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## Parent Grief 1–13 Months After Death in Neonatal and Pediatric Intensive Care Units

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### Abstract

**Objective**—Describe changes in mothers' and fathers' grief from 1 to 13 months after infant/child neonatal/pediatric intensive care unit death and identify factors related to their grief.

**Methods**—Mothers ( $n = 130$ ) and fathers ( $n = 52$ ) of 140 children (newborn–18 years) completed the Hogan Grief Reaction Checklist at 1, 3, 6, and 13 months post-death.

**Results**—Grief decreased from 3 to 13 months for mothers and from 3 to 6 months for fathers. Grief was more intense for: mothers of deceased adolescents and mothers whose child was declared brain dead.

**Conclusion**—Mothers' and fathers' grief intensity may not coincide, resulting in different needs during the 13 months after infant/child death.

### Keywords

child death; father grief; grief; infant death; mother grief

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Death of an infant or child is one of the most difficult, devastating and profoundly painful experiences for parents. Half of US infant and child deaths occur in hospitals (Centers for Disease Control & Prevention, 2015) and most in intensive care units (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013) with extensive equipment, fast pace, and staff often unfamiliar to parents. The child's death brings grief and suffering that can significantly affect parents' health and functioning (Hunt & Greeff, 2011–2012; Werthmann, Smits, & Li, 2010; Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). The intensity and duration of parents' grief can be affected by characteristics of the parents (gender, race, expected death or not) and the deceased child (age, mode of death).

While these differences in parent and child characteristics may affect intensity and duration of grief, the research in these areas is limited. Research to date has focused largely on parents whose child died outside of the hospital. Despite the US's growing racial/ethnic diversity, studies of differences in grief for White, Black and Hispanic parents after their child's death are lacking (Kavanaugh & Hershberger, 2005; Laurie & Neimeyer, 2008; Whitaker, Kavanaugh, & Klima, 2010). Many studies are qualitative (Boyden, Kavanaugh, Issel, Eldeirawi, & Meert, 2014) or cross sectional (Lannen, Wolfe, Prigerson, Onelov, &

Kreicbergs, 2008; Michon, Balkou, Hivon, & Cyr, 2003) and most have been conducted with samples of mainly White mothers (Youngblut & Brooten, 2012). Recruitment of parents has been up to 30 years after the death from support groups or through advertisements, introducing potential recall and sample bias. Time between the child's death and parents' interviews ranged from 1 to 70 years with child age at death from newborn to 30 years old (Youngblut & Brooten, 2012). Few longitudinal studies exist of parents' grief during the first year after the child's death. The purpose of this study was to describe changes in mothers' and fathers' grief from 1 to 13 months after their infant's or child's death in the neonatal or pediatric intensive care unit (NICU, PICU) and to identify factors related to grief at 1, 3, 6, and 13 months.

## PARENT CHARACTERISTICS

Characteristics which may influence parent grief include parent gender, possibly race, and whether the child's death was expected or not. Grief has been described as severe physical pain, almost total lack of energy (Hunt & Greeff, 2011–2012), and long-lasting sadness (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012) which may begin before the child's death and/or persist a long time after the death.

### Differences in Mothers' and Fathers' Grief Have Yielded Mixed Results

In a sample of Dutch couples, Stroebe et al. (2013) found that grief was greater for women than men at 6, 13, and 20 months post child death, findings similar to those of Michon et al. (2003) who found intensity of mothers' grief greater than fathers' grief up to 4 years after child death. In their qualitative study of mostly married and white bereaved parents who were college graduates, Alam et al. (2012) found that mothers experienced more intense and prolonged grief, while fathers were more angry and private about their grief at 6 and 18 months post-death. By 18 months, mothers had more control of when and how they expressed their grief and fathers were more open about their grief. Mothers may face greater difficulty in adapting to the child's death than fathers (Avelin, Rådestad, Säflund, Wredling, & Erlandsson, 2013). At 3 months and 1 and 2 years after a stillbirth, Avelin et al. (2013) found that most of the 33 mothers and 22 fathers felt that they were grieving differently than their spouse/partner. Some couples thought it brought them closer together; a few mothers thought it had a negative effect on their dyadic relationship, consistent with other's findings (Rubin & Malkinson, 2001). In a sample of 78 primarily White parents (25 couples) of 53 infants who died in the NICU an average of  $33 \pm 7.0$  months earlier, parent grief was not related to parent gender, and grief scores of mother-father dyads were not significantly different (Caeymaex et al., 2013). Lannen et al. (2008), in a Swedish national sample of 449 parents 4 to 9 years after a child's cancer death, also found that mothers were no more likely than fathers to have worked through their grief.

In studies of mothers, Laasko and Paunonen-Ilmonen (2002), Arnold and Gemma (2008), and Cacciatore (2010) found that the death of a child is one of the most stressful experiences in a mother's life and that coping may take a long time. Grieving mothers may have thoughts of self-harm; feelings of regret, guilt, and despair; and symptoms of physical distress (Barr & Cacciatore, 2008; Cacciatore, 2010). They also may have positive experiences such as

personal growth and greater forgiveness, empathy and hope after their child's death (Laasko & Paunonen-Ilmonen, 2002).

