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# Parent Perspectives of Neonatal Intensive Care at the End-of-Life<sup>1</sup>

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This descriptive qualitative study explored parent experiences related to their infant's neonatal intensive care unit (NICU) hospitalization, end-of-life care, and palliative care consultation. "Life and death in the NICU environment" emerged as the primary theme with the following categories: ups and downs of parenting in the NICU, decision-making challenges in the NICU, and parent support. Parents encountered challenges with areas for improvement for end-of-life and palliative care in the NICU. Further research is necessary to understand barriers with integrating palliative care and curative care in the NICU, and how NICU care affects bereavement and coping outcomes after infant death.

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Advanced healthcare technology has extended the lives of many infants thereby creating ethical dilemmas that consequently necessitate dignified, compassionate care for infants in the neonatal intensive care unit (NICU) and their parents (Institute of Medicine, 2003). In 2013, 23,446 infants died with the majority of deaths occurring in neonates, or in the first 28 days of life (Mathews, MacDorman, & Thoma, 2015) and 86% of infant and child deaths in acute care settings occurred in the pediatric intensive care unit (PICU) and NICU (Brandon, Docherty, & Thorpe, 2007). A significant number of infants

and their parents require specialized end-of-life (EOL) care, and pediatric palliative care (PPC).

EOL care is the management of the end-stage of a medical condition and may include palliative and hospice care (Institute of Medicine, 2003). In contrast, pediatric palliative care (PPC) is specialized healthcare that provides relief from symptoms resulting from serious illness for patients and their families (CAPC, 2015). PPC is explained to parents during the initial consultation session in the NICU and is provided by an interdisciplinary team of healthcare providers. While often misunderstood to only include hospice or EOL care, PPC can be provided at any stage of illness and during curative treatment (CAPC, 2015). The American Academy of Pediatrics (2000) and Institute of Medicine (2003) recommend integrating PPC at the time of diagnosis to provide family-centered care and improve care for both infants who succumb to illness, and those who survive. However, initiating PPC in NICU settings is severely

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limited due to the complex nature of the ethical challenges parents and healthcare professionals encounter, problems in determining futility of treatment, and the uncertainty of medical prognosis for infants (Catlin & Carter, 2002; Meier, Isaacs, & Hughes, 2010; Rushton, 2005). Further, there is a lack of education among parents and healthcare providers regarding the use of PPC for infants (Armentrout & Cates, 2011; Nicholl & Price, 2012; Pector, 2004), and is commonly misconceived as EOL or hospice care (Himmelstein, 2006).

Samsel and Lechner (2015) conducted a retrospective chart review and found that implementing a neonatal palliative care protocol was associated with increased palliative care interventions that may enhance EOL care. While PPC usage has increased with the burgeoning number of PPC teams in children's hospitals, Keele, Keenan, Sheetz, and Bratton (2013) compared demographic and clinical characteristics of patients who did and did not receive PPC in children's hospitals across the country and found that although infants with conditions in the newborn period accounted for 41% of all hospital deaths only 2% of these infants received PPC. Therefore, more research is necessary to understand why these beneficial PPC services are underused or avoided for infants and their families until death is imminent in the NICU.

Nurses are in a central position to influence the quality of EOL and PPC parent experiences during their infant's NICU hospitalization, subsequently affecting parent grief and potential health outcomes after infant death. Parent perceptions of the quality of health care providers' interactions and symptom management during PPC are negatively associated with long-term grief symptoms in parents of children who died from cancer (van der Geest et al., 2014). The need to provide quality, evidence-based care at the EOL is further underscored because bereaved parents are at a higher risk for mortality rates, psychiatric hospitalizations, and poor mental and physical health outcomes after infant or child death (Li, Laursen, Precht, Olsen, & Mortensen, 2005; Li, Precht, Mortensen, & Olsen, 2003; Youngblut, Brooten, Cantwell, Del Moral, & Totapally, 2013). Parent experiences surrounding EOL and PPC consultation during an NICU hospitalization remain poorly understood and understudied (Moro, Kavanaugh, Okuno-Jones, & VanKleef, 2006). This exploratory study contributes to a gap in the literature by exploring parent perceptions of EOL and PPC consultation in the NICU that is needed to improve the quality of care infants and parents receive in the NICU.

## Design and Methods

A descriptive qualitative design aims to present an inclusive summary of the phenomena in question in everyday language (Sandelowski, 2000, 2010) and was used to explore and describe parent experiences related to their infant's NICU hospitalization, EOL care, and PPC consultation. In-depth, face-to-face interviews occurred up to four years after infant death in the NICU.

## Research Question

1. How do bereaved parents describe their experiences related to their infant's NICU hospitalization, end-of-life care, and palliative care consultation?

## Theoretical Framework

The Dual Process Model of Coping with Bereavement was used as the theoretical framework for this study. Within this model, individuals oscillate between loss-oriented and restoration-oriented stressors in a dynamic process confronting and avoiding the loss (Stroebe & Schut, 1999). The Dual Process Model of Coping with Bereavement informed the interpretation of findings by helping to explain how parents live with decisions that were made during their infant's NICU hospitalization after infant death.

## Sample

Institutional review board (IRB) approval was obtained before any recruitment procedures were initiated. Potential participants who met the inclusion criteria were accessed through the NICU bereavement program. Purposive sampling was used to obtain a sample of bereaved parent participants ( $N = 10$ ) whose infant was hospitalized and subsequently died in a level-III NICU in the Southeastern U.S. Of these 10 parents, six parents of infants received PPC consultation during their NICU hospitalization. Maximum variation sampling was used to purposefully select information-rich diverse cases, specifically targeting both mothers and fathers to represent a range of maternal and paternal experiences (Sandelowski, 1995). Redundant themes were noted throughout the interviews and data saturation was verified by conducting additional interviews. Data saturation was achieved with a sample size of 10 because of the rich and in-depth interviews and redundancy of common themes throughout each interview (Sandelowski, 1995).

Inclusion criteria for parents were: (a) over the age of 19, (b) English speaking, (c) had an infant hospitalized in the NICU (level III) before infant death, (d) at least 15 months post-infant death (timeframe based on hospital policy), and (e) infant death occurred on or after February 1, 2009 (after the PPC program was initiated). A two-step recruitment procedure was used: 1) mailed study information packets; and 2) a follow-up phone call using an approved IRB script. In an effort to minimize distress in parents not interested in study participation, recruitment procedures were not conducted on or around difficult grief holidays (e.g., Mother's and Father's Day, infant's date of birth or death, etc.). A total of 181 packets of information were mailed to potential participants; however, only 78 parents could be reached due to invalid addresses and phone numbers. Of these, 10 parents agreed to participate. Another 10 participants discussed the study with the PI and were interested, but did not re-contact PI to schedule an interview, and 10 parents did not want to participate due to time demands associated with events in their life.

## Data Collection

In-depth, individual interviews were conducted by an NICU nurse (EC) between January 2014 and June 2014. Participants selected a convenient location, including the participants' homes ( $n = 6$ ), place of employment ( $n = 2$ ), or

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