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Parent Spirituality, Grief, and Mental Health at 1 and 3 Months After Their Infant's/Child's Death in an Intensive Care Unit



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Key words:

Spirituality; Bereaved parents; NICU/PICU death **Problem:** The death of an infant/child is one of the most devastating experiences for parents and immediately throws them into crisis. Research on the use of spiritual/religious coping strategies is limited, especially with Black and Hispanic parents after a neonatal (NICU) or pediatric intensive care unit (PICU) death.

Purpose: The purpose of this longitudinal study was to test the relationships between spiritual/religious coping strategies and grief, mental health (depression and post-traumatic stress disorder) and personal growth for mothers and fathers at 1 (T1) and 3 (T2) months after the infant's/child's death in the NICU/PICU, with and without control for race/ethnicity and religion.

Results: Bereaved parents' greater use of spiritual activities was associated with lower symptoms of grief, mental health (depression and post-traumatic stress), but not post-traumatic stress in fathers. Use of religious activities was significantly related to greater personal growth for mothers, but not fathers. **Conclusion:** Spiritual strategies and activities helped parents cope with their grief and helped bereaved mothers maintain their mental health and experience personal growth.

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IN 2008 IN the United States, 28,033 infants (0–1 year old) and 22,844 children and adolescents under the age of 18 died (Matthews, Minino, Osterman, Strobino, & Guyer, 2011). Most died in an intensive care unit (Fontana, Farrell, Gauvin, Lacroix, & Janvier, 2013). The death of an infant/child is unimaginable and one of the most devastating events that parents can experience. The resulting stress disrupts their mental and physical health (Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013). While parents' symptoms of

Some parents turn to spirituality and religion to cope with their loss. Although often used interchangeably, spirituality involves caring for the human spirit; achieving a state of wholeness; connecting with oneself, others, nature and God/life forces; and an attempt to understand the meaning and

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depression and PTSD diminished over the first 13 months post-death, about one-third continued to have symptoms indicative of clinical depression and/or PTSD. The number of chronic health conditions parents reported at 13 months post-death was more than double that before the ICU death (Youngblut et al., 2013). Physical and emotional symptoms occur during the early phase of grieving and continue for years afterwards (Werthmann, Smits, & Li, 2010).

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purpose of life (O'Brien, 2014) even in the most difficult circumstances. In contrast, religion is an organized system of faith with a set of rules that individuals may use in guiding their lives (Koenig, 2009). Religion may be an explicit expression of spirituality. Therefore an individual may be spiritual without espousing a specific religion or very religious without having a well-developed sense of spirituality (Subone & Baider, 2010).

Research about bereaved parents' use of spiritual coping strategies and its effects on their psychological adjustment after their child's NICU/PICU death is limited. Most studies in this area have focused on religious coping neglecting the potential effect of non-religious spiritual coping strategies in helping bereaved parents (primarily White) cope with their grief. There is minimal research on whether bereaved parents use religious and/or spiritual coping strategies in early grief and on the differences between mothers' and fathers' coping strategies. Additionally, most studies on spirituality as a coping strategy in the grieving process have examined spirituality at one time point with very little research on the use of spirituality over time. The purpose of this longitudinal study with a sample of Hispanic, Black non-Hispanic, and White non-Hispanic bereaved parents was to test the relationships between spiritual/religious coping strategies and grief, mental health, (depression and post-traumatic stress disorder) and personal growth for mothers and fathers at 1 (T1) and 3 (T2) months after the infant's/child's death in the NICU/PICU, with and without control for race/ethnicity and religion.

Use of Spirituality/Religion as a Coping Strategy

The few studies on the use of spiritual/religious coping strategies by bereaved parents whose infants/children died in the NICU/PICU have described using rituals, sacred text, and prayer; putting their trust in God; having access to their clergy/pastor; connecting with others and remaining connected to the deceased child as spiritual strategies that help to alleviate the parents' pain, provide inner strength and comfort, and give meaning and purpose to their child's death (Ganzevoort & Falkenburg, 2012; Meert, Thurston, & Briller, 2005).

Bereaved parents may find solace (Klass, 1999) in using spiritual and/or religious coping strategies. Parents who believe in a heaven or an afterlife find comfort in believing that their deceased child is in a better place and close to God and that when they die they will be reunited with their child (Armentrout, 2009; Ganzevoort & Falkenburg, 2012; Klass, 1999). Similar beliefs were identified by Lichtenhal, Currier, Neimeyer, and Keese (2010) who found that bereaved parents' reliance on spiritual or religious beliefs proved helpful in coping with their grief. In that study, 28 (18%) of 156 bereaved parents believed that their child's death was God's will and 25 parents (16%) believed that their child was safe in heaven. Bereaved parents also can find healing or bring meaning to their own lives through spirituality, independent of religion, with meditation, inspirational

writings, poetry, nature walks, listening to or creating music, painting or sculpting, and therapeutic touch, among others (Klass, 1999; Meert et al., 2005).

Research has found that some bereaved parents expressed anger with God for their infant's/child's death. Some felt that God was punishing them; others questioned or abandoned their belief in a perfect omniscient and omnipotent God, instead choosing to believe in a higher power that can make mistakes (Armentrout, 2009; Bakker & Paris, 2013). Meert et al. (2005) found that 30 to 60% of bereaved parents expressed anger and blame at themselves and God for their infant's/child's death.

An infant's/child's admission, stay and subsequent death in the NICU/PICU is overwhelming and painful for parents. Many are faced with the difficult decision of limiting treatment or withdrawing life support from their very sick infant/child (Buchi et al., 2007). Researchers have found that bereaved parents described their grief as feelings of emptiness, sadness, deep suffering, emotional devastation and being nonfunctional following the death of their infant/child in the ICU (Armentrout, 2009; Meert, Briller, Myers-Shim, Thurston, & Karbel, 2009).

Parent Mental Health and Personal Growth

Research on the effects of an infant's/child's death on parents' mental health and personal growth has found symptoms of PTSD, depression, and anxiety; lower quality of life; and minimal involvement in social activities up to 6 years after the loss (Werthmann et al., 2010). However few studies have examined parent mental health and personal growth following an infant's/child's death in the NICU/PICU. In bereaved parents 13 months after the death of their infant/child in the NICU/PICU, Youngblut et al. (2013) found that 30% of parents had scores indicative of depression and 35% of PTSD.

Personal growth is described by bereaved parents as a positive change in themselves, their family and social life (Armentrout, 2009; Buchi et al., 2007). These changes included beginning to find meaning and purpose in their lives, moving forward with their lives and becoming emotionally stronger (Armentrout, 2009; Buchi et al., 2007). They describe their values and priorities as being redefined, often finding material things less important and a greater appreciation for family relationships (Armentrout, 2009). Parents often became involved in community activities that transformed their lives and honored the memory of the deceased infant/child; some joined organizations whose goals were to help others (Armentrout, 2009).

In summary, parents have difficulty dealing with their infant's or child's death, even when studied years after the death. Youngblut et al. (2013) found that bereaved parents had symptoms of depression, panic attacks, anxiety, chest pain, hypertension, and headaches after the child's death. Religion and spirituality have been used interchangeably in research, so it is unclear whether religious and spiritual activities are equally effective or have differing effects. Most of the research on bereaved parents has been after a child's death due to cancer or trauma in primarily White families

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