Fathers' initial reactions to their child's death include disbelief and shock followed by strong emotional reactions, somatic symptoms, difficulties in social interaction and a challenge to the meaning of life (Aho, Tarkka, Astedt-Kurki, & Kaunonen, 2009; Wood & Milo, 2001). Burden et al. (2016) in a systematic review of the impact of stillbirth on parents found that fathers suppressed their grief and resorted to substance use while mothers focused on body image and quality of life. Wood and Milo (2001) found that fathers experienced the death of their children with disabilities as the second loss of their child and their hopes and dreams for the child's future, with the first loss at diagnosis of the disabilities. These fathers believed that their grief was as great as the mothers' grief, but demonstrated differently. Fathers also reported that their grief became less intense over time (Wood & Milo, 2001). In another study (Reilly, Huws, Hastings, & Vaughan, 2008), mothers reported that sons and fathers "pushed it to one side and wouldn't deal with it." Bereaved fathers may discover their strengths and resources as they reconstruct the meaning of the loss and achieve personal growth (Aho et al., 2009; Wood & Milo, 2001).

Although the parents' intensity of grief may diminish over time (Alam et al., 2012; Meert et al., 2011; Stroebe et al., 2013), some parents continue to grieve for their deceased infants and children for many years, often longer than adults bereft of other family members (Malkinson & Bar-Tur, 2005). O'Leary and Warland (2013), in parents interviewed at 68 to 81 years of age and whose infant died in the first month of life, found that parents' grief persisted for 5 or more decades. Some researchers report complicated grief (persistent symptoms of chronic stress response including intense yearning for the deceased, shock, disbelief, anger, bitterness) that lasts more than 6 months post-death and interferes with daily functioning (Zhang, El-Jawahri, & Prigerson, 2006). Hogan, Greenfield, and Schmidt (2001) found parents within 3 years of their child's death had higher grief than parents 3 or more years after the death. Parents' grief remained at 1 and 2 years after a stillbirth (Rubin & Malkinson, 2001), and was present 50 to 70 years after the death (O'Leary & Warland, 2013). Stroebe et al. (2013) and Caeymaex et al. (2013) found little to no relationship between intensity of grief and time since the child's death.

Ronen et al. (2009) studied grief adjustment and continuing bonds for parents who lost a child. Parents in the high grief group reported being drawn to infants who reminded them of their child, which they found distressing, suggesting a need to regain physical proximity. Parents in the low grief group were able to be comforted through psychological proximity and mental representation of their child. This latter finding is consistent with the research of Scholtes and Browne (2015) who found that items such as obtaining comfort through fond memories, dreams, looking at pictures of the deceased and a sense of presence were predictive of more positive grief outcomes.

### **Race/Ethnicity Differences**

Traditional Western/Anglo grief theories of Freud, Kubler-Ross, and Parkes promote detachment from the deceased as an expression of acceptance and hence, healthy grieving (Cutcliffe, 2002; Shapiro, 1995). The Western/Anglo medical model continues to place an

emphasis on severing ties to the deceased, accepting the finality of death, and expecting grief to be a process that is both private and finite (Shapiro, 1995). Many Hispanic families believe in a spiritual and psychological continuity with the dead, a continuing relationship, nurtured by prayer, manifested in home shrines, candle lightings, graveside visits and formal mourning (Brooten et al., 2016; Clements et al., 2003; Lobar, Youngblut, & Brooten, 2006). Grief is resolved by the adaptation and life-long revision of the relationship between the deceased and the living (Whitaker et al., 2010). Blacks also hold a belief in maintaining continuity with the deceased and the passing of the deceased to another life. African Americans use social support, maintaining a relationship with the deceased, spirituality and religion, and remaining strong to cope with loss of a child (Boyden et al., 2014; Kavanaugh & Hershberger, 2005). While beliefs and coping strategies may be culturally specific, they are also moderated by generation and acculturation. Laurie and Neimeyer (2008) found that African American and White college students have very similar grief reactions to the loss of immediate family members and friends. Studies of differences in grief in White, Black and Hispanic parents after their child's death are lacking.

### **Expectation of Child Death**

Parent grief can begin before the child's death when parents learn of the child's terminal illness and prognosis. This anticipatory grieving can last for months or even years (Al-Gamal & Long, 2010). Certainty that the child's cancer could not be cured, the ability to disentangle their own needs, and the ability to parent meaningfully allowed parents to "let their child go (die)" in one qualitative study (Kars, Grypdonck, Beishuizen, Meijer-van den Bergh, & van Delden, 2010). Parents who postponed grief and enjoyed the remaining time with their child with cancer were better able to cope with the end of the child's life and to sustain their parenting role (Kars, Grypdonck, & van Delden, 2011). In a study of 219 couples, parents who could say good bye to their child (before, at the moment of death, or after the death) had lower grief scores than parents who did not or could not (Wijngaards-De Meij, Stroebe, Stroebe, Schut, & Van Den Bout, 2008). Even when death is anticipated, parents may experience it as a surprise (Brooten et al., 2013).

