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Experiences of African American Parents Following Perinatal or Pediatric Death: A Literature Review

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Abstract

A child's death is one of life's most difficult experiences. Little is known about the unique factors that influence the grief experience for bereaved African American parents. Through an integrative review of 10 publications, the authors describe the grief responses, outcomes, and implications for African American parents who experience the death of a child. Four themes emerged: (a) emotional response to loss; (b) factors that added to the burden of loss; (c) coping strategies; and (d) health consequences of grief. Healthcare providers, administrators, and policymakers should be sensitive to the unique needs of African American parents following a child's death.

Keywords

African American; parents; grief; bereavement; perinatal death; pediatric death; death of child

The death of a child is noted to be one of the most difficult life experiences (Hendrickson, 2009; Meert, Thurston, & Thomas, 2001). Bereaved parents experience more intense grief than adults who experience other losses (Sanders, 1979), in part because of the uniqueness of the parent-child relationship (Braun & Berg, 1994). Parental grief is profound, regardless

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of the number of years since the loss, the age of the child at the time of death, or the cause of death (Arnold & Gemma, 2008), and lasts throughout a parent's lifetime (Dyregrov & Dyregrov, 1999). African American parents are at greater risk for experiencing the loss of a child through perinatal (pregnancy or newborn) or pediatric death due to significantly higher mortality rates (Kochanek, Kirmeyer, Martin, Strobino, & Guyer, 2012).

Parental bereavement following the death of a child relates to long-term mental and physical morbidity (Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004; Lannen, Wolfe, Prigerson, Onelov, & Kreicbergs 2008), psychological distress (McCarthy, Clarke, Ting, Conroy, Anderson, & Heath, 2010), psychiatric hospitalizations (Li, Laursen, Precht, Olsen, & Mortensen, 2005), depression (McCarthy et al., 2010; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008), increased health service use, increased sick leave (Lannen et al., 2008), poorer overall well-being (Rogers et al., 2008), cancer (Levav, Kohn, Iscovich, Abramson, Wei, & Vigdorovich, 2000), multiple sclerosis (Li, Johansen, Brønnum-Hansen, Stenager, Koch-Henriksen, & Olsen, 2004), myocardial infarction (Li, Hansen, Mortensen, & Olsen, 2002), and mortality, even 25 years post-loss (Li, Precht, Mortenson, & Olsen, 2003). However, it is possible that poor parental health may also increase the risk for childhood illness and potentially, mortality (Cnattingius, Zack, Ekbom, Gunnarskog, Kreuger, Linet, & Adami, 1995).

The consequences of grief for any bereaved parent are significant. However, the grief experienced by bereaved African American parents may be of particular concern, given the unique aspects of their experience and culture. A major aspect of that experience is their higher rates of mortality, including in children. From 1999 to 2008, an average of 14,148 deaths per year occurred among African American children birth to 19 years of age (CDC, 2011), which translates into nearly 30,000 newly bereaved African American parents per year and a crude mortality rate of 106.9 per 100,000. This mortality rate is nearly double that of white children in the same age group (CDC, 2011).

Additionally, each culture has its own belief systems about healing practices, life after death, death-related rituals, and behavioral styles (York & Stichler, 1985). In one study, African American participants who had lost an adult loved one were more likely than Caucasian participants to maintain connections with the deceased and be distressed over the loss (Laurie & Neimeyer, 2008). The researchers interpreted this as reflecting the complexity and resilience of kinship ties in the African American culture. Although African American participants had more family support, they also were less likely to talk about the loss in both professional and personal contexts. This relative silence may be related to the cultural value of being strong. Less time spent talking about the loss was associated with greater grief intensity and complicated grief symptoms, leading to poorer outcomes (Laurie & Neimeyer, 2008).

