandparents were employed before (68%) and after (63%) the grandchild's death¹⁶. More grandmothers (80%) took time off from work than grandfathers (45%). Most employed grandparents returned to work by 14 days post-grandchild death. Grandparents who had provided some childcare for this grandchild had significantly more trouble focusing on their work than grandparents who rarely/never provided childcare¹⁶. When on the job, black grandparents thought about their deceased grandchild significantly more often than white grandparents, regardless of time since the death. The quality of the grandparent's relationship with their spouse/partner was not affected by their race/ethnicity, level of childcare, or time since the grandchild's death¹⁶.

Sibling Study

Youngblut, Brooten, Cantwell, Del-Moral, Totapally, and Yoo¹⁹ conducted a longitudinal study to describe the physical health, mental health, and functioning of 132 surviving

children, ages 6–18, over the first 13 months after their sibling’s death. Most of the surviving children were girls (58%) and school-aged (6–12 years old). Most of the 71 deceased siblings were boys (62%), died in the PICU (63%), and had unsuccessful resuscitation (35%) or limitations in treatment (30%). The group of deceased siblings were 37% adolescents, 37% infants, 21% school aged, and 5% preschoolers.

Children’s Health.

Parents reported a total of 207 illnesses among 50% of the surviving children and a total of 674 treatments and health services among 70% of the children during the 13 months after their sibling’s NICU/PICU/Emergency Department (ED) death²⁰. Illnesses included gastrointestinal problems, allergies, gynecological problems, headaches, colds/flu, ear infections, eye problems and anxiety. Most (64%) of these occurred in the first 6 months. Most of the treatments and health services were used by girls (66%) in the first 6 months (65%). Treatments and health services included psychiatric referrals and/or therapy, medications, and office visits to pediatric health care providers, dentists, and specialists. Hispanic children used significantly more treatments/health services than black children. Children’s pattern of illnesses, treatments, and health service use²⁰ was consistent with the pattern of parents’ illnesses, hospitalizations, and medication changes¹⁵ in an earlier study, with most occurrences in the first 6 months and an increase in occurrences around the anniversary of the brother’s or sister’s death in the PICU, NICU, or ED. Parent and child distress also increased around the anniversary of the infant’s/child’s death¹⁵.

Although more research is needed on the health and functioning of parents and family members after the death of an infant or child, the findings to date have provided guidance on interventions to help parents and family members after the death. It is clear that the first 6 months after the infant’s/child’s death are especially challenging and a time where interventions to prevent acute and chronic illnesses are needed to help parents and surviving children. In the US, black and Hispanic families seem especially vulnerable and need monitoring of their health and preventive interventions. Parents and other family members need to be reminded by healthcare providers about frequent handwashing to prevent infection, getting enough sleep, and eating a healthy diet soon after the infant’s or child’s death.

Nursing curricula need to include information about bereaved families, especially from research evidence, and address individual beliefs and myths. For nurses in practice, annual workshops could be designed to provide the latest research news about bereaved families. Role-playing sessions incorporated into the workshop would allow nurses to practice communication with families of dying and deceased family members. This is especially important for nurses who work in units where death is most common, such as intensive care units. Having a counselor or therapist available to nurses and other healthcare providers who deal with death and dying would allow them to discuss and work through their feelings and thoughts about the deaths they have experienced.

Findings from this body of research with US parents and families call for studies to determine if parents from other countries and cultures experience the same health and functioning outcomes after losing a child. Do parents from other countries and cultures

experience similar acute and chronic conditions in the first year after an infant's or child's death? Do mothers and fathers in these countries and cultures differ in their responses? What is the response of grandparents and surviving siblings to the death? Much research is needed to find answers to these questions.

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