## **CHILD CHARACTERISTICS**

### **Infant/Child Age at Death**

Greater infant gestational age has been strongly related to higher levels of parent grief in a study of perinatal loss (Bennett, Litz, Maguen, & Ehrenreich, 2008). Stroebe et al. (2013) found that greater grief was weakly related to younger age of the deceased, whether the death was expected, fewer surviving children, and less parent education. Burke and Neimeyer (2012) in a systematic review of risk factors for prolonged grief found younger or older age of the deceased, being female, violent and/or sudden death, low income and low social support to be important risk factors. Zetumer et al. (2015) found that, since the loss, parents who lost younger children (<25 years old) were more likely to have wished to be dead than parents who lost older children (>25 years). Michon et al. (2003) found parents who lost a child after the perinatal period (>1 month of age) showed higher grief intensity than parents who lost a child in the perinatal period (0–1 month). However, others have found that parent grief was not related to child age or gender at death in the NICU, parent

age, education, or employment status; or whether the parent was with the child at the time of death or perceived the death as sudden or unexpected (Caeymaex et al., 2013; Harper, O'Connor, & O'Carroll, 2014). Older age of the deceased child and presence of other children in the home at the time of the death were related to longer recovery time (Sirchia, Saarinen-Pihkala, & Hovi, 2000).

### **Type/Mode of Infant/Child Death**

Accidental injury, sudden infant death syndrome (SIDS), and suicide deaths have been associated with prolonged grief and bereavement or more pathologic symptoms than other causes of death (Meert et al., 2010). These events are generally sudden or unexpected with no warning and no time for anticipatory grief. Death may occur at the scene of the event, shortly after hospital admission, or after prolonged hospitalization. Parents of children who died suddenly or violently experienced severe grief symptoms and a greater risk for PTSD up to 5 years post-death (Murphy, Johnson, Chung, & Beaton, 2003). Stroebe et al. (2013) found greater parent grief if the cause of death was an accident or illness vs. other (unspecified) causes. Mothers of murdered children had greater grief than mothers whose child died from suicide, accident, or illness (Hogan et al., 2001). When trauma was the cause of the child's death, higher grief scores were found in biologic mothers or female guardians who were not married and who had less education (Meert et al., 2010). At 18 months after the death, improvement in grief was greatest for parents whose child died of trauma (Meert et al., 2011). Lindqvist, Johansson, and Karlsson (2008) found a child's traumatic death was associated with greater improvement in parent grief over time.

As Price (2007) notes, SIDS deaths occur in close proximity to the child's birth when changes have been made to accommodate the infant into the family system. As a result the family system may be thrown into a state of emotional and functional crisis due to a shift in family roles, especially families with other children. A child's suicide can be perceived as the ultimate rejection of family, significant others, and society (Lindqvist et al., 2008). Mitchell, Sakraida, Kim, Bullian, and Chiappetta (2009) found that parents reported guilt, shame and shock at the suicide. Bereavement after suicide may differ qualitatively from that of other types of losses with prolonged reactions of grief and loneliness, shame, and a prolonged search for the motive behind the suicide (Kovarsky, 1989). Rodgers, Floyd, Seltzer, Greenberg, and Hong (2008) in a study of the long-term effects of child death on parent's adjustment in midlife found that recovery from grief was unrelated to the cause of the child's death or the amount of time since the death but was associated with parents having a sense of life purpose and having additional children.

The intensity of parents' grief may be affected by their experiences surrounding the child's death. Parents are stressed by the NICU/PICU environments, seeing their dying child in pain or frightened, and being unable to communicate with their child. ICU environments are characterized by a mix of new and familiar people, unfamiliar machines and tubes, high noise levels, little privacy, loss of the parent caretaking role, and periods of separation from the infant or child during the dying process (Meert, Briller, Schim, Thurston, & Kabel, 2009). Memories of the experience in the ICU environment remain with parents for years after the child's death. Positive memories may be comforting post-death, but negative

memories exacerbate parents' grief (Meert, Briller, Schim, & Thurston, 2008). Parents' memories may be positively or negatively affected by the child's mode of death – life-prolonging treatment limited or withdrawn, unsuccessful resuscitation, or brain death. Limiting or withdrawing treatment may allow the parents more time to say goodbye and perhaps begin anticipatory grieving. However, disagreements between and among healthcare providers, parents, and extended family members may be more stressful (Brooten et al., 2013) leaving parents with more negative memories. Death after cardio-pulmonary resuscitation (CPR) is often sudden, but may provide parents with the comforting thought that everything possible was done to save their child. Diagnosis of brain death is definitive, leaving parents with no choice or control in their child's death.

Use of advanced and high technology in PICU care may fuel parents' dreams of their child's recovery and later be crushed by the child's death (Meert, Thurston, & Thomas, 2001). A study by the Pediatric Critical Care Research Network revealed that after their child's PICU death, parents had high levels of complicated grief symptoms for 6 months. The intensity of complicated grief symptoms decreased for some parents from 6 to 18 months after their child's PICU death (Meert et al., 2011).

