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Original Article

Supporting the neonatal nurse in the role of final comforter

Amber C. Welborn, MSN, RN, Staff Nurse, Lecturer

The University of North Carolina at Greensboro School of Nursing, USA

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KEYWORDS

Neonatal intensive care unit; NICU; Grief; Death and dying; Coping; Comfort Abstract The death of an infant in the neonatal intensive care unit (NICU) without the presence of family members can be a stressful event for the care nurse, who may feel obligated to provide love and comfort to the infant, in addition to medical care. The nurse may experience role conflict while attempting to meet all of the infant's perceived needs. This article explores the unique needs and circumstances of the NICU nurse in the role of final comforter for a dying infant when a family member is not present. The provision of such emotionally demanding work requires the nurse to receive education, mentoring, and support from colleagues and administration. NICU nurses who receive education on grief management and palliative care, mentorship from experienced nurses, and post-mortem grief support are better able to manage their own experiences with grief after the death of an infant in their care.

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Many nurses working in a neonatal intensive care unit (NICU) have been asked, "How do you handle taking care of those sick babies?" This is a well-meaning question, but most NICU nurses do not consider caring for critically ill babies and their families a burden (Discenza, 2014). NICU nurses verbalize intense feelings of guardianship and protection toward their patients and frequently refer to them as "my babies." In order to provide and experience such affection, the nurse must

become emotionally vulnerable. This article explores the unique needs and circumstances of the NICU nurse caring for a dying infant when a family member is not present to provide comfort. Educational and practice strategies that promote optimal infant care and support for healthcare team members surrounding the death event are offered.

NICU nurses hold a unique vantage point, a perspective that is different from the infant's family or other healthcare team members (Discenza, 2014). The nurse's clinical judgment considers all

E-mail address: alcrawfo@uncg.edu.

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facets of physical, developmental, and family-centered needs. Nurses engage with every medical device, ancillary specialist, and family member. The nurse interprets data with the medical team, listens to the concerns of the family, and offers suggestions to members of the healthcare team. This interconnection allows the nurse to form a holistic view of the baby's strengths and needs; the result is highly individualized, expert plans of care. When the baby is progressing or struggling with milestones, the nurse offers distinctive insight.

NICU nurses often become personally invested in the welfare of the babies for whom they provide care. Once emotionally invested, NICU nurses usually experience sadness and grief if the baby decompensates or dies (Lee and Dupree, 2008). These raw human emotions are difficult to navigate at any time, but the NICU nurse may experience them while providing direct nursing care to a dying infant. This emotional experience may be deepened if a family member is not present in the time surrounding death.

Background and significance

Approximately 4% of infants die within the first 28 days of life, with most deaths occurring in a NICU and resulting from a complication related to low birth-weight and/or prematurity (Child Health USA, 2013). Various scenarios may lead to infant death, including but not limited to birth defects, prematurity, and maternal complications of pregnancy (CDC, 2015). Death may be anticipated by precipitating events, such as traumatic delivery, extremely low-birth weight, multi-system organ failure, or a planned withdrawal of medical support; or death may be completely unexpected.

Neonatal death is devastating and stressful for families and healthcare team members (Epstein, 2010). Death is more distressing for the care team when the infant dies without the presence of family. Geographic or situational circumstances may prevent family from being with the infant at the time of death. Parents may feel unable to experience the emotions of witnessing the death or withdrawal of care. Some parents choose to relinquish custody early in the infant's life without choosing a designated caregiver. Alternatively, death may occur suddenly and unexpectedly in the absence of family.

In most situations, when a baby dies without the presence of a family member, the NICU nurse assumes the role of final comforter to the infant. The assumption of this role may be initiated by the nurse near the time of death or previously assigned

to a nurse by the family. NICU nurses exclusively provide almost all of the hands-on care and are an integral participant in the planning of care. Nurses are at the infant's bedside 24 hours a day providing optimum care and comfort, especially in the time surrounding death. Anecdotal evidence suggests nurses feel an obligation to comfort a dying infant. The provision of such emotionally demanding work requires the nurse to receive education, mentoring, and support from colleagues and administrators.

Literature review

NICU nurses experience the tragic circumstance of infant death on a regular basis. The nurse is challenged to provide direct nursing care while simultaneously attempting to meet the perceived comfort needs of the baby. Support of nurses during and after an infant's death promotes their mental and emotional health, prevents burnout, and supports their ability to provide quality patient care (Adwan, 2014; Kain, 2012; Lee and Dupree, 2008; Martin, 2013; Mendel, 2014). The literature offers suggestions to support families and physicians during the experience of infant death and dying; however, there is a dearth of literature addressing the specific support needs of nurses caring for a dying infant without the presence of family. The nurse's role is dramatically altered when caring for a dying baby in the role of final comforter, as compared to their role when parents are present at the bedside.

Grief as a part of the nurse's role

Nurses must identify a therapeutic approach to grief management and grief support of colleagues as a part of their daily work (Stayer and Lockhart, 2016). The literature identifies several themes related to care-related grief which may be magnified for the nurse in the role of final comforter. Caring for critically ill babies is stressful and emotionally intense in the high-mortality and high-stress environment of the NICU (Lee and Dupree, 2008; Mendel, 2014; Stayer and Lockhart, 2016).

Although sadness is the most commonly cited emotion in the literature, this feeling has been viewed positively as a marker of "humanity and emotional availability" (Lee and Dupree, 2008, p. 988; Stayer and Lockhart, 2016). Younger and less experienced nurses may find these feelings to be even more extreme, as they usually have less life experience and fewer coping mechanisms to help

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