Other factors may also affect the loss experience that may not be fully understood. For example, compounded loss and trauma from the beginnings of slavery in this country 400 years ago, to racism and segregation, to present-day realities of high rates of poverty, single-parent families, incarceration, educational disadvantage, and health disparities, have been part of the experience of African Americans in the United States (Pinderhughes, 2004), and

may play a significant role in how some cope with further loss and trauma. These factors may overlap significantly with cultural factors to affect the loss experience.

Although certain aspects of the experience of losing a child may be similar for all parents, African Americans have distinct cultural experiences that may greatly influence grief and coping. The purpose of this paper is to describe the grief responses, outcomes, and implications for African American parents who have experienced the death of their child during pregnancy, infancy or childhood.

Method

We searched five major online databases: PubMed, CINAHL Plus, PsychINFO, ProQuest Databases, Web of Knowledge- ISI, and JSTOR. Search terms included 'African American,' 'Grief,' 'Parental grief,' 'Death of Child,' 'Loss of child,' 'Child mortality,' 'Infant mortality,' 'Fetal loss,' 'Perinatal grief,' 'Sudden Infant Death Syndrome,' 'Traumatic Child Death,' and 'Adolescent death.' We screened studies from January 1975 through January 2011 and their reference lists. In all, we identified 12 studies, 10 of which met inclusion criteria: (a) included a description of the experiences of parents who lost a fetus, infant, or child (up to 18 years of age), (b) comprised a sample of at least 12% Black or African American parents, (c) were from the U.S., (d) were published, and (e) had results and implications analyzed for African American parents separately. The 12% African American criterion reflects the portion of the U.S. population estimated to be African American or Black (U.S. Census Bureau, 2010). We included both groups, as many publications also included both groups and did not break down the results separately. Data analysis consisted of data reduction, data display, and data comparison (Whittemore & Knafl, 2005).

Results

Of the 10 publications, 5 were published dissertations and 5 were journal articles. Several publications (Kavanaugh & Robertson, 1999 and Kavanaugh & Hershberger, 2005; Van & Meleis, 2003, Van & Meleis, 2010, and Patterson, 2000) shared data sets; however, each publication reported unique results and implications. In design, 6 were qualitative, 3 quantitative, and 1 mixed methods. In the sample, 9 had exclusively Black or African American samples, and 1 also included Caucasian participants (Willis, 1991). All studies included mothers, two studies also included fathers (Foyt, 1997; Kavanaugh & Hershberger, 2005), and two studies included grandmothers, who were identified as the primary caregiver for the deceased child (Foyt, 1997; Palmer, 1996). The age of the child at the time of death ranged from 12 weeks gestation to 9 months of age. Sociodemographic data (e.g., parental age, educational attainment, income, marital status, employment) varied across studies.

Four major themes emerged from this analysis. We discuss and illustrate these below.

Emotional Response to the Loss

Most investigators portrayed the intense emotions African American parents experienced after the loss of a pregnancy or the death of an infant, including feelings of shock (Kavanaugh & Hershberger, 2005), going crazy, being irritable and ready to fight with

others (Van & Meleis, 2003), and self-blame (Palmer, 1996). The loss was the worst moment in their life (Kavanaugh & Hershberger, 2005), a burden like no other (Foyt, 1997), and one for which they felt unprepared, even if they had previous experience with loss (Kavanaugh & Robertson, 1999). Many parents felt they had no idea what it meant to hurt so much (Foyt, 1997). Two researchers also noted suicidal thoughts or attempts (Foyt 1997; Kavanaugh & Hershberger, 2005). Emotions were pervasive and enduring, with an average of two to three years before mothers felt like they could resume normal activities, and high levels of grief as late as three years post-loss (Patterson, 2000). One report described the loss experience for fathers, who described feelings of hurt, loss of control, controlling emotions to avoid upsetting the mother, and being unsure of how to support the mother (Kavanaugh & Hershberger, 2005). Thus, African American parents in the reviewed literature often experienced intense feelings following the death of their child, similar to responses reported in other racial groups. These feelings were complex and lasted for many years (Foyt, 1997; Kavanaugh & Hershberger, 2005; Palmer, 1996; Patterson, 2000; Van & Meleis, 2003).