**In summary**, death of an infant or child is devastating for parents whose grief is immediate and may continue for many years after the death. Mothers and fathers may experience grief differently, with mothers' responses more intense and immediate than fathers' responses. Parent grief may be affected by type or mode of the child's death and whether or not it was expected. Research on parent grief has been focused largely on non-ICU child deaths from cancer, suicide, or traumatic injury with samples of mainly White parents, often recruited up to 30 years later from support groups or through advertisements introducing potential recall and sample bias (Youngblut & Brooten, 2012). Time between child death and parent interview ranged from 1 to 70 years and child age at death, from newborn to 30-year-old adult children. In addition, many studies have used measures of "complicated grief," a measure of prolonged grief even in the first year post-death (Meert et al., 2008, 2009, 2011). Thus, the pattern of parents' grief over the first year after an infant's or child's NICU/PICU death is not clear. The present study helps to fill these knowledge gaps by describing changes in mothers' and fathers' grief from 1 to 13 months after their infant's/child's NICU/PICU death and identifying parent (gender, race, expected death or not) and child (age group, mode of death) factors related to grief at 1, 3, 6, and 13 months in Hispanic, Black and White parents.

## METHOD

### Sample

The sample for this longitudinal study consisted of 130 mothers and 52 fathers whose infant or child died in the NICU or PICU in one of four referral hospitals or another hospital identified through death certificates from the Florida Department of Health (DOH). English- and Spanish-speaking parents were eligible for the study if their critically ill newborn through 18-year-old child died in a PICU or NICU at least 2 hours after admission. Parents were not eligible if (1) deceased newborn was from a multiple gestation pregnancy, (2) deceased infant/child lived in a foster home before PICU admission, (3) the deceased's

injuries involved child abuse, or (4) death of a parent or sibling occurred as a result of the same event (e.g., motor vehicle crash, giving birth, preterm birth).

## Measures

The dependent variable, Parent Grief after a child's NICU/PICU death, was measured with the Hogan Grief Reaction Checklist (HGRC). Parents rated each of the 61 items on a scale from 1 "Does not describe me at all" to 5 "Describes me very well" for the past 2 weeks. Correlations of HGRC subscales with subscales of the Grief Experience Inventory and Texas Revised Inventory of Grief support the HGRC's validity (Hogan et al., 2001). In this study, the range of internal consistency reliabilities for mothers and fathers, separately, and across the 4 time points were: Despair .90–.93 (13 items), Panic Behaviors .87–.93 (14 items), Blame & Anger .80–.88 (7 items), Detachment .82–.90 (8 items), Disorganization .83–.92 (7 items); and Personal Growth .83–.90 (12 items).

Independent variables were parent self-identified Race/Ethnicity (Hispanic, Black non-Hispanic, White non-Hispanic), and whether they Expected the Death (yes, no), and the deceased child's Age Group: infant (<13 months), preschool (13 to 60 months), school age (61 to 144.5 months) and adolescent (144.51 to 227.9 months); and Mode of Death (treatment limited, life support withdrawn, brain death, unsuccessful CPR).

## Procedures

After study approval by the IRBs at the University and each recruitment site, collaborators at the four hospitals and the DOH identified potentially eligible families. Introductory letters (Spanish & English) were mailed to these families at 3–4 weeks post child death. A research assistant called the parents, further explained the study, answered their questions, and scheduled a first data collection visit with interested parents in their home, where parents signed consent forms for their own participation and review of their child's medical record. Data were collected in English and Spanish at 1, 3, 6, and 13 months post-death.

## Data Analysis

Analyses to address the study's purpose were conducted separately for mothers and fathers with SPSS Version 21. Changes in mothers and fathers HGRC subscales over time were analyzed separately with RM-ANOVA with post hoc analyses to identify where the significant changes occurred. Differences for mother-father dyads (couples) were analyzed at each time point with paired t-tests. Group differences by mother or father race/ethnicity, child age group, and mode of death were analyzed with oneway ANOVA with Scheffe tests for post hoc comparisons. Differences for mothers and fathers by whether the death was expected (yes/no) were analyzed with two-sample t-tests. Analyses with  $p < .05$  were considered statistically significant.

## RESULTS

### Sample

Mothers ( $n = 130$ ) and fathers ( $n = 52$ ), including 52 mother-father couples, provided grief data at 1, 3, 6, and 13 months post-death. Mothers were younger and fewer were employed

after the child's death than fathers; most parents were high school graduates, partnered, and Hispanic or Black non-Hispanic (Table 1). Of the 140 deceased children, more than half were infants, male, and died in the PICU; 52 (37%) were first-born, and 41 (29%) were the family's only child. Most died after treatment was limited or withdrawn (Table 2). Relationships among child sex, unit and mode of death; mothers' and fathers' family income and expecting the death; and fathers' race/ethnicity and religion were not significant. Mothers' and fathers' levels of education were significantly and positively related to annual family income,  $X^2 = 32.35, p < .001$  and  $X^2 = 25.10, p < .001$ , respectively. Significantly more Black (72%) and Hispanic (64%) mothers than White (38%) mothers had annual family incomes under \$50,000,  $X^2 = 9.89, p = .04$ . Mothers' religions differed significantly by race/ethnicity,  $X^2 = 18.22, p = .006$ ; 92% of Black mothers were Protestant, and 63% of Hispanic mothers were Catholic.

