

## Original article

# A qualitative study of nurse observations of symptoms in infants at end-of-life in the neonatal intensive care unit

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## ABSTRACT

**Objectives:** Assessment and management of symptoms exhibited by infants can be challenging, especially at the end-of-life, because of immature physiology, non-verbal status, and limited symptoms assessment tools for staff nurses to utilize. This study explored how nurses observed and managed infant symptoms at the end-of-life in a neonatal intensive care unit.

**Methodology/Design/Methods:** This was a qualitative, exploratory study utilizing semi-structured face-to-face interviews, which were tape-recorded, transcribed verbatim, and then analyzed using the Framework Approach.

**Setting:** The sample included 14 staff nurses who cared for 20 infants who died at a large children's hospital in the Midwestern United States.

**Main outcome measures:** Nurses had difficulty recalling and identifying infant symptoms. Barriers to symptom identification were discovered based on the nursing tasks associated with the level of care provided.

**Results:** Three core concepts emerged from analyses of the transcripts: Uncertainty, Discomfort, and Chaos. Nurses struggled with difficulties related to infant prognosis, time of transition to end-of-life care, symptom recognition and treatment, lack of knowledge related to various cultural and religious customs, and limited formal end-of-life education.

**Conclusion:** Continued research is needed to improve symptom assessment of infants and increase nurse comfort with the provision of end-of-life care in the neonatal intensive care unit.

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## Implications for clinical practice

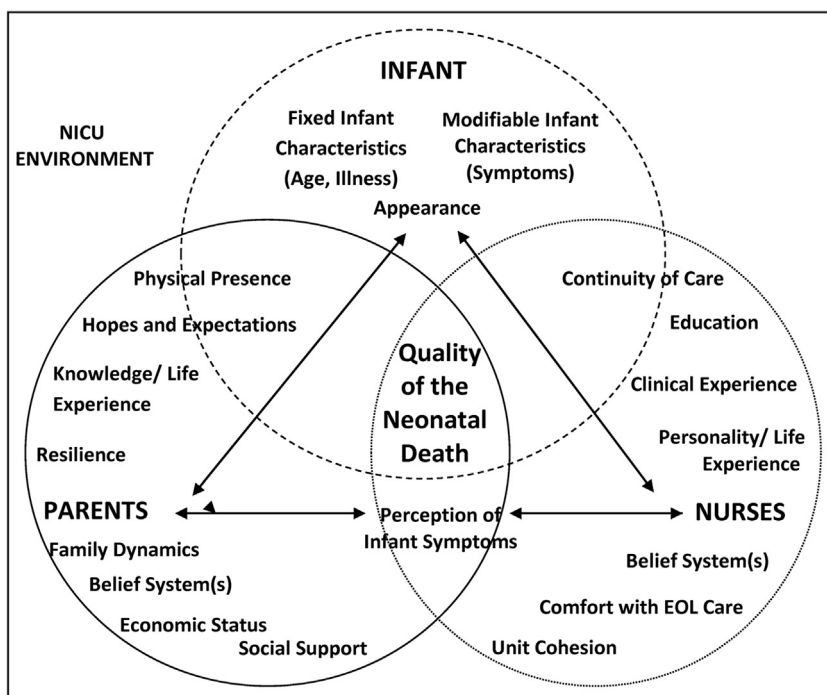
- Nurses should recognize that, while uncertainty surrounds the timing in changing from curative care to end-of-life care, they are in a position to provide information and support to families.
- Formal and informal educational opportunities related to end-of-life care is greatly needed by staff nurses in the Neonatal Intensive Care Unit. A better educated nursing staff will be in a position to provide competent and compassionate end-of-life care.
- Because of the uncertainty and chaos that can surround an infant's death in the Neonatal Intensive Care Unit, it is important that nurses have a formalized mechanism to process and debrief about the events surrounding the infant's death.

## Introduction

Symptom management is a critical component of end-of-life (EOL) care in the neonatal intensive care unit (NICU). When parents make the decision to withdraw or withhold life-sustaining treatment they make this decision with the goal of ending pain and suffering for their infant. However, the greatest parental concern is that their infant will suffer when life-sustaining treatment is discontinued (Meyer et al., 2002) and they want to be reassured that

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**Fig. 1.** Framework to evaluate the quality of a neonatal death. Reprinted from Fortney & Steward (2014). A new framework to evaluate the quality of a neonatal death. *Death Studies*, 38 (5), 294–301. Permission has been obtained from Taylor and Francis for use in ICCN. The license is included in a separate file.

their infant will not suffer during the dying process (Armentrout, 2009; Coughlin et al., 2007). Compounding the issue is the difficulty in predicting the length of time from discontinuing treatment to death. Death may take minutes to days to occur (Janvier et al., 2011; Saha & Kent, 2014).

Unfortunately, there is limited evidence available to guide symptom recognition and management during EOL care. The lack of evidence results in less than ideal pharmacologic intervention for dying infants (Williams et al., 2008). Researchers have demonstrated that variability exists in the pharmacologic management of symptoms, including pain, during and after the discontinuation of life-sustaining interventions (Janvier et al., 2011; Zimmerman et al., 2015). Consequentially, infants may be under-medicated during the dying process. Partial explanation for under-medication is the lack of recognition of symptoms exhibited by dying infants. The immature physiology of the infant most likely inhibits obvious symptom manifestations. However, many parents perceive that their infant is uncomfortable during the dying process (Cortezzo et al., 2015). Parents are distressed by physical symptoms such as unpleasant noises, color changes, and gasping. This leads parents to believe that their infant suffered while dying (McHaffie et al., 2001; Pector, 2004). Thus, symptom manifestation is important to parents.

Given the variable amount of time between the cessation of life-sustaining interventions and death coupled with parental concerns about their infant suffering during the dying process, identifying symptoms exhibited by infants during the dying process as well as symptom management strategies is crucial to developing evidence-based standards to guide EOL care in the NICU. The purpose of this study was to characterize physical and behavioral symptoms commonly exhibited by infants at the EOL and identify the strategies employed to manage these symptoms.

### Setting

Staff nurses were recruited from a NICU in a large, metropolitan children's hospital in central Ohio, United States of America (USA).

Nurses who had cared for a dying infant during the last 24 hours of the infant's life were invited to participate in a face-to-face interview. Interviews took place in a private hospital conference room away from the clinical unit when the nurse was not on shift.

### Ethical approval

This study received approval and maintained compliance with ethical standards set forth by the hospital Institutional Review Board where the study was conducted. Informed written consent was obtained from all nurse participants.

### Methods

The framework "Evaluate the Quality of a Neonatal Death" (Fortney and Steward, 2014) guided this exploratory study. This theoretical framework (Fig. 1) describes components of care and relationships among infants, parents, and nurses in the NICU environment. A variety of factors, such as comfort level with EOL care, experience with palliative care education and assessment of infant symptoms of critical illness, as well as the ability of the nurse to recognize and interpret infant behavioral and physiologic cues can influence the delivery of care. In this exploratory study, semi-structured interviews were used to gather data related to nurse's experiences with infants who had died in the NICU. Semi-structured interviews were utilized to keep the interview focused, however, the nurse participants were given ample opportunity to talk about anything they thought was important to their experience.

### Demographic data

A very brief demographic survey was included as a part of the interview. Data collected included: years of nursing experience, years of NICU experience, age, race/ethnicity, and educational preparation. As a part of the survey, nurses were asked to rate their comfort level in providing EOL care on a scale of 1-5,

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