Factors That Added to the Burden of Loss

Many investigators found that the realities of everyday life added to the burden African Americans faced after the loss of a child. This included socioeconomic stressors, the prevalence of illness and death in families, a lack of support by others, and negative encounters with healthcare and other professionals.

Socioeconomic factors mattered—Lower income and educational attainment were significantly associated with greater despair (Van & Meleis, 2010) and higher levels of depression after an involuntary pregnancy loss or an infant's death for African American parents, even after controlling for types of mental health treatment and living arrangements (Page Edwards, 1998). Funeral and burial expenses were a great stressor for many parents (Foyt, 1997). One mother said she, "still didn't have enough money to buy a (head) stone…I couldn't find his grave so I cried" (p. 71). Other burdensome socioeconomic factors included losing public assistance and child support after the child's death (Foyt, 1997); having insufficient bereavement leave from work (Foyt, 1997); having unsatisfactory housing arrangements (Kavanaugh & Hershberger, 2005); losing a job and experiencing adverse work conditions (Kavanaugh & Hershberger, 2005; Foyt, 1997).

Other life events caused additional stress for grieving parents, such as illness and hospitalizations in the family (Kavanaugh & Robertson, 1999; Kavanaugh & Hershberger, 2005) and the untimely deaths of loved ones due to natural and unnatural causes (Kavanaugh & Hershberger, 2005; Palmer, 1996; Van & Meleis, 2010). In one study, 50% of participants reported experiencing one to five family deaths to both natural and violent causes within one year of their infant's death (Palmer, 1996). Other researchers (Van & Meleis, 2010) asserted that high morbidity and mortality among loved ones amplifies grief after the loss of a pregnancy or child.

Relationships made a difference—Some participants described feeling unsupported and abandoned by their families, some of whom were absent due to substance abuse and/or incarceration (Kavanaugh & Hershberger, 2005). Some significant others deserted bereaved

mothers, leaving them without the support person they craved the most (Foyt, 1997). Participants reported feeling unable to talk about the loss with loved ones (Foyt, 1997; Kavanaugh & Robertson, 1999; Patterson, 2000; Van, 2001), who were uncomfortable and unable to understand their loss (Kavanaugh & Robertson, 1999; Van, 2001), and made insensitive comments and behaviors (Foyt, 1997; Van & Meleis, 2003). This lack of support often caused distress among bereaved parents (Foyt, 1997; Palmer, 1996).

Negative treatment from professionals made things worse—Many African American parents experienced negative treatment by healthcare providers that added to the trauma of losing a child. For example, one mother felt that healthcare providers did not listen to her concerns and requests for treatment through her experiences with four perinatal losses (Kavanaugh & Robertson, 1999). Some parents felt that their insurance status led to unfair treatment, and that their babies born at the threshold of viability did not receive adequate resuscitation attempts after birth (Kavanaugh & Hershberger, 2005). Some parents also mistrusted the healthcare system, which often discouraged them from seeking help after the child's death (Page Edwards, 1998).

Some parents also perceived negative treatment by other professionals surrounding the time of their child's death. One mother received unfair treatment from a funeral director, who buried her son without her presence (Kavanaugh & Hershberger, 2005). The police accused one mother of causing her baby's SIDS death (Foyt, 1997). Other parents spoke of the trauma of having their remaining children removed from their homes by Child Protective Services after a SIDS death (Foyt, 1997).

Many parents reported not attending a support group or seeking counseling (Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Even parents who did attend support groups found them unhelpful because many groups had few or no other African American participants (Van & Meleis, 2003). This lack of diversity constrained them from sharing their feelings, and many women greatly preferred talking with other women from their own culture. One mother asserted that, "Support groups and counselors are thought to be only for White women with money. Cultural differences make our grieving that much harder" (Van & Meleis, 2003, p. 32).