### Change Over Time

For mothers, HGRC scores for Despair, Panic Behaviors, Blame & Anger, Detachment, and Disorganization decreased significantly from 3 to 6 and 6 to 13 months post-death. Mothers' Personal Growth scores increased significantly between 3 and 6 months post-death. For fathers, HGRC Despair scores decreased significantly from 3 to 6 months; changes in the fathers' other 5 HGRC scores were not significant (Table 3).

### Parent Factors

In mother-father dyads, paired comparisons showed that mothers had significantly higher HGRC scores than fathers for Panic Behaviors at all 4 time points, Despair at 1 and 3 months, and Disorganization at 1 and 6 months (Table 4). Differences on Blame & Anger, Detachment, and Personal Growth were not statistically significant.

For mothers, 3 of the HGRC subscales were significantly different across *racial/ethnic groups*. Black mothers reported greater Personal Growth than Hispanic mothers at 1, 3, and 6 months post-death. Hispanic mothers reported more Panic Behaviors at 1 month and greater Detachment at 13 months than White mothers and greater Detachment at 6 months than Black mothers (Table 5). For fathers, HGRC subscale scores did not differ by race/ethnicity. Grief scores were not significantly different for mothers or fathers by whether they *expected* the child's death.

### Child Factors

For mothers, many of their HGRC subscale scores were significantly different by the *deceased child's age group*. Mothers of deceased adolescents experienced significantly greater Despair and Panic Behaviors at all 4 time points and greater Detachment at 1 and 6 months, Blame & Anger at 6 months, and Disorganization at 6 and 13 months than mothers of deceased infants. Mothers of deceased adolescents also expressed significantly more Despair than mothers of deceased preschoolers at 13 months. Mothers' Disorganization scores at 1 and 3 months were significantly different, but post hoc testing did not identify which age groups were significantly different (Table 5). For fathers, none of the HGRC subscale scores differed significantly by the age group of the deceased child.



For mothers, grief scores differed significantly at each time point by the child's *mode of death*. Mothers whose child was declared brain dead reported greater Despair at 1, 3, and 6 months and greater Panic Behaviors, Blame & Anger, and Detachment at 6 months than mothers whose child died after failed CPR or life support withdrawal. Mothers in the brain death group also reported greater Despair at 6 months than those in the treatment limited group and greater Panic Behaviors and Disorganization at 13 months than mothers in the failed CPR group (Table 5). For fathers, none of the HGRC subscale scores differed significantly by the child's mode of death.

## DISCUSSION

Grief surrounding the death of a child can profoundly affect the grieving parents' lives emotionally, physically, psychologically and spiritually and take an enormous toll on them (Rini & Loriz, 2007). Grieving parents describe severe pain and a ripple effect of grief over their lifetimes (O'Leary & Warland, 2013). Studies of these parents find greater mortality (Espinosa & Evans, 2013; Li, Precht, Mortensen, & Olsen, 2003; Rostila, Saarela, & Kawachi, 2012) and negative long term morbidities in physical health and mental health (Blackmore et al., 2011; Fang et al., 2011; Li, Johansen, Hansen, & Olsen, 2002; Li, Laursen, Precht, Olsen, & Mortensen, 2005; O'Leary & Warland, 2013; Surkan, Rådestad, Cnattingius, Steineck, & Dickman, 2009; Youngblut et al., 2013). Most studies of parent grief have quite heterogeneous parent samples regarding time since infant or child death and age at death (newborn through adult child). Few studies of parents' grief for an infant or child who died in the NICU or PICU have been reported. This study of mothers' and fathers' grief within the first 13 months of the death of their child (newborn through 19 years old) in a NICU or PICU controlled for these factors by design.

Mothers' grief intensity diminished from 3 to 13 months post child death, while fathers' grief remained constant through 13 months except for a decrease in despair from 3 to 6 months. A decrease in mothers' grief over varying periods of time has been found in a number of studies (Hogan et al., 2001; Meert et al., 2011; Wood & Milo, 2001). In this study, panic, despair, and disorganization were more intense for mothers than fathers in the same family, which is consistent with findings of others (Alam et al., 2012; Stroebe et al., 2013). In some studies, mothers and fathers report that they manifest their grief differently (Avelin et al., 2013; Wood & Milo, 2001). Perhaps this finding is related to mother-father differences in degree of openness (Alam et al., 2012) or level of denial (Reilly et al., 2008).

Few differences in grief intensity for Hispanic, Black, and White mothers were statistically significant. Hispanic mothers reported greater feelings of panic and detachment than White mothers at 1 and 13 months, and greater ratings of detachment than Black mothers at 6 months. Perceptions of grief intensity were similar for Hispanic, Black, and White fathers. Most other studies in this area did not investigate racial/ethnic differences, primarily due to their mostly White samples of parents.