Thus, the realities of everyday life often added to the burden of a child's death for African American parents. Factors such as the prevalence of economic disadvantage, discrimination, and health disparities often made the loss of a child much more difficult for these parents.

Coping Strategies

This section describes African American parents' coping strategies used to deal with the loss of a child.

Social support from family, friends, and remaining children were important (Foyt, 1997; Kavanaugh & Robertson, 1999; Palmer, 1996; Patterson, 2000; Van & Meleis, 2003). In particular, having a loving relationship with one's own mother helped bereaved mothers change their perspective on the death and on life after the loss of their child (Foyt, 1997).

Talking about the loss was also seen as helpful, including talking to the researcher (Kavanaugh & Hershberger, 2005).

Maintaining a relationship with and preserving memories of the deceased child were also used as coping strategies after the loss. Many mothers described the importance of holding the baby at the time of death (Van & Meleis, 2003; Kavanaugh & Hershberger, 2005; Palmer, 1996); noticing family resemblances (Kavanaugh & Hershberger, 2005); and retaining memorabilia from the baby (e.g., pictures, ID bracelets, blankets) (Kavanaugh & Hershberger, 2005; Van & Meleis, 2003). Furthermore, regularly thinking about the deceased baby was helpful, no matter if the loss occurred 9 to 30 months earlier (Palmer, 1996). One mother found comfort in taking her subsequent children to visit the grave of the deceased child (Foyt, 1997). Overall, mothers tried many ways to keep the child in their lives.

Turning to spirituality and religion played a significant role in coping with parental grief, including going to church; praying; maintaining, renewing, or developing a relationship with God; and attributing the death to God's will (Foyt, 1997; Kavanaugh & Hershberger, 2005; Kavanaugh & Robertson, 1999; Page Edwards, 1998; Palmer, 1996; Patterson, 2000; Van, 2001; Van & Meleis, 2003; Willis, 1991). Belief in life after death and the "comfort in knowing that ancestors were caring for their babies" were important (Van, 2001, p. 237). Spirituality sustained parents through this very difficult time (Kavanaugh & Hershberger, 2005).

Not all parents turned to religion to cope with the loss, although even parents with no religious affiliation found spirituality helpful (Palmer, 1996; Van, 2001; Van & Meleis, 2010). For example, one mother who denied religious affiliation felt "comfort in receiv[ing] messages from her dead baby during dreams" (Van, 2001, p. 237).

Calling upon internal strategies helped mothers to cope with the loss, including utilizing "instinctive resources" (Patterson, 2000); making sense of the loss (Foyt, 1997; Kavanaugh & Hershberger, 2005; Palmer, 1996; Van, 2001); changing perspective (Foyt, 1997); and using the inner voice of healing (Van, 2001; Van & Meleis, 2003). Many parents reported keeping busy, moving forward, making plans for the future, accomplishing goals, and simply living through it (Foyt, 1997; Kavanaugh & Hershberger, 2005; Palmer, 1996). To cope, some mothers avoided being around other pregnant women and babies (Foyt, 1997; Kavanaugh & Hershberger, 2005; Palmer, 1996). Lastly, some mothers used the cultural value of being strong as a way to move forward with life after loss (Page Edwards, 1998; Palmer, 1996). One mother noted that, "We are not expected to go to counseling and [are] brought up to make it on our own, to be strong…" (Van & Meleis, 2003, p. 32).

In summary, African American parents in the reviewed literature utilized many strategies to cope with the loss of a child. Strategies such as utilizing social support, maintaining a relationship with the child, turning to spirituality and religion, and relying on cultural values such as being strong may be particularly important.