Black mothers experienced greater personal growth than Hispanic mothers from 1 to 6 months post child death. In a qualitative study, Youngblut and Brooten (2013) found that Black mothers, but not Hispanic or White mothers, spoke about heaven and the deceased's

being “in a good place.” Perhaps their stronger beliefs in a “higher power” (Bullock, 2011) contribute to their ability to identify positive consequences of their child’s death. Although Scholtes and Browne (2015) found a negative relationship between personal growth and the deceased’s age, personal growth did not differ in this study by the deceased’s age or mode of death.

Grief intensity of mothers of deceased adolescents was consistently greater than that of mothers of deceased infants. Stroebe et al. (2013) found a weak relationship between grief and the deceased’s age ( $10 \pm 10$ ), but Caeymaex et al. (2013) with a NICU sample and Harper et al. (2014;  $19 \pm 13$  years) found no relationship. Perhaps more changes and tasks follow a teen’s death than an infant’s death, such as needing someone to take over the deceased teen’s chores and roles in the family (Price, 2007). Their parents also have to notify all of the activities and organizations in which the teen was involved – e.g., school, sports, band/orchestra/chorus, instrument or dance lessons, community service, colleges, jobs – and the teen’s network of friends. Perhaps these activities provide more triggers of grief reactions for parents of deceased adolescents than for parents of infants.

Mothers of children with brain death reported greater despair at all time points and greater panic, blame and anger, and detachment at 6 months than mothers whose child died after unsuccessful CPR efforts or withdrawal of treatment. Research in this area has not been reported. Brain death often occurs after a traumatic injury or anoxic event. When brain death is determined, any hopes for survival or a miracle are dashed, and parents generally have little say about removal of life support. If determined in the first day or two after ICU admission, parents may not have enough time to marshal the needed support from family and friends or develop a relationship with healthcare professionals. In contrast, when treatment is withdrawn or limited, parents can maintain hope until the child’s death; some may begin anticipatory grieving (Kars et al., 2010, 2011). Friends and family have time to travel to be with the parents; some healthcare professionals may be regarded as confidantes and family members (Brooten et al., 2013). These dramatically different experiences may help to explain the more intense grief in parents whose child was declared brain dead.

### Limitations

Parents were well educated with 68% having attended or graduated from college. More minority mothers than white mothers had annual family incomes below \$50,000, suggesting that the differences by mothers’ race/ethnicity may be due in part to differences in incomes. Fewer fathers participated than mothers. More than half (63.6%) of the deceased in the sample were infants. Given these sample characteristics, it is not clear if study results would hold in a sample with more fathers, older deceased children and parents with less education and/or income. More research is needed in these areas.

From 1 to 13 months, mothers’ grief decreased but was higher than fathers’ grief which didn’t decrease. Mothers’ and fathers’ grief intensity may not coincide resulting in different needs and perhaps conflict during the 13 months after infant/child death. Parents of deceased adolescents reported more intense grief than parents of deceased infants and may need more help in dealing with decision making, daily functioning and life without the adolescent. This requires reorganization and changed roles within the family unit. Parents whose child was

declared brain dead had more intense grief and may need more support and time with the child to say good bye before life support is removed.

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**Table 1**

## Description of parents

Characteristic		Mothers ( <i>n</i> = 130)	Fathers ( <i>n</i> = 52)
Age	M (SD)	31.5 (7.91)	37.9 (9.00)
Race/ethnicity	White non-Hispanic	29 (22.3%)	12 (23.1%)
	Black non-Hispanic	52 (40.0%)	15 (28.8%)
	Hispanic	49 (37.7%)	25 (48.1%)
Education	<High school	12 (9.2%)	6 (11.5%)
	High school graduate	33 (25.4%)	9 (17.3%)
	Some college	51 (39.2%)	19 (36.6%)
	College graduate	34 (26.2%)	18 (34.6%)
Religion	Protestant/Christian	67 (51.5%)	27 (51.9%)
	Catholic	40 (30.8%)	12 (23.2%)
	Jewish	5 (3.8%)	2 (3.8%)
	Other	2 (1.6%)	1 (1.9%)
	None	16 (12.3%)	10 (19.2%)
Partnered?	At 1 month	99 (76.2%)	46 (88.5%)
	At 13 months	95 (73.1%)	45 (86.5%)
Employed at 13 months	Yes	80 (61.5%)	45 (86.5%)
Timing of return to job	<7 days	9 (6.9%)	15 (28.8%)
	7–14 days	11 (8.5%)	12 (23.1%)
	15–30 days	28 (21.5%)	6 (11.5%)
	31–120 days	32 (24.6%)	9 (17.3%)
	>120 days	18 (13.9%)	7 (13.5%)
	Not employed after child's death	32 (24.6%)	3 (5.8%)



**Table 2**

Description of families and deceased children

		Families (N = 140)
Annual family income	<\$20,000	41 (29.3%)
	\$20,000–49,999	43 (30.7%)
	\$50,000	52 (37.1%)
	Not reported	4 (2.9%)
Number of living children	None	41 (29.3%)
	1	43 (30.7%)
	2	21 (15.0%)
	3 or more	35 (25.0%)
Sex of deceased child	Boys	78 (55.7%)
	Girls	62 (44.3%)
Deceased's age group	Infant	89 (63.6%)
	Preschool	22 (15.7%)
	School age	13 (9.3%)
	Adolescent	16 (11.4%)
Unit	NICU	68 (48.6%)
	PICU	72 (51.4%)
Mode of death	Treatment limited	40 (28.6%)
	Life support withdrawn	38 (27.1%)
	Brain death	15 (10.7%)
	Failed CPR	47 (33.6%)

**Table 3**

Significant changes in mothers' grief scores over time

HGRC subscale	Mothers' grief subscale scores ( <i>N</i> = 130)			RM-ANOVA <i>F</i>	Significant change (months)
	3 months <i>M</i> (SD)	6 months <i>M</i> (SD)	13 months <i>M</i> (SD)		
Despair <sup>a</sup>	32.3 (14.02)	29.8 (13.43)	26.8 (12.60)	30.79**	3 > 6 > 13
Panic behaviors	28.4 (12.57)	28.3 (12.80)	25.6 (12.26)	9.26**	6 > 13
Blame & anger <sup>a</sup>	12.8 (5.95)	12.8 (6.66)	11.6 (5.62)	5.93**	6 > 13
Detachment <sup>a</sup>	14.8 (7.70)	14.2 (6.68)	13.1 (6.22)	7.08**	6 > 13
Disorganization	14.5 (6.47)	14.3 (6.76)	12.7 (5.90)	11.46**	6 > 13
Personal growth	37.8 (10.61)	39.7 (10.03)	40.8 (10.46)	8.12**	3 < 6

\*  $p < .05$ ,\*\*  $p < .01$ .<sup>a</sup>Greenhouse Geysler estimates of *F* used because sphericity assumption was not met.

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**Table 4**

Paired comparisons of grief subscales for mother-father dyads

	Mother-father dyads			
	1 month (45 dyads) <i>M</i> (SD)	3 months (52 dyads) <i>M</i> (SD)	6 months (52 dyads) <i>M</i> (SD)	13 months (46 dyads) <i>M</i> (SD)
Despair				
Mothers	34.3 (13.17)	31.3 (12.88)	28.7 (13.61)	25.6 (13.11)
Fathers	30.4 (12.21)	27.9 (11.63)	25.6 (10.41)	24.4 (12.31)
Paired <i>t</i> value	2.71 **	2.22 *	1.89	.77
Panic behaviors				
Mothers	30.1 (12.39)	27.2 (11.11)	27.4 (12.50)	25.4 (12.55)
Fathers	23.7 (9.30)	23.2 (10.49)	21.83 (9.24)	21.4 (8.87)
Paired <i>t</i> value	3.40 **	2.45 *	3.17 **	2.15 *
Disorganization				
Mothers	16.8 (10.00)	14.0 (6.44)	14.1 (6.56)	12.9 (6.45)
Fathers	13.3 (5.91)	12.9 (5.93)	11.5 (5.24)	12.0 (5.97)
Paired <i>t</i> value	2.29 *	1.12	2.78 **	.84

\*  $p < .05$ ,\*\*  $p < .01$ .

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**Table 5**

Differences in mothers' grief subscale scores by mothers' race/ethnicity, and her deceased child's age group and mode of death

Mother's subscale		Mother's race/ethnicity			F
		White non-Hispanic (n = 29)	Black non-Hispanic (n = 52)	Hispanic (n = 49)	
T1	Panic behavior	24.6 (8.10) <sup>a</sup>	26.3 (12.30)	32.0 (13.69) <sup>a</sup>	3.32 <sup>*</sup>
	Personal growth	37.1 (10.98)	41.2 (9.97) <sup>a</sup>	35.6 (8.26) <sup>a</sup>	3.35 <sup>*</sup>
T2	Personal growth	36.8 (9.22)	41.5 (9.95) <sup>a</sup>	35.0 (10.87) <sup>a</sup>	5.34 <sup>**</sup>
T3	Detachment	12.8 (5.16)	12.8 (5.71) <sup>a</sup>	16.2 (7.75) <sup>a</sup>	4.21 <sup>*</sup>
	Personal growth	38.0 (8.32)	43.4 (9.88) <sup>a</sup>	36.8 (10.18) <sup>a</sup>	6.32 <sup>**</sup>
T4	Detachment	11.6 (4.18) <sup>a</sup>	12.1 (5.83)	14.7 (6.97) <sup>a</sup>	3.33 <sup>*</sup>

Mother's subscale		Child's age group <sup>§</sup>				F
		Infant (n = 85)	Preschool (n = 21)	School age (n = 12)	Adolescent (n = 11)	
T1	Despair	29.6 (12.35) <sup>a</sup>	34.9 (15.29)	36.9 (15.02)	50.3 (15.16) <sup>a</sup>	5.69 <sup>**</sup>
	Panic behaviors	25.7 (10.86) <sup>a</sup>	33.0 (14.16)	29.5 (12.79)	40.0 (14.26) <sup>a</sup>	4.19 <sup>**</sup>
	Detachment	13.2 (5.91) <sup>a</sup>	15.0 (8.37)	15.2 (8.38)	21.3 (8.16) <sup>a</sup>	3.19 <sup>*</sup>
	Disorganization	13.2 (5.39)	17.1 (7.07)	15.9 (7.51)	17.7 (6.97)	2.89 <sup>*</sup>
T2	Despair	29.2 (12.09) <sup>a</sup>	34.6 (15.24)	36.4 (15.79)	47.0 (14.02) <sup>a</sup>	6.78 <sup>**</sup>
	Panic behaviors	26.3 (11.21) <sup>a</sup>	31.3 (14.24)	27.4 (13.17)	38.4 (13.87) <sup>a</sup>	3.74 <sup>**</sup>
	Disorganization	13.0 (5.54)	16.8 (7.62)	17.3 (7.55)	18.0 (7.00)	4.44 <sup>**</sup>
T3	Despair	26.7 (11.81) <sup>a</sup>	32.7 (14.29)	34.3 (13.79)	43.4 (13.82) <sup>a</sup>	6.89 <sup>**</sup>
	Panic behaviors	26.4 (12.33) <sup>a</sup>	31.6 (13.79)	26.6 (9.56)	38.6 (13.54) <sup>a</sup>	3.70 <sup>**</sup>
	Blame & anger	12.2 (6.62) <sup>a</sup>	12.6 (5.50)	12.2 (8.01)	18.2 (5.96) <sup>a</sup>	2.76 <sup>*</sup>
	Detachment	13.1 (6.09) <sup>a</sup>	14.9 (6.61)	15.3 (6.43)	19.6 (8.45) <sup>a</sup>	3.69 <sup>**</sup>
	Disorganization	12.6 (5.58) <sup>a</sup>	16.8 (7.77)	16.1 (7.99)	20.1 (7.67) <sup>a</sup>	6.34 <sup>**</sup>
T4	Despair	23.7 (10.17) <sup>a</sup>	28.1 (12.15) <sup>b</sup>	31.0 (13.31)	43.8 (15.69) <sup>ab</sup>	11.05 <sup>**</sup>
	Panic behaviors	23.7 (11.34) <sup>a</sup>	26.3 (12.48)	25.7 (10.31)	36.8 (15.03) <sup>a</sup>	4.10 <sup>**</sup>
	Detachment	12.1 (5.57)	12.9 (5.03)	13.6 (5.09)	19.1 (9.41)	4.64 <sup>**</sup>
	Disorganization	11.2 (4.91) <sup>a</sup>	14.3 (5.75)	15.3 (7.68)	17.8 (6.55) <sup>a</sup>	6.78 <sup>**</sup>
Mother's subscale		Mode of death <sup>§</sup>				F

		Support withdrawn ( <i>n</i> = 33)	Treatment limited ( <i>n</i> = 37)	Brain death ( <i>n</i> = 14)	Failed resuscitation ( <i>n</i> = 45)	
T1	Despair	30.2 (14.5) <sup>a</sup>	32.4 (13.74)	44.2 (17.45) <sup>ab</sup>	31.0 (12.13) <sup>b</sup>	2.98 <sup>*</sup>
T2	Despair	29.9 (14.73) <sup>a</sup>	32.1 (13.56)	43.5 (14.30) <sup>ab</sup>	30.7 (12.51) <sup>b</sup>	3.70 <sup>**</sup>
T3	Despair	27.3 (13.97) <sup>a</sup>	29.2 (12.83) <sup>b</sup>	42.6 (12.90) <sup>abc</sup>	28.2 (11.79) <sup>c</sup>	5.36 <sup>**</sup>
	Panic Behaviors	26.2 (13.73) <sup>a</sup>	28.1 (12.43)	37.5 (13.77) <sup>ab</sup>	27.2 (11.36) <sup>b</sup>	2.93 <sup>*</sup>
	Blame & anger	11.1 (5.84) <sup>a</sup>	13.5 (6.39)	17.5 (7.88) <sup>ab</sup>	11.9 (6.52) <sup>b</sup>	3.67 <sup>**</sup>
	Detachment	12.9 (6.09) <sup>a</sup>	14.6 (6.55)	19.9 (8.22) <sup>ab</sup>	12.8 (5.62) <sup>b</sup>	5.09 <sup>**</sup>
T4	Despair	25.3 (13.76) <sup>a</sup>	26.9 (12.18)	39.3 (14.67) <sup>ab</sup>	23.9 (8.88) <sup>b</sup>	6.24 <sup>**</sup>
	Panic behaviors	25.2 (13.08)	26.1 (11.84)	33.7 (15.53) <sup>a</sup>	22.4 (9.52) <sup>a</sup>	3.31 <sup>*</sup>
	Disorganization	11.8 (5.33)	13.4 (6.24)	16.6 (6.59) <sup>a</sup>	11.4 (5.15) <sup>a</sup>	3.44 <sup>*</sup>

\*  $p < .05$ ,

\*\*  $p < .01$ .

§ Groups with the same superscript letter were significantly different on post hoc testing.