Health Consequences of Grief

Some investigators found high levels of depression for African American parents one year after their infants' deaths (Page Edwards, 1998), and some parents showed little to no improvement three years after the death. African American mothers reported high levels of drug and alcohol use, eating, weight gain, and sleep disturbances three years after the child's death (Foyt, 1997), which were higher than levels found in Caucasian mothers 18 months post loss (Willis, 1991).

One study found no association between level of grief and perception of general health (Patterson, 2000), which the researcher attributed to the women defining health solely within the context of physical symptoms and functioning. Paradoxically, in another study, the better mothers perceived their health to be, the higher their level of depression (Page Edwards, 1998), which the researcher interpreted as because African Americans may view mental illness as a sign of weakness, not as a part of overall health. Consequently, many denied needing professional support (Page Edwards, 1998).

The reviewed literature described significant mental and physical health consequences of grief for African American parents. These parents may experience higher levels of depression, increased recreational drug and alcohol use, increased eating and weight gain, greater sleep disturbances, and greater perceived severity of health problems following the loss of a child.

Discussion

The experience of a child's death may be somewhat different for African American parents. Parents, regardless of race and culture, often express feelings of regret, guilt, vulnerability, shock, and self-blame (Arnold & Gemma, 2008; Cacciatore, 2010), and experience life long grief (Arnold & Gemma, 2008). However, this review indicates that factors such as the prevalence of socioeconomic hardships, illness, and loss among African Americans (Foyt, 1997; Kavanaugh & Hershberger, 2005; Kavanaugh & Robertson, 1999; Page Edwards, 1998; Palmer, 1996; Van & Meleis, 2010) often add to the burden of a child's death. Experts further note that the experience of loss may be unique for these parents, as the prevalence of illness and exposure to loss at an early age often causes a heavy burden of anger and resentment entangled in grief (Rosenblatt & Wallace, 2005a). Racism, discrimination, economic disadvantage, and health disparities greatly influence bereavement (Rosenblatt & Wallace, 2005a), and may create a high vulnerability to further disruption, loss, and trauma for many African Americans (Pinderhughes, 2004).

Negative treatment by healthcare providers may also be a stressor for many African American parents, as investigators who included other populations of bereaved parents found that positive experiences with healthcare providers impact grief intensity and coping (Brosig, Pierucci, Kupst, & Leuthner, 2007; Kavanaugh, 1997; Meert et al., 2001). Many bereaved African American parents may also not utilize professional counseling and support groups, even though parents who receive counseling are more likely to work through their grief (Kreicbergs, Lannen, Onelov, & Wolfe, 2007). Some of these parents may find it difficult to share their experiences and emotions in groups that often have few or no other

parents from their own race or culture (Van & Meleis, 2003). One bereaved mother observed that, "[the support group] was all white and I did not feel like going back" (Barnes, 2008, p. 301). A mistrust of the healthcare system, high cost, and a lack of cultural understanding among healthcare providers (Sanders Thompson, Bazile, & Akbar, 2004) may further discourage the use of these services.

Some coping strategies may be more highly utilized among bereaved African American parents. Studies of primarily European American parents find spirituality and religion to be important for coping (Arnold & Gemma, 2008); however, African American religion "has elements…connected to the history of slavery, racism, and oppression that bring religious meaning making in grief to somewhat different places" (Rosenblatt & Wallace, 2005a, p. 85). Consequently, African American parents may be more likely to rely on religion to cope with the loss of their child. Cultural values such as being strong may also be particularly important for these parents (Page Edwards, 1998; Palmer, 1996). Being 'strong in grief' is unique to the African American culture because of the enormous adversity that this population has historically faced. Strength is learned, modeled, and valued across generations (Rosenblatt & Wallace, 2005a).

However, not all coping strategies are health-promoting. For example, in this review, drug and alcohol use was high among African American parents (Foyt, 1997), and was greater when compared to Caucasian parents (Willis, 1991). Roberts (1999) also described the experience of a low-income, inner-city African American mother who lost her child, "I got no hope, no control; stopped for 2 months in prison but went right back to crack" (p. 627). This author notes that the environment in which these women lived played a major role in how they managed loss.

Lastly, bereaved parents regardless of race or culture experience negative mental and physical health outcomes; however, bereaved African American parents may experience higher levels of depression and poorer overall health than other parents (Sudha, Mutran, Williams, & Suchindran, 2006; Willis, 1991). Sudha et al. (2006) concluded that the death of a baby continues to resonate in later life, particularly for African American women.

The fact that a thorough search identified only 10 reports highlights the limited knowledge of the experiences of bereaved African American parents. Further, these reports examined several child loss experiences (e.g., pregnancy, neonatal, infant), although no publications investigated parents' experience of losing an older child or adolescent. The sudden loss of a child may carry significant implications for parental health (Li et al., 2003), as sudden deaths do not allow parents to psychologically prepare for the death (Davies, 2004; Meert et al., 2001). Thus, it would be important to study the experience of African American parents who lose an older child, particularly as many of these deaths are violent and traumatic.

Another limitation is the lack of differentiation within the reviewed studies of the different groups that comprise the African American and Black populations, although these groups may carry differences in customs, social class, spirituality, beliefs, experiences, and cultural identification. Thus, the present findings may not be generalized to all African American parents. Future studies should examine the experiences of these different groups, as differing

beliefs and experiences may greatly affect grief and coping. Furthermore, the reviewed studies fall short of differentiating cultural factors from other contributing factors that may be prevalent within a culture but not necessarily unique to that culture (e.g., socioeconomic disadvantage, prevalence of illness and death). Future studies should determine which factors are culture-specific, which factors are simply prevalent within the culture, and how these different factors uniquely influence the grief experience.

It will also be important to identify how African American fathers experience and cope with the loss of a child, as well as the unique experience of grandparents who face the death of a grandchild. African American grandparents may often fill a parental role, so their grief experience may also be more complicated. Grandparents grieve not only for the grandchild, but also for the pain their own child is enduring (Callister, 2006; Nehari, Grebler, & Toren, 2007).

It is critical for healthcare providers who work with African American parents to be sensitive to and aware of the unique aspects of the individual that play a role in how these parents perceive and cope with the loss of a child (e.g., spiritual beliefs and practices, cultural values, attitudes toward seeking health services). It is also important to evaluate additional stressors that affect the loss experience, such as economic hardship, racism and discrimination, lack of social and professional support, and history of illness and death in the family. In such a way, healthcare providers can intervene appropriately, such as by directing parents to financial assistance for burial services (McCarthy et al., 2010), or finding support groups where parents may feel comfortable.

On a policy level, it is important to ensure the availability of cost-effective and culturally-sensitive mental health support for African American parents after a child's death, particularly as many parents may also be dealing with other significant losses, illnesses, and socioeconomic stressors. Furthermore, healthcare providers, police, and funeral directors should be trained in providing culturally-sensitive care surrounding the time of a child's death. There should be a consistent system for timely and appropriate follow-up for bereaved parents, particularly for African American parents who may experience relatively greater physical and mental health consequences. Overall, there needs to be broader awareness among healthcare providers, hospital administrators, and policymakers of the complex needs of these parents, and the necessity of culturally-sensitive healthcare and bereavement supports following the death of a child.

The experience of perinatal loss or the death of a child is a serious concern for all parents, as parental grief is often associated with serious long-term health consequences. African American parents' early grief responses may be similar to that of all parents; however, factors such as racism, discrimination, and economic disadvantage; the prevalence of illness, loss, and life stressors; the lack of culturally-appropriate professional support; cultural values such as being strong; and the importance of religion and spirituality may greatly affect the grief experience for these parents. The burden of this grief may consequently lead to significant adverse health outcomes. Thus, it is critically important to consider the uniqueness of the experience of the death of a child for African Americans and address the disparities faced by these parents through research, practice, and